Australian Government
Productivity Commission

National Disability Insurance Scheme (NDIS) Costs

Productivity Commission Study Report

October 2017

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The Productivity Commission

The Productivity Commission is the Australian Government's independent research and advisory body on a range of economic, social and environmental issues affecting the welfare of Australians. Its role, expressed most simply, is to help governments make better policies, in the long term interest of the Australian community.

The Commission's independence is underpinned by an Act of Parliament. Its processes and outputs are open to public scrutiny and are driven by concern for the wellbeing of the community as a whole.

Further information on the Productivity Commission can be obtained from the Commission's website (www.pc.gov.au).

Foreword

The National Disability Insurance Scheme (NDIS) is a new scheme designed to change the way that support and care are provided to people with permanent and significant disability.

This study is a review of NDIS costs. The Heads of Agreement between the Australian and State and Territory Governments on the NDIS stated that the Productivity Commission would undertake a review of NDIS costs in 2017, to inform the final design of the full scheme prior to its commencement.

The Commission, and this study, benefited from discussions and submissions from people with disability, advocacy groups, peak bodies, disability care and support workers and government. We are grateful for the valuable contribution of all those who contributed to this study.

Angela MacRae
Commissioner

Richard Spencer
Commissioner

October 2017

Terms of reference

REVIEW OF NATIONAL DISABILITY INSURANCE SCHEME COSTS

I, Scott Morrison, Treasurer, pursuant to Parts 2 and 4 of the *Productivity Commission Act 1998*, hereby request that the Productivity Commission (the Commission) undertake a study into the National Disability Insurance Scheme (NDIS) costs.

Background

The Heads of Agreement between the Commonwealth and the States and Territories (States) on the NDIS stated that the Commission would undertake a review of scheme costs in 2017. This review is intended to inform the final design of the full scheme, prior to its commencement.

Scope of the study

The Commission should address the following issues identified in the Heads of Agreement for the review of scheme costs:

- the sustainability of scheme costs;
- jurisdictional capacity;
- cost pressures (including wages pressures);
- changes in the agreed escalation parameters;
- if efficiencies have been achieved within the scheme;
- whether there has been any impact on mainstream services; and
- examine the most appropriate levers to manage any potential cost overruns.

In addressing these issues, the Commission should consider:

1. Commonwealth and State funding and governance arrangements for the NDIS, including financial contributions and risk-sharing;
2. the interaction with, and role of, other services in meeting reasonable and necessary support for people with severe and profound disability; and

3. whether there are any issues with the scheme's design, including the application of market and insurance principles, in ensuring the best possible outcomes for people with severe and profound disability.

In conducting the analysis, the Commission should take into account its 2011 report into disability care and support and subsequent agreements between governments for the implementation of the NDIS. The Commission will be provided with all the data on scheme rollout it considers necessary for the analysis.

Process

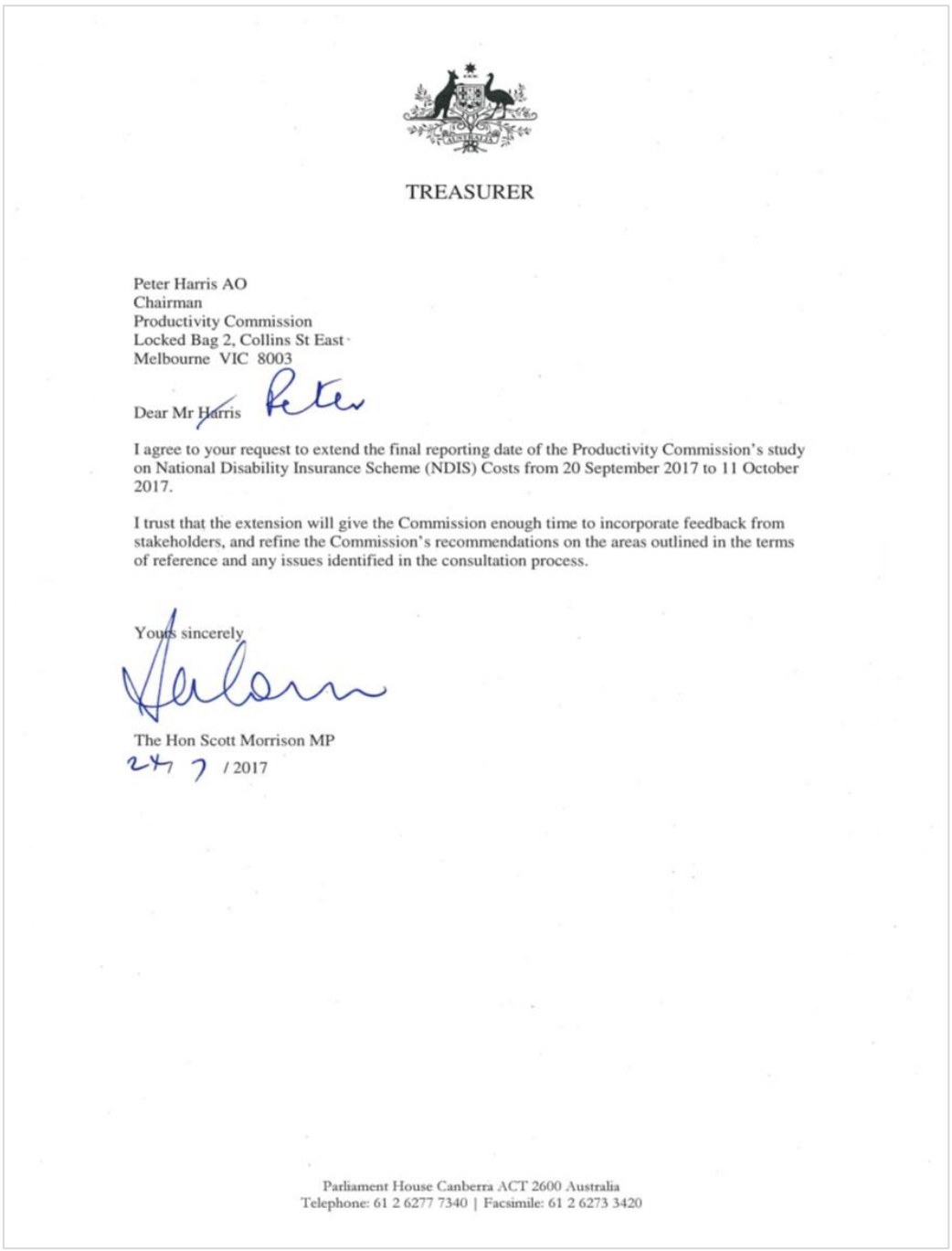
The Commission is to consult broadly, including with the Australian, State and Territory Governments.

The Commission will report within eight months of receipt of the terms of reference, or by 15 September 2017, whichever is later.

Scott Morrison
Treasurer

[Received 20 January 2017]

Letter of extension



TREASURER

Peter Harris AO
Chairman
Productivity Commission
Locked Bag 2, Collins St East
Melbourne VIC 8003

Dear Mr Harris Peter

I agree to your request to extend the final reporting date of the Productivity Commission's study on National Disability Insurance Scheme (NDIS) Costs from 20 September 2017 to 11 October 2017.

I trust that the extension will give the Commission enough time to incorporate feedback from stakeholders, and refine the Commission's recommendations on the areas outlined in the terms of reference and any issues identified in the consultation process.

Yours sincerely

The Hon Scott Morrison MP
24 7 / 2017

Parliament House Canberra ACT 2600 Australia
Telephone: 61 2 6277 7340 | Facsimile: 61 2 6273 3420

Contents

Foreword **iii**

Terms of reference **iv**

Letter of extension **vi**

Abbreviations **x**

Overview **1**

Recommendations and findings **49**

1 About this study **67**

1.1 About the NDIS 67

1.2 The benefits of the NDIS 69

1.3 The NDIS is a major reform 72

1.4 The Commission's approach to the study 76

1.5 A guide to this report 84

2 How is the scheme tracking? **87**

2.1 The rollout of the scheme so far 88

2.2 Projections of scheme costs 96

2.3 Key insights from trial and transition data 103

3 Scheme benefits **127**

3.1 Expected benefits and measurement of outcomes 128

3.2 Outcomes for participants, families and carers 131

3.3 Employment outcomes 138

3.4 The broader benefits of the NDIS 148

4 Scheme eligibility **151**

4.1 The eligibility criteria 152

4.2 Are entry and exit pathways effective? 161

4.3 Psychosocial disability and the NDIS 172

5 Scheme supports **181**
5.1 What supports are funded under the NDIS? 184
5.2 About plans and the planning process 189
5.3 How is the planning process tracking? 200
6 Boundaries and interfaces with the NDIS **221**
6.1 Linking people to the right services 222
6.2 The NDIS and other disability services 236
6.3 The interface between NDIS and mainstream services 244
6.4 Interface with aged care 255
6.5 Interface with the National Injury Insurance Scheme 257
7 Provider readiness **263**
7.1 The changing disability support market 264
7.2 Thin markets and the Provider of Last Resort 268
7.3 In-kind services 281
7.4 Other factors affecting provider readiness in transition 284
8 Pricing of disability supports **291**
8.1 How does the NDIA set prices? 292
8.2 What is the effect of the NDIA's prices on the market? 296
8.3 How should price caps be set? 305
9 Workforce readiness **319**
9.1 The disability care workforce 320
9.2 What workforce will be needed? 323
9.3 What can be done to improve workforce readiness? 337
9.4 How does informal care affect the workforce? 348
10 Participant readiness and market stewardship **357**
10.1 What is participant readiness? 358
10.2 How can participant readiness be improved? 366
10.3 Market stewardship 389

11 Governance **397**
11.1 Overview of governance arrangements 398
11.2 Lack of clarity around roles and responsibilities 401
11.3 NDIS Rules 402
11.4 Structure and governance of the NDIA 407
11.5 Western Australian NDIS 414
11.6 Review processes 417
11.7 Regulation and quality assurance 422
11.8 Performance reporting and monitoring 427
11.9 The rollout 431
12 NDIS funding arrangements **439**
12.1 How is the NDIS funded? 440
12.2 A framework for evaluating funding arrangements 447
12.3 Raising funds to pay for the NDIS 451
12.4 Escalation parameters 454
12.5 Funding an insurance-based scheme 459
13 Data and evidence **469**
13.1 The pivotal role of data for the NDIS 470
13.2 Data on disability services outside the NDIS 477
13.3 Linking data 482
13.4 Sharing data 484
13.5 A way forward 488
A Conduct of the study **493**
References **505**

Abbreviations

AAT	Administrative Appeals Tribunal
ABS	Australian Bureau of Statistics
ACC	Accident Compensation Corporation
ACFI	Aged Care Funding Instrument
AIHW	Australian Institute of Health and Welfare
ALNSW	Ability Links NSW
ANAO	Australian National Audit Office
ANZSCO	Australia-New Zealand Standard Classification of Occupations
ASIC	Australian Securities and Investments Commission
CALD	Culturally and linguistically diverse
CEO	Chief Executive Officer
COAG	Council of Australian Governments
CSIRO	Commonwealth Scientific and Industrial Research Organisation
DCAF	DisabilityCare Australia Fund
DES	Disability Employment Service
DRC	COAG Disability Reform Council
DSO	Disability Support Organisation
DSS	Department of Social Services
ECEI	Early Childhood Early Intervention
ELNSW	Early Links NSW
FTE	Full-time equivalent
FWC	Fair Work Commission
GDP	Gross Domestic Product
HRM	Hourly Rate Model
IAC	Independent Advisory Council
ICT	Information and communication technology
ILC	Information, Linkages and Capacity Building

LAC	Local Area Coordinator
LCAS	Lifetime Care and Support
MS	Multiple Sclerosis
NDA	National Disability Agreement
NDAP	National Disability Advocacy Program
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Services
NEC	National Efficient Cost
NEP	National Efficient Price
NIIS	National Injury Insurance Scheme
OECD	Organisation for Economic Cooperation and Development
PC	Productivity Commission
PEDI-CAT	Paediatric Evaluation of Disability Inventory-Computer Adaptive Test
PGPA	Public Governance, Performance and Accountability
POLR	Provider of last resort
QSC	Quality and Safeguards Commission
SDAC	Survey of Disability, Ageing and Carers
SDF	Sector Development Fund
SLES	School Leaver Employment Support
SNAT	Support Needs Assessment Tool
SSA	Shared Supported Accommodation
TAC	Transport Accident Commission
VET	Vocational Education and Training
WA NDIS	Western Australian National Disability Insurance Scheme

OVERVIEW

Key points

- The National Disability Insurance Scheme (NDIS) is a complex and highly valued national reform. If implemented well, it will substantially improve the wellbeing of people with disability and Australians more generally.
- The level of commitment to the success and sustainability of the NDIS is extraordinary. This is important because 'making it work' is not only the responsibility of the National Disability Insurance Agency (NDIA), but also that of governments, participants, families and carers, providers, and the community.
- The scale, pace and nature of the changes that the NDIS is driving are unprecedented in Australia. To reach the estimated 475 000 participants in the scheme by 2019-20, the NDIA needs to approve hundreds of plans a day and review hundreds more. The reality is that the current timetable for participant intake will not be met. Governments and the NDIA need to start planning now for a changed timetable, including working through the financial implications.
- Based on trial and transition data, NDIS costs are broadly on track with the NDIA's long-term modelling, but this is in large part because not all committed supports are used. While some cost pressures are emerging (such as higher numbers of children entering the scheme), the NDIA has put in place initiatives to address them. The benefits of the NDIS are also becoming apparent. Early evidence suggests that many (but not all) NDIS participants are receiving more disability supports than previously, and they have more choice and control.
- In the transition phase, the NDIA has focused too much on quantity (meeting participant intake estimates) and not enough on quality (planning processes), supporting infrastructure and market development. For the scheme to achieve its objectives, the NDIA must find a better balance between participant intake, the quality of plans, participant outcomes, and financial sustainability.
  - Greater emphasis is needed on pre-planning, in-depth planning conversations, plan quality reporting, and more specialised training for planners.
- A significant challenge in the transition phase is developing the supply of disability services and growing the disability care workforce. It is estimated that 1 in 5 new jobs over the next few years will need to be in disability care, but workforce growth remains way too slow.
  - Emerging shortages should be addressed by independent price monitoring and regulation, more effective coordination among governments to develop markets (including intervening in thin markets), a targeted approach to skilled migration, and equipping participants to exercise choice.
- The interface between the NDIS and other disability and mainstream services is critical for participant outcomes and the financial sustainability of the scheme. Some disability supports are not being provided because of unclear boundaries about the responsibilities of the different levels of government. Governments must set clearer boundaries at the operational level around 'who supplies what' to people with disability, and only withdraw services when continuity of service is assured.
- NDIS funding arrangements should better reflect the insurance principles of the scheme. Governments need to allow flexibility around the NDIA's operational budget and commit to establishing a pool of reserves.

Overview

1 About the National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is a new scheme designed to change the way that support and care are provided to people with permanent and significant disability (a disability that substantially reduces their functional capacity or psychosocial functioning). The NDIS is currently being rolled out across Australia. At full scheme, about 475 000 people with disability will receive individualised supports, at an estimated cost of $22 billion in the first year of full operation.

The NDIS is based on the premise that individuals' support needs are different, and that scheme participants should be able to exercise choice and control over the services and supports they receive. The scheme differs from previous approaches in a number of ways:

- it adopts a person-centred model of care and support
- it is an insurance-based scheme — it takes a long-term view of the total cost of disability to improve participant outcomes and to meet the future costs of the scheme (box 1)
- funding is determined by an assessment of individual needs (rather than a fixed budget)
- it is a national scheme.

The NDIS funds reasonable and necessary supports for Australians with permanent and significant disability. Reasonable and necessary supports are those that help participants live as ordinary a life as possible, including care and support to build their skills and capabilities, so they can engage in education, employment and community activities.

The NDIS also funds supports for people who meet early intervention criteria. This covers cases where early intervention can significantly improve an individual's outcomes and is cost effective. The focus on early intervention reflects the lifetime approach of the scheme (which is consistent with insurance principles, box 1).

Individuals eligible for the scheme are assessed, and individualised support packages are developed and funded for them. NDIS access, planning and payments are managed by the National Disability Insurance Agency (NDIA). (In Western Australia, arrangements are different, but intended to be consistent with the NDIS.)

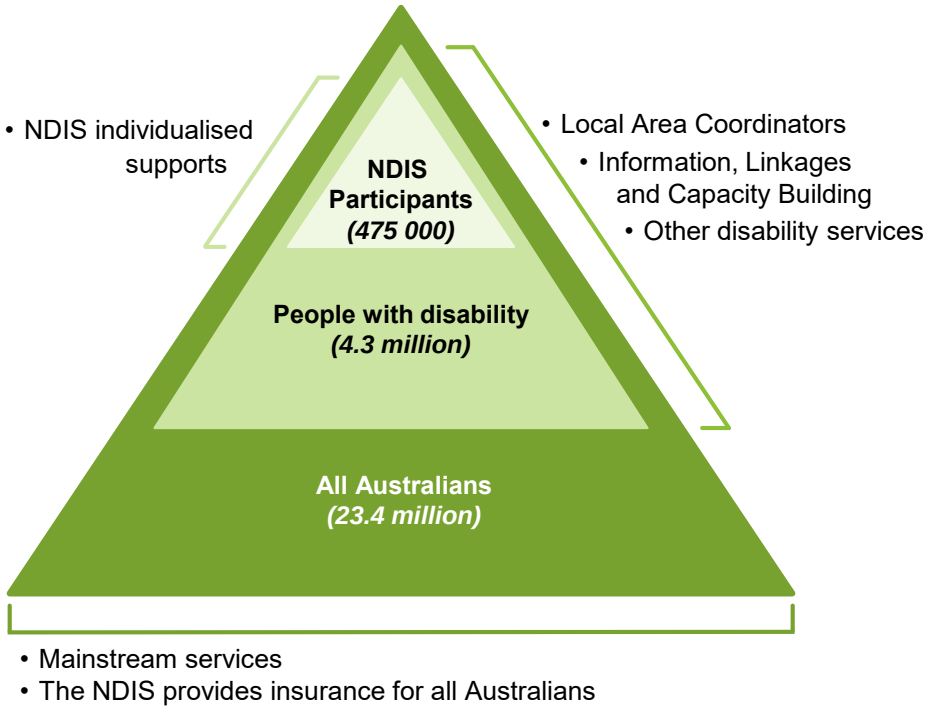
Information, Linkages and Capacity Building (ILC) services are also provided under the NDIS. ILC services provide information about, and referrals to, community and mainstream services (including health, education, employment, transport, justice and housing). These services are available to the 4.3 million people with disability in Australia (figure 1).

Box 1 The NDIS is based on insurance principles

The National Disability Insurance Scheme provides universal coverage by pooling risk across all Australians and taking the risk of disability support costs away from individuals. It is based on four insurance principles.

1. Actuarial estimates of long-term costs — updated to reflect the experience of the scheme, and used to help ensure the scheme is financially sustainable and continuously improved.
2. A long-term view of funding requirements — takes a lifetime view of participant needs and seeks early investment and intervention for people in order to maximise their independence and social and economic participation, and reduce their long-term support requirements.
3. Investment in research and innovation — to encourage and build the capacity and capability for innovation, outcome analysis and evidence-based decisions on early intervention.
4. Investment in community participation and building social capital — to make the community accessible and inclusive for people with disability, and provide participants and non-participants with necessary supports outside the scheme, through: mainstream services; Information, Linkages and Capacity Building initiatives; and education programs.

Figure 1 The NDIS is part of a broader system of supports[a]



[a] Number of Australians and those with disability are based on 2015 data. NDIS participants are the projected number of people eligible in 2020.

The governing legislation for the NDIS is the *National Disability Insurance Scheme Act 2013* (Cwlth) (NDIS Act). The Act establishes the NDIA, the independent statutory agency responsible for administering the NDIS. The NDIS Rules and Operational Guidelines set out the operational details of the NDIS. Funding for the NDIS is shared by the Australian, and State and Territory Governments.

Some background to the scheme

The Commission's inquiry in 2011 on *Disability Care and Support* found that Australia's system of disability support was inequitable, underfunded, fragmented, inefficient, and gave people with disability little choice and no certainty of access to appropriate supports. The Commission recommended a new national scheme to provide insurance cover to all Australians in the event of significant disability. This recommendation was based on the finding that such a scheme would generate substantial net benefits, including:

- improved wellbeing of people with disability (and their families and carers)
- better options for people with disability for education, employment, independent living and community participation
- efficiency gains and cost savings in the disability support system and savings to other government services.

The Commission's recommendations on the national scheme were largely accepted by Australian governments. The *Intergovernmental Agreement for the NDIS Launch* was signed by the Australian and State and Territory Governments in December 2012.

2 What we were asked to do and our approach

In the Heads of Agreement on the NDIS signed by the Australian and the State and Territory Governments in 2012 and 2013, it was agreed that the Productivity Commission would review NDIS costs in 2017 to inform the final design of the full scheme prior to its commencement.

The terms of reference for this study ask the Commission to look at:

- the sustainability of scheme costs, including current and future cost pressures, and how to manage any potential cost overruns
- whether jurisdictions have the capacity to deliver disability care and support services as the scheme expands
- how the NDIS impacts on, and interacts with, mainstream services
- whether efficiencies have been achieved within the scheme

- whether there are any issues with scheme design, including the application of market and insurance principles, in ensuring the best possible outcomes for people with profound or severe permanent disability
- funding and governance arrangements, including escalation parameters.

What factors drive scheme costs?

The majority (about 90 per cent) of NDIS costs are for individualised supports, but there are also the costs of operating the scheme and funding ILC activities. Key factors driving scheme costs include the:

- number and characteristics of participants
- scope of supports covered by the scheme
- quantity of supports received by participants
- proportion of supports in a plan that is utilised by a participant
- price paid for supports under the scheme
- costs associated with operating the scheme.

Scheme culture is also an important driver of costs. Moving away from the welfare culture of current disability systems to one of providing reasonable and necessary supports, and managing down the total cost of disability over a participant's lifetime, will be critical for the financial sustainability of the scheme.

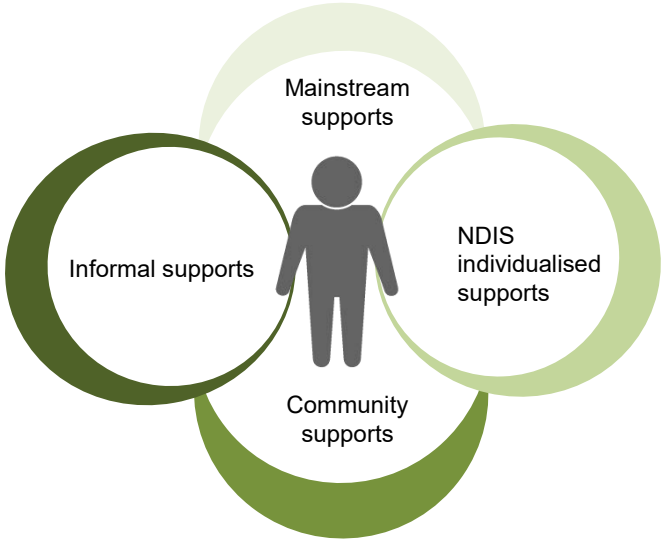
Other support systems can also affect scheme costs. The NDIS, as a person-centred approach to providing disability supports, relies on supports and services outside the scheme, including informal supports (family, friends and neighbours), community supports (sporting, social and interest groups), and mainstream supports (public transport, health and education), to help people with disability to live ordinary lives (figure 2). If these supports are not available, people with disability could seek NDIS funding to fill the gap, and this could pose a risk to scheme costs.

Costs are one side of the equation — benefits are just as important

While the focus of this study is on scheme costs and the financial sustainability of the scheme, the Commission examined costs in light of the benefits and impacts of the scheme on the lives of people with disability, and Australians more generally, using a wellbeing framework.

The NDIS was introduced because it has potential to improve the lives of people with disability and the community more generally (by providing insurance for all Australians and lowering future costs of providing disability support). It is therefore essential that the costs to the community are considered in the context of scheme outcomes.

Figure 2 **A person-centred approach relies on supports beyond the NDIS**



Taxpayers' willingness to fund the NDIS will depend on their perception of value for money, in terms of:

- people with disability experiencing better lives as a result of the scheme
- the scheme making it easier for families and carers to play a supporting role
- the way the scheme invests in people with disability
- the confidence taxpayers have that the NDIS will be available to cover their care needs (or those of their loved ones) should a disability be acquired in the future
- the supports that are funded (and the evidence base to support what is funded)
- efficiency gains and cost savings in the disability support system and other government services.

While the NDIS is sometimes described as an 'uncapped scheme', the ultimate cap — and test of financial sustainability — is taxpayers' continuing willingness to pay for it. In line with this, the NDIA defines financial sustainability for the NDIS as:

- the scheme is successful on the balance of objective measures and projections of economic [and] social participation and independence, and on participants' views that they are getting enough money to buy enough high-quality goods and services to allow them reasonable access to life opportunities — that is, reasonable and necessary support; and
- contributors think that the cost is and will continue to be affordable, under control, represents value for money and, therefore, remain willing to contribute.

The NDIA's actuarial estimates of long-term costs (which reflect the experience of the scheme and management responses to cost pressures) play an important role in

demonstrating to the Australian community that the scheme is sustainable. Governments also need to demonstrate that the NDIS funds are dollars well spent.

Financial sustainability of the NDIS also needs to be considered in the context of the efficiency and effectiveness of the NDIA, the readiness of participants and providers, and the integration of the scheme with mainstream and other disability services. Only a system that is integrated and holistic in its focus will bring the benefits that the scheme is expected to deliver.

3 An enormous challenge

The NDIS is a major, complex national reform — the largest social reform since the introduction of Medicare. It will:

- involve a shift away from a block-funded welfare model of support, to a fee-for-service market-based approach
- increase funding in the sector from about $8 billion per year to $22 billion in 2019-20
- involve assessing the reasonable and necessary needs of about 475 000 people
- require about 70 000 additional disability support care workers (or about 1 in 5 of all new jobs created in Australia over the transition period)
- substantially improve the wellbeing of people with disability and Australians more generally (if implemented well).

It is therefore no surprise that the NDIS is described as 'ground-breaking' and a 'once-in-many-generation reform'.

The level of commitment to the NDIS is extraordinary

There is an extraordinary level of commitment to the success and sustainability of the NDIS (and to preserving the core principles of the scheme) shared by governments, people with disability and their families and carers, providers of disability services and disability advocates (box 2). As the Australian Disability Discrimination Commissioner said:

> Yes — the NDIS is big, it is complex, and it changes everything, but it is the change that we need. And when we think about what life might be like for people with disability without the NDIS, I think it becomes clear that it is the change we cannot afford to prevent. … If we want real and lasting change for people with disability, we cannot absolve ourselves of our responsibility to make the NDIS work.

Box 2 **There is overwhelming support for the NDIS**

NSW Council for Intellectual Disability:

> … we have been strong supporters of the development of the NDIS and we continue to see [the] scheme as having a fundamental capacity to improve the lives of people with disability around Australia.

Flourish Australia:

> … strongly supports the NDIS and the opportunity it provides for greater certainty, choice and control, and economic and social participation for people with disability who require life-long support.

JFA Purple Orange:

> … the NDIS is a major, once-in-many-generations opportunity to invest in the life chances of people living with disability, to achieve a fair go, so that people living with disability take their rightful place as … valued active members of Australian community life and the economy.

National Disability Services:

> The principles on which the NDIS is founded remain compelling and inspiring.

Australian Federation of Disability Organisations:

> We want to begin … by emphasising our unwavering support for the NDIS. AFDO and its members regularly hear from people with disability and their families about the difference the NDIS is making to their lives. People who now have the dignity of appropriate and timely support, the opportunity to be more involved in their communities, the chance to move out of home, the economic freedom of a new job. These are the kinds of differences the NDIS is making.

Anglicare Australia:

> … strongly believes that the establishment of the NDIS is a major achievement. Our member agencies are already witnessing the transformative power of the scheme for participants, and finding that reconfiguring services to reflect their needs and aspirations is creating opportunities to reimagine and create better outcomes in people's lives.

New South Wales Government:

> The NSW Government is a strong advocate of the National Disability Insurance Scheme (NDIS). The improvement in the lives of people with disability, as outlined by the Productivity Commission (PC) in its 2011 inquiry report into Disability Care and Support, is a goal embraced by NSW.

The rollout schedule

The NDIS was trialled from 2013 in different jurisdictions across Australia in four trial sites (including two whole-of-state age cohort trial sites, table 1). The Bilateral Agreements between the Australian and the State and Territory Governments set out the timeframes, and the estimated number of people who will become participants in the scheme, for the transition to full scheme in each jurisdiction. The full scheme is scheduled to be rolled out nationally by 2019-20, but some jurisdictions are scheduled to move to full scheme earlier.

Table 1 **NDIS transition arrangements by jurisdiction**

	Trial period			Transition to full scheme			Full scheme
	2013-14	2014-15	2015-16	2016-17	2017-18	2018-19	2019-20
NSW	Hunter area trial			Transition to full scheme (by region)		Full scheme	
			Early Transition in Nepean Blue Mountains area (children aged 0–17 years)				
Vic	Barwon area trial			Transition to full scheme (by region)			Full scheme
Qld				Transition to full scheme from July 2016 (by region). Early Transition from January 2016 in Townsville, Charters Towers and Palm Island			Full scheme
SA	Statewide trial (children aged 0–14 years)			Transition to full scheme (by age and region)		Full scheme	
Tas	Statewide trial (people aged 15–24 years)			Transition to full scheme (by age)			Full scheme
NT		Barkly region trial		Transition to full scheme (by region)			Full scheme
ACT[a]		Territorywide trial		Full scheme			
WA[b]		Perth Hills area trial		Transition to locally administered NDIS			
		MyWay trial					

[a] The Bilateral Agreement for the NDIS launch between the Australian Government and the ACT Government notes that from 2016-17 the ACT will be in 'transition to full scheme'. This transition has been categorised as 'full scheme' because all residents who meet the eligibility criteria will have access to the scheme. [b] In February 2017, the Australian Government and Western Australian Government signed a Bilateral Agreement for a nationally consistent, but locally administered, NDIS.

Transition — a unique and challenging period in the life of the scheme

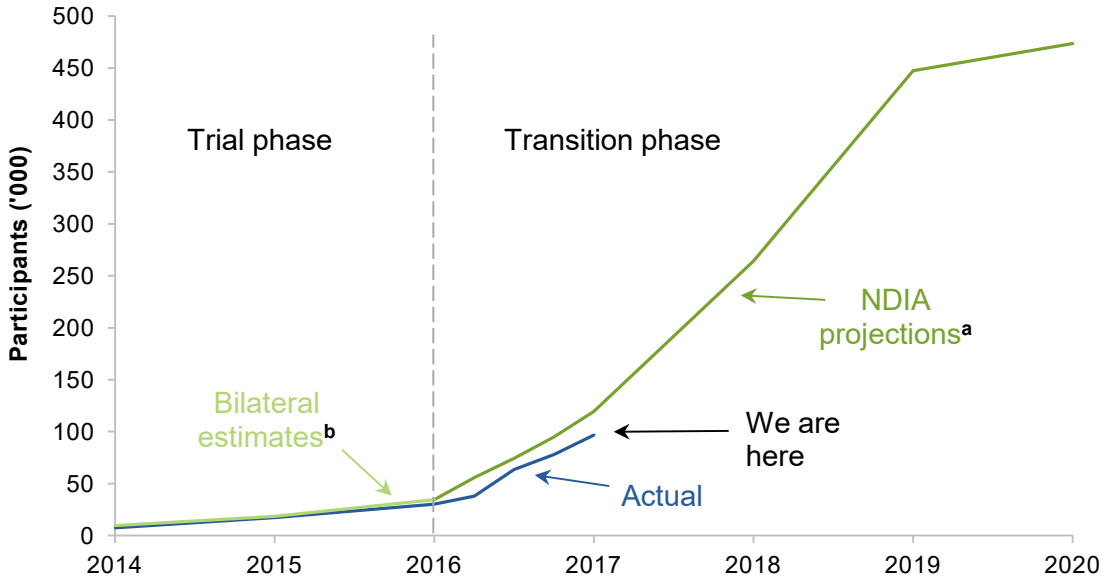
The transition period is a unique period in the life of the scheme. Never again will:

- the number of new participants be entering the NDIS over such a compressed timeframe
- so many disability support service providers be facing the challenge of transitioning from a block-funded model of support to a fee-for-service market-based approach
- so many new scheme participants be learning how to navigate a new scheme where they have choice and control over disability supports (making the change from passive recipients of supports to informed consumers).

Participant intake

The NDIA has been given an extremely difficult task — the rollout schedule is highly ambitious given the magnitude of the reform. To reach the estimated 475 000 participants at full scheme by 2019-20 (figure 3), the NDIA needs to approve hundreds of plans a day.

Figure 3 **Participant numbers will increase substantially over the next three years[a]**



[a] Scheme participant projections are based on projections prepared by the Scheme Actuary for the NDIA's 2015-16 Annual Financial Sustainability Report using data at 30 June 2016. The Commission adjusted the projected number of participants for the four quarters of 2016-17 to be consistent with the bilateral estimates reported in the latest NDIA quarterly report. [b] Bilateral estimates based on the NDIA's quarterly reports.

In the June 2017 quarter, the NDIA approved about 15 000 plans, or roughly 165 plans a day. In 2018-19 (the final year of transition), the NDIA will need to approve about 500 plans a day, while also reviewing hundreds more.[1]

One study participant described the transition arrangements as 'a tsunami of new participants' that will need to be processed into the scheme over the next two years. A number of study participants questioned whether the intake timetable could, or should, be met. And many raised concerns about the NDIA's focus being on participant numbers with little attention on planning processes. House with No Steps, for example, said:

> … the Scheme has aggressive ramp-up targets. These are putting pressure on the NDIA's capacity to develop quality plans for participants. Unfortunately, the need to achieve high growth in participant numbers appears to be outweighing considerations of plan quality and consistency.

The intake of participants with approved plans is already falling behind the expected pace. If the trend of delivering about 80 per cent of the bilateral estimates continues (figure 3), it will take an additional year before all eligible participants are in the scheme. (And this delay could be longer if the scheme falls further behind when the participant intake ramps up in 2017-18.)

1 Based on NDIA modelling.

The reality is that the rollout timetable for participant intake will not be met.

This means that 'full scheme' (the time when everyone eligible to enter the NDIS will be able to do so and have an approved plan) will be delayed beyond 2019-20 — that is, beyond the date anticipated in the Bilateral Agreements. Governments need to start planning now for a new participant intake timetable, including working through the financial implications.

NDIA's focus on participant intake has compromised the quality of plans and participant outcomes. Quality plans are critical, not only for participant outcomes but also for sending the right signals to providers about demand for supports and containing long-term costs of the scheme. The Commission makes several recommendations in this report on the quality of planning and participants' experiences with the NDIA (section 7). Implementing these recommendations will increase the NDIA's workload, at least in the short term, making the timetable even more ambitious. But without these changes the objectives of the scheme will not be achieved.

Supply of disability supports and demand pressure from participants

Another significant transition challenge is developing the disability support market — both in terms of the scale and scope of services — so there are enough providers and workers to meet the increased demand for disability supports (section 9). The large increase in funding and considerable unmet need in the disability support sector means that the number of workers and providers will need to grow quickly over the transition period.

Prices are critical for market development and participant outcomes. But there is a risk that demand for disability supports will exceed supply, creating inflationary and quality pressures in the market. The Commission recommends independent price monitoring and regulation, as well as more effective coordination among governments to develop markets (including intervening in thin markets).

It will also take time for scheme participants to exert the influence and control over their supports that will bring about the kind of competitive pressures that characterise mature markets. Participants need the skills and information to exercise informed choice. It is essential that participants get the supports they need to navigate the scheme (section 9).

Ensuring continuity of support

There is also evidence of service gaps (section 8). Some disability supports are not being provided because of unclear boundaries. Clearer boundaries must be set at the operational level around 'who supplies what' to people with disability, and services only withdrawn when continuity of service is assured. All governments need to work together to better manage the integration of the NDIS and other services.

Transitional issues, if not addressed, will pose risks to the scheme

Each of these transitional issues is challenging in its own right, but in combination, the task as currently planned, becomes even more difficult. And all this is against a backdrop of significant change in governance and funding arrangements (with some arrangements still to be bedded down). The arrangements are also tied to insurance-based principles that do not fit easily within the existing model of government oversight. The newly established Agency also needs to find and skill staff, while developing operational guidelines from scratch under circumstances where legislation is untested.

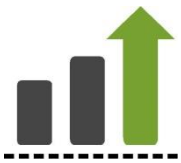
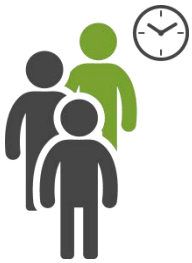
The transition period is going to be more protracted than previously expected. Based on evidence to date:

- the participant intake will not match the estimates in the Bilateral Agreements — adjustments need to be made now on a state-by-state basis
- supply shortages will persist for some time
- many participants will need more time and assistance to be equipped to exert the influence and control over their supports that will bring the kind of competitive pressure that characterises mature markets
- underutilisation will continue for some time — while this will keep scheme costs in check, it will mean poorer outcomes for some participants.

Recommendations made by the Commission to deal with the challenges and risks are outlined in table 2 and discussed in more detail in the sections below.

Scheme costs are discussed in the next section.

Table 2 **National Disability Insurance Scheme rollout challenges**

	The change	*The challenge*	*PC recommendations*
	Move from block-funded welfare model of support to a fee-for-service, market-based approach. Give scheme participants choice and control over disability supports.	Build the capabilities of providers and participants to engage in a market-driven scheme. Some participants do not have the capacity to navigate the new market. Some providers can struggle to adapt to a market-driven scheme.	Ensure participants get the supports they need to navigate the scheme, including information about providers and services. Provide stronger price incentives to encourage providers to deliver supports.
	Assess the reasonable and necessary needs of 475 000 people with disability based on insurance principles and individualised planning.	Assess eligibility and develop plans for a large number of participants within short timeframes (to meet bilateral estimates). Build a planning workforce with sufficient skills to administer the plans over scheme transition. Plans will be rushed or completed by planners without experience in disability – leading to a lack of supports for participants.	Rebalance the focus from numbers to better quality plans (the right plans will lead to the correct signals to the supply side of the market). Greater focus on pre-planning. More specialisation of planners. Allow NDIA more flexibility over its staffing arrangements.
	Increase funding to the sector from $8 billion per year to $22 billion in 2019-20.	Ensure funding arrangements do not create incentives for cost-shifting by jurisdictions. Ensure funding arrangements are based on insurance principles.	Clearly delineate what supports are provided to participants, and what are not. Establish clear boundaries around ‘who’ provides ‘what’. Establish a reserve fund to allow the scheme to take a long-term approach to participant needs.
	Build the supply side of the scheme — both in terms of the scale and scope of provider services, and the size of the workforce to deliver supports.	The supply side of the scheme may not respond fast enough to meet participant demand.	Implement independent price monitoring and regulation to get the right price signals to encourage supply. Bolster market stewardship through better collaboration among governments, providers and the NDIA.

4 Modelling the costs of the scheme

In 2011, the Commission estimated that a national disability insurance scheme would cover 411 000 participants and cost $13.6 billion (gross) at maturity. The NDIA's current projections are that the NDIS will cover 475 000 participants and cost $22 billion at full scheme commencement.[2]

The NDIA's estimates are based on a more refined costing methodology than that used by the Commission in 2011, and are broadly consistent with the Commission's 2011 modelling after accounting for wage and population growth. Of the $8.9 billion difference between the Commission's original estimates and the NDIA's current estimate, $6.4 billion is due to pay rises awarded to social and community services employees by the Fair Work Commission in 2012. Adding population changes and the cost of participants aged over 65 years (who were not included in the Commission's estimates), the estimates come within one per cent of each other (table 3).[3]

Table 3 **Comparing the Commission's and the NDIA's costings**

	Participant numbers	*Scheme costs ($ billions)*
Productivity Commission estimates 2011[a]	**411 250**	**12.82**
Population projections to 2019-20	49 544	1.54
Inflation in disability sector (wages)	..	6.38
Participants aged 65 years and older	15 285	1.09
Updated Productivity Commission estimates 2017	**476 079**	**21.84**
The NDIA's projections for participants 2017[b]	**473 653**	**21.76**
Difference (%)	2 426 (0.5%)	0.08 (0.4%)

[a] Excluding operating costs and offsets associated with the National Injury Insurance Scheme and assumed efficiency dividends. [b] Excluding operating costs ($1.5 billion), offsets associated with the National Injury Insurance Scheme ($0.7 billion) and assumed efficiency dividends ($0.3 billion). .. Not applicable.

It is too early and the data are too limited for new cost projections

In terms of reliable cost data, it is still very early days in the transition to full scheme. And while the transition experience should inform estimates of full scheme costs, the NDIA has decided that, at this early stage, the data have too many limitations to update the prevalence and package cost assumptions. Important limitations include small and unrepresentative trial

2 While the gross cost of the NDIS is estimated to be $22 billion in 2019-20, the scheme is expected to reduce the funding required for a range of government programs. A review by the Australian Government Actuary in 2011 estimated that these offsets were about $11 billion.

3 Participants must be aged under 65 years to *enter* the NDIS but can remain in the scheme after they reach 65 years.

populations, and concerns about the integrity of transition data. Approaches to planning and assessments were also changed at the beginning of the transition period (July 2016).

The Commission supports the NDIA's approach to projecting scheme costs, including the decision to delay integrating data from the trial and transition. We therefore did not revise the projections of scheme costs for this study. However, it is imperative that new data are incorporated into the NDIA's assessment of longer-term costs as soon as possible. The Commission's assessment is that, in the absence of major new data reliability issues, there should be sufficient data for the NDIA to update the estimates of scheme costs based on scheme experience for the 2017-18 Annual Financial Sustainability Report.

5 Insights from the trial and transition period

Costs in the trial phase aligned with expectations

Given the uncertainties around the costings of the scheme before it commenced, an important rationale for trial sites was to inform more reliable estimates of full scheme costs (and for testing and refining the scheme). At the end of the trial phase:

- the number of participants with an approved plan (30 281) was 83 per cent of bilateral estimates (36 307) (there were 35 695 people who had been determined eligible but who did not necessarily have an approved plan)
- the average annualised package cost was $36 049.

The scheme, at the end of the trial, also came in under budget — there was a surplus of about 1.5 per cent of the funding envelope over the three years. However, this was in large part because not all committed supports were used — in 2015-16, 76 per cent of committed supports were used.

Transition — the latest data

Post-trial data are also available. At the end of June 2017, an additional 86 000 people were eligible for the scheme, taking the total number of participants to 122 065. About 90 000 participants are currently active[4] and have an approved plan. Some insights from the transition data are presented in figure 4.

4 Participants who have not exited the scheme.

Figure 4 **Key insights from the transition data**
Data at 30 June 2017

[a] Psychosocial disability is the next most common disability, accounting for about 6 per cent of participants. [b] The annualised average level of committed support for packages after 1 July 2016. For participants with multiple plans over the time period, the latest plan is used. [c] NDIA modelling projects that the percentage of scheme participants who are aged 14 years and under will decrease to 30 per cent by 2019-20.

Emerging cost pressures

The Commission compared trial and transition data with the assumptions in the NDIA's modelling. Noting the limitations of the data, scheme costs are broadly on track compared to expectations.

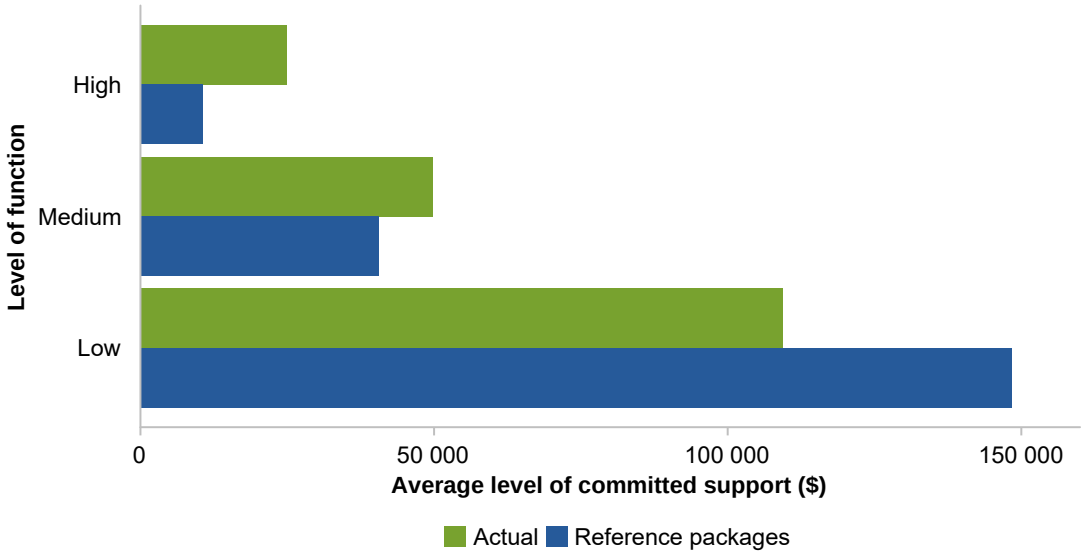
- For most disabilities, participant numbers broadly match the modelling assumptions for all but the largest disability groups. However, there are more children with autism and intellectual disability than expected.
- Average package costs (for plans effective from 1 July 2016) are broadly in line with modelling assumptions (after accounting for disability, age and level of function).[5] However, there are differences when the data are disaggregated by level of function. The average package cost for participants:
  - with low levels of function is $40 000 less than expected
  - with medium levels of function is $9000 higher than expected
  - with high levels of function are higher on average by $14 000 (figure 5).

5 For the position paper, the Commission conducted the same analysis with data from the first three quarters of transition, and found that package costs were higher than modelling assumptions.

- Utilisation rates — the proportion of committed supports that are used by participants — are lower than expected. Underutilisation is currently more than offsetting the increase in scheme costs attributable to higher prevalence rates for children.

Figure 5 **Average annualised committed support compared with reference packages, by level of function[a,b]**

Plans effective from 1 July 2016



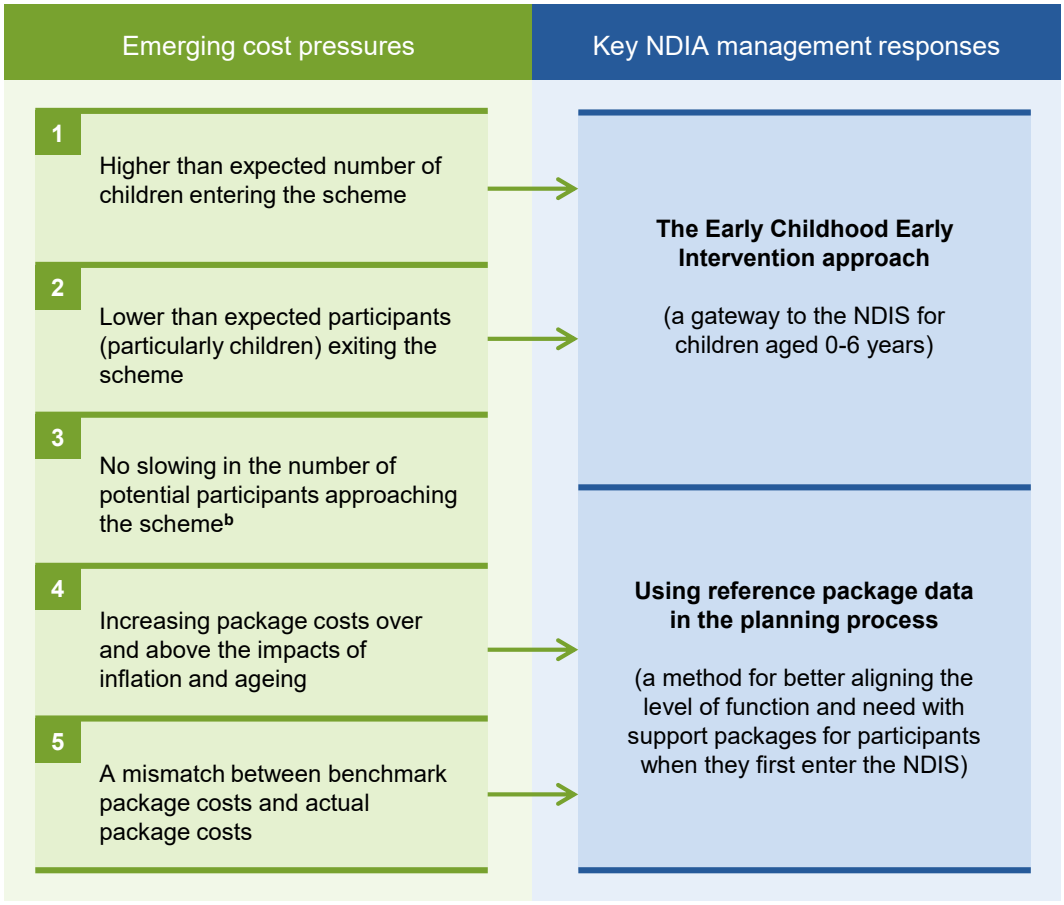
[a] Reference packages are the average package cost assumed in the NDIA's long-term modelling based on age, disability and level of function. They *are not* what an individual should expect to receive in an individualised funded package at any given time. [b] For participants with multiple plans over the time period, the latest plan is used.

The NDIA is tasked with ensuring the NDIS is financially sustainable. The insurance approach involves identifying and managing emerging cost pressures. The NDIA has identified five early cost pressures that need to be managed for the full scheme going forward (figure 6).

- The number of children entering the scheme is higher than expected.
- The number of people approaching the scheme in trial sites that have been operating the longest (since 2013) is higher than would be expected if only people with newly acquired conditions were approaching the scheme.
- The number of participants exiting the scheme is lower than expected (particularly for children entering under the early intervention requirements).
- Levels of committed support tend to increase as participants move to their second and third plans (over and above the impacts of inflation and ageing).
- There is greater than expected variability in package costs for participants with similar conditions and levels of function (suggesting inconsistencies in planners' decisions).

While the NDIA has not updated its baseline cost projections to reflect these cost pressures, it has put in place initiatives to address them. These include the Early Childhood Early Intervention (ECEI) approach for children aged 0–6 years (section 6, box 3), and the use of reference package data in the planning process to reduce variability in the level of support provided to participants (section 7, box 4).

Figure 6 **The NDIA's responses to emerging cost pressures**[a]



[a] The NDIA's two main responses to emerging cost pressures. The NDIA has also initiated several smaller projects to address emerging cost pressures, such as an analysis of reasonable and necessary costs across the lifespan of participants. [b] Potential participants continuing to approach the scheme is not a cost pressure that can easily be addressed by the NDIA.

While it is too early to conclusively assess the effectiveness of these initiatives, there are some signs from 2016-17 data that the new planning process may be helping to alleviate cost pressures related to package costs.

Benefits are already being realised

Realising the benefits of the scheme is critical for the wellbeing of people with disability and for ensuring that the community continues to be willing to pay for the scheme. However, at this early stage, only some of the benefits are being realised.

The NDIS Outcomes Framework and a National Institute of Labour Studies evaluation of the NDIS provide some early insights (based on trial data) into the scheme's benefits. Both find that the NDIS has:

- increased supports — more hours of support, a wider range of supports and greater access to equipment — than under the previous system
- on average, improved wellbeing of NDIS participants and their families and carers
- given people more choice and control over their supports
- increased social participation for some scheme participants and their carers.

The Commission also received numerous submissions supporting these findings. As one disability advocate said:

> … I have seen the life changes in people with disability who now have NDIS funding. They are now accessing community, having a good life and have hope for their futures. The burdens are off the family, some aged carers, and there is job creation. Broken wheelchairs are now being replaced and people who never had wheelchairs, now have and can access the community. I now see happy people.

However, not all are reporting improved outcomes under the NDIS. The groups at risk of having a less positive experience include those with psychosocial disability, complex and multiple disabilities, and language and cultural barriers, as well as people with disability transitioning into the community from the criminal justice system, the homeless and the socially isolated.

Participants reporting that they were satisfied or very satisfied with the scheme has also fallen since the scheme entered the transition phase — from 95 per cent in 2015-16 to 84 per cent in 2016-17. This could be linked to the speed of the rollout, and changes to the planning process (discussed below).

6 Scheme eligibility

The eligibility criteria are the main instrument available to influence how many people will be able to access individualised supports through the NDIS. It is important that these criteria are clear, aligned with the objectives of the scheme, and rigorously upheld.

When the Commission designed the national disability insurance scheme, it recommended that, to be eligible for the scheme, individuals should:

- have a disability that is or is likely to be permanent
- have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support, or be in an early intervention group where there is good evidence that the intervention is safe, significantly improves outcomes and is cost effective
- meet residence and age requirements.

The eligibility criteria for the NDIS are broadly in line with what the Commission recommended, with two exceptions — the inclusion of supports to undertake activities of *learning* or *social interaction*, and the inclusion of developmental delay in the early intervention criteria. Both these criteria allow more people to qualify for individualised supports under the NDIS than the Commission included when costing the scheme.

Adding learning or social interaction — what effect?

The Commission was unable to assess the effect of adding learning or social interaction to the eligibility criteria, because the NDIA does not collect data on which (or how many) of the six activity domains are relevant to each participant when they enter the NDIS. Speech Pathology Australia, however, said that their members who are NDIS providers are not providing services to children whose *only* disability relates to learning and literacy.

The NDIA should collect data at entry on the domains to provide information on the impact of each part of the eligibility criteria on participant numbers (and therefore scheme costs). This information would also allow for more granular analysis of who is in the scheme and what their needs are likely to be (and could also be used by the NDIA in its monitoring and forecasting roles).

Adding developmental delay — what effect?

The evidence suggests that providing individualised supports for children with developmental delay can improve outcomes for individuals and reduce costs — it is therefore consistent with the early intervention insurance principles of the scheme.

A review undertaken for the Department of Social Services (DSS) estimated that about 11 600 children with developmental delay or global developmental delay would be eligible for support under the scheme at a cost of $155 million each year. While no definitive data are available to test this estimate, trial site data (which may not be reflective of full scheme prevalence rates) suggest higher prevalence rates than the estimate provided to the DSS.

For children with developmental delay to be eligible for individualised supports, they need to have a delay across multiple domains. This suggests that the eligibility criteria set an

appropriately high hurdle. However, the NDIA tested a sample of children who entered the NDIS during trial with the PEDI-CAT assessment tool and found that 40 per cent of the children did not have any identified deficits compared to the normal range for their age.

The NDIA's recently introduced ECEI approach (box 3), put in place in response to the higher than expected number of children entering the scheme in the trials, should tighten the entry pathway for children aged 0–6 years, and help ensure that only children who meet the eligibility criteria receive supports through the scheme. The NDIA is also developing an early intervention approach for the 7–14 years cohort.

Box 3 Early Childhood Early Intervention

The Early Childhood Early Intervention (ECEI) approach is designed to be a 'gateway' to the National Disability Insurance Scheme for children aged 0–6 years. It aims to ensure that only those children who meet the eligibility criteria of the NDIS become participants of the scheme. Under the ECEI approach, families meet with an early childhood intervention service provider to discuss the needs of their child. The provider then identifies appropriate supports for the child and family, and whether the supports should be provided through the NDIS or through mainstream services. As the National Disability Insurance Agency put it, 'the ECEI approach aims to ensure children are provided with the right level of support at the right time for the right length of time'.

The ECEI approach is also aimed at ensuring early intervention supports are effective and result in the exits expected in the 0–6 years cohort. The National Disability Insurance Agency plots a child's progress against development milestones and supports the child to access mainstream supports when NDIS supports are no longer required.

It is too early to gauge the success of the ECEI in upholding the eligibility criteria of the NDIS and to assess its effectiveness in supporting children who are not eligible for individualised supports. However, given that children receiving early intervention supports are one of the largest groups in the scheme, it is critical that the NDIA builds an evidence base to inform the types of intervention that are most beneficial and should be funded. The NDIA has developed an evaluation and monitoring framework for the ECEI approach, but the effectiveness of this framework is yet to be tested.

The role of diagnostic lists

The NDIA maintains a list (List D in the latest NDIA operational guidelines) that allows for streamlined entry into early intervention supports for children who have a condition on this list. List D contains about 130 conditions, including Global Developmental Delay.

Maintaining such a list represents a trade-off. The appeal of such a list is that it places less onus on families to demonstrate eligibility, reduces the administrative burden on the NDIA and provides a degree of certainty for the families of children with these conditions. However, the list can also affect incentives, and can be an overly-generous entry gateway if set too expansively. Also, if diagnosis forms the basis of early intervention, a child would remain eligible for early intervention supports so long as their condition is present, even if

the expected benefits from early intervention have been realised (or are unlikely to be realised).

The NDIA also maintains a list of conditions (List A) that allows for streamlined entry into the NDIS through the disability requirements.

While there is little evidence that these lists are resulting in people entering the scheme who would not meet the wider eligibility criteria, the NDIA did point to Autism Spectrum Disorders as potentially representing a difficulty for List A:

> … there is evidence to suggest that use of the diagnosis process for autism may differ from the process's intent (resulting in access to the Scheme where eligibility requirements would not otherwise be met).

Because the lists are a key entry pathway, monitoring them is essential to ensure they work as intended. A process for quickly changing the lists as new information comes to light is necessary, as is transparency about what is on the lists and why changes are made.

Psychosocial disability and the NDIS

In 2011, the Commission recommended that people with psychosocial disability (the term used to describe disabilities that can arise from mental health issues) be supported through the NDIS. This was on the basis that:

- the day-to-day support needs of people with significant and enduring psychosocial disability are often the same as people who have an intellectual disability or an acquired brain injury
- some important parts of the care requirements of people with psychosocial disability — namely community supports — are best met through the NDIS
- providing supports to people with psychosocial disability through the NDIS provides them with the wider benefits of the scheme, including individualised supports and more choice in what supports are provided, when and by whom.

These points remain salient, and lend support to people with psychosocial disability being supported through the NDIS. And, while the Commission heard a range of views about whether the NDIS is the 'right' vehicle to provide support to people with psychosocial disability, most stakeholders supported its inclusion.

Concerns were also raised about the need for permanency under the NDIS Act being incompatible with the recovery models used in supporting people with psychosocial disability. However, the investment approach of the NDIS and the recovery model of mental health are both about building capacity, and appear to be well aligned. The NDIS Rules and operational guidelines accept that a permanent condition may be episodic requiring different levels of support at different times.

Scheme participant numbers suggest that people with psychosocial disability are able to demonstrate that their condition is, or is likely to be, permanent. At the end of June 2017, about 6000 people with psychosocial disability received individualised supports. And data to December 2016 shows just over 80 per cent of people with psychosocial disability who lodged an access request to the NDIS were eligible for the scheme.

While the Commission does not support changing the eligibility criteria to relax the definition of permanency and how it relates to psychosocial disability, it does recommend a change in the way that people with psychosocial disability engage with the scheme. A psychosocial gateway, involving specialised staff, designed in consultation with experts in mental health, has the potential to improve how the scheme engages with people with psychosocial disability at an operational level.

Estimating the number of people with psychosocial disability eligible for the scheme is difficult because a robust and comprehensive database from which to draw is lacking. While there are estimates by a number of stakeholders and agencies, they vary greatly. It would be beneficial for the different methodologies to be made transparent, so they can be used to better project the numbers of participants with psychosocial disability at full scheme.

Concerns about gaps in support for people with psychosocial disability not eligible for the NDIS are discussed in section 8.

7 Supports and plans

Scope of supports

The NDIS is designed to cover specialist disability supports that are reasonable and necessary. This includes supports that help people with disability to:

- pursue their goals and maximise their independence
- live independently and be included in the community as fully participating citizens
- participate in the community and in employment.

The extent of support coverage directly impacts the costs and benefits of the NDIS — too little will result in lost benefits within the scheme, but too much could create cost pressures and pose a risk to the financial sustainability of the scheme.

The scope of supports covered by the NDIS is governed by legislation, rules and guidelines and, over time, will be shaped by court and tribunal decisions. What legislation and case law say about reasonable and necessary supports is important because it sets parameters for how the NDIA can operationalise support allocation. It also provides future courts and tribunals with a framework for evaluating whether decisions about supports have been properly made.

Ongoing monitoring and evaluation can help ensure that the body of law around reasonable and necessary supports is operating in a way that is consistent with community expectations and the objectives of the scheme. The review of the NDIS Act scheduled for 2021, agreed to by COAG, should look at the impact of court decisions on the content of the law as well as other issues raised in this study relating to the drafting of the NDIS Act.

About plans and the planning process

The planning process is about matching scheme participants with supports. It involves conversations between the participant and the NDIA to ascertain each participant's goals and aspirations, level of function and appropriate supports. The NDIS Act requires that a plan is developed and, where possible, is individualised, directed by the participant, and maximises participant choice and control.

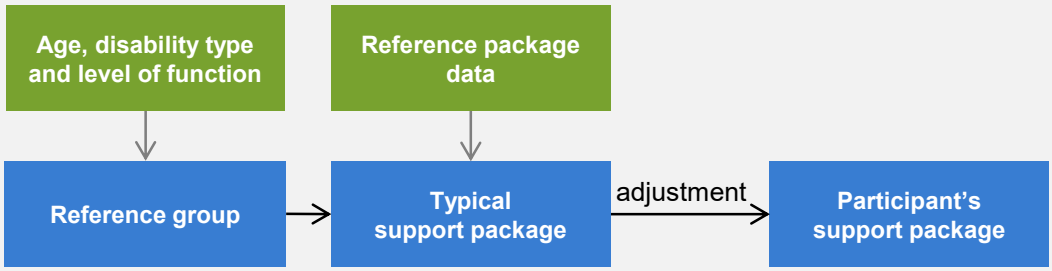
The quality of planning processes is a key determinant of the success and long-term sustainability of the NDIS — it influences what costs are incurred; the predictability of costs; the market for disability supports; outcomes for participants; and the integrity of, and community support for, the scheme.

Participants need to understand the planning process

The planning process has changed significantly since the NDIS commenced in 2013. At the beginning of the transition period the NDIA introduced a new process for determining participants' support packages, using reference package data (box 4). This approach has resulted in more plans being in line with benchmark costs (compared to the trial period). As with all insurance-based schemes, the tools and processes for handling claims and assessing entitlements are a matter of ongoing refinement. This is necessary to ensure that the insurance scheme remains 'on track' and is viable in the long term. Dynamic processes are also important to allow the scheme to adapt to changing circumstances or incorporate information that becomes available over time.

Box 4 **Using reference package data in planning**

Participants are first allocated a 'typical support package', based on their reference group (which is determined by their age, disability type and level of function). The typical support package may include funding across the following eight core domains: daily activities; social participation; consumables; transport; home modifications; assistive technology; capacity building; and support coordination.



For each participant, the level of funding is adjusted according to the participant's circumstances. This is done using a questionnaire, which asks the participant about each of the domains, including what supports they already have in place, and whether these are sufficient and sustainable. For example, where it is reasonable that sustainable informal, community or mainstream supports continue to assist the participant, or where the participant believes that other informal, community or mainstream supports may provide a better outcome, funding is adjusted in the participant's support package.

In light of this, it is important that stakeholders can access accurate and up-to-date information about planning processes. Clear messaging about how and why things are changing is also important to maintain the credibility of evolving planning practices.

The NDIS planning process is complex and confusing, and often lacks clarity and transparency. It is difficult to access information about assessment tools that are used by the NDIA and how support allocation is determined. There is also limited information to help scheme participants and their families, carers and advocates navigate the planning system. Scheme participants are often not aware of their rights and options, such as their entitlement to request a face-to-face meeting or have an advocate present during the planning meeting.

There needs to be greater transparency and clarity around the NDIA's planning processes. There also needs to be clear and up-to-date information about what participants should expect during the planning conversation, when it will occur, and how the information gathered during the conversation will be used.

Phone planning

The move to transition saw a shift from face-to-face to phone planning. The NDIA adopted this approach to allow people to enter the scheme as quickly as possible, with the intention of adjusting and improving plans over time. During trial, people indicated that they wanted to join the scheme as soon as they could. The speed of the transition placed a lot of pressure on the NDIA to finalise plans quickly and phone planning was part of the solution.

But there is a lot of dissatisfaction with phone planning (box 5). A number of participants said they felt rushed during their planning meetings. As one study participant put it:

> … the transition time pressures [appear] to have resulted in a reduction in the time available to assist people to resolve their plan; in some cases this is reported to have reduced to a 30 minute phone call. This could not be further removed from the feature of a 'person centred model of care and support' that is meant to distinguish the NDIS from previous approaches.

Box 5 Dissatisfaction with phone planning

Social Support & Precarious Workforce Research Discussion Group:

> … some participants are not fully aware that the phone conversation occurring with the NDIS staff member is actually their planning process occurring. This confusion is also evident in the NDIS marketing of phone-planning as a 'planning conversation', where the suggestion is you will 'talk-about' the plan whereas the reality is that it is a full and structured assessment and plan procedure.

The Disability Services Commissioner:

> Planners are not providing clear and accessible information about the planning process including when and how planning will take place. A sister of a participant said that someone from NDIA had rang her while she was in the car. They advised that they were 'only collecting answers' and it would 'only take a minute'. Following that conversation, her sister received a plan for approval from the NDIA, with less funds than she had previously received.

Alzheimer's Australia:

> Annie called the Parkinson's 1800 support line as she worried about an over the phone NDIS planning session that had taken place earlier that day. Annie's volume and quality of speech has been impaired due to Parkinson's and she also requires longer to respond to questions. She felt rushed and because her response is delayed she felt that the assessor didn't get a clear indication of her needs. Annie and a Parkinson's Nurse Specialist were able to take the time [to] put information together in order to apply for a review for Annie's plan.

Blind Citizens Australia:

> [Phone planning] severely compromises the ability of people who are blind or vision impaired to demonstrate the difficulties they may face with completing tasks like reading, navigating the environment or household chores.

The Commission also heard (on numerous occasions) that participants were called with no forewarning of the planning conversation, or were not informed that the call was a planning conversation (so the person was not prepared and could not have an advocate present).

An individualised approach to planning is a key feature of the NDIS and sufficient time is required to match participants with the supports that are right for them. Phone planning can mean that planners do not 'get the full picture'. For example, the living environment of participants may not be adequately reviewed (which means issues such as accessibility, safety and appropriate assistive technology can be difficult to identify).

Phone planning is not appropriate for some participants, including those with particular accessibility requirements, mental illness, cognitive impairment and neurodegenerative diseases, and people of culturally and linguistically diverse backgrounds. However, it may be appropriate for others, particularly if there is adequate pre-planning. The Commission

recommends that the NDIA review its protocols relating to phone planning. The NDIA recently said that, in response to feedback from scheme participants, it intends to use face-to-face planning as a default approach.

Pre-planning

The pre-planning phase of the planning process has not received adequate attention. As a result, many participants are ill-prepared for planning, and this is affecting the quality of plans. The NDIA acknowledged that, because of the speed of the transition, it was not able to engage Local Area Coordinators (LACs) in time to provide participant and community development during the pre-planning stages.

A greater focus on pre-planning should make phone planning suitable for a larger pool of participants. LACs need to be in place six months in advance in the areas in transition to assist with pre-planning. This is a better (and potentially less costly) approach than trying to 'fix' plans over time. It will also mean that participants are better able to exercise choice and control (and this is more likely to induce a provider response).

Planners need more disability knowledge

Planners' limited disability knowledge is a real concern (box 6). Many advocacy groups said that planners do not have sufficient knowledge of particular disabilities or the impact that particular conditions have on people's lives, and they often do not know what supports are most effective for the participant's disability. Alzheimer's Australia, for example, reported that a person with Multiple Sclerosis (MS) was asked by the LAC at a planning meeting, 'How long will MS last?'.

Planners should, at a minimum, have a general understanding about different types of disability. There should be specialised planning teams for some types of disability, including psychosocial disability. The NDIA should also make better use of expertise from within the industry, including by getting specialist disability organisations or service providers more involved in the planning process. A risk-based approach to managing potential conflicts of interest that could arise from such arrangements should be adopted by the NDIA. This would also mean that the NDIA would not need to compete with others in an already thin market to recruit planners with specialist qualifications or experience.

Box 6 **Planners — not enough disability knowledge**

MND Australia:

> LAC's do not have the expertise to support people with [motor neurone disease]. … They have no understanding of MND and the disability it creates. They attempt to plan via a telephone conversation, when speech and communication can be one of the early losses created by MND.

Alzheimer's Australia:

> Peter, the carer of a woman with younger onset dementia, felt unprepared when he and his wife attended their first NDIS planning session. … The NDIS planner had no understanding of dementia and the needs of people living with dementia and as a result the planning session focused on physical needs and solutions … Feedback from people with progressive neurodegenerative diseases has revealed that [LACs] have also shown insufficient knowledge of their disease, the impact of that condition on their lives, the most effective service interventions and the degenerative and fatal nature of their disease.

Amaze:

> Amaze's 2017 survey found: 65% of respondents rated their planner's knowledge and understanding of autism as none to moderate a level (with the remainder rating the planner's knowledge as high). … given 30% of participants identify autism as their primary diagnosis, a high level of ongoing training in autism will be a necessity to developing and maintaining their capacity to reliably develop plans.

New South Wales Government:

> … planner knowledge and capability is highly varied, as is their interpretation of reasonable and necessary supports and understanding of interim working arrangements with mainstream services. Approved supports are less likely to be based on a participant's needs and more on a planner's knowledge of the disability and/or how effectively the participant or their carer advocate for certain supports.

8 Boundaries and interfaces — the NDIS and services outside the scheme

People with disability, their families and carers rely on a wide range of services — including mainstream services, specialist disability services and community supports. For the NDIS to work efficiently and effectively, the interface of the scheme with these other services must be as seamless as possible.

While the level of funding provided to the NDIS recognised that the aggregate level of funding available to people with disability was inadequate, it was not expected that the NDIS would fill *all* the service gaps that predated the scheme. Providing services to people with disability remains a shared responsibility between all levels of government.

The interface between supports for people with disability will take time to clarify, but in the meantime it is important that governments do not prematurely withdraw from services, as any gaps that emerge will place added burdens on people with disability and their families. As the interface issues become clearer, it is important that incentives do not exist for individuals to prefer one system over another. Most critically, the NDIS should not be seen as an oasis of support, surrounded by a desert where little or nothing is available.

While there is much detail yet to be worked through, establishing clear and robust boundaries (and appropriately tailored supports) is essential to the fiscal sustainability of the NDIS, and for the surrounding network of supports.

Linking people to the right services

The Commission's 2011 report recommended a bridging and capacity building service for people with, or affected by, a disability (known as Tier 2 supports). The ILC program is a key component of the NDIS. It is designed to provide information, linkages and referrals to people with disability, their families and carers, with community and mainstream supports. The focus of ILC is on individual development and community inclusion.

ILC will be important for scheme sustainability. It is expected to reduce reliance on NDIS funded support over time by:

- reducing the demand for individualised supports and the need for supports within funded packages
- making supports more effective at helping people achieve their goals.

In July 2017, the NDIA began rolling out the ILC program. Funding for ILC will gradually increase over transition (from $33 million in 2016-17 to $131 million in 2019-20). The timing of ILC funding is determined by governments (it starts with a small budget that increases over time) and has prevented the NDIA from investing in ILC activities and rolling out a national ILC framework. At the same time, State and Territory Governments are withdrawing from existing ILC-type activities.

It is a false economy to have too few resources for ILC activities in the transition period — it is critical to have structures in place to ensure that people eligible for the NDIS can access the scheme, and those who are not eligible can access supports and services outside the NDIS.

ILC funding should be increased to the full scheme amount ($131 million) for each year during the transition and be focused on national ILC activities. The effectiveness of the ILC program in improving the outcomes for people with disability and its impact on the sustainability of the NDIS should be assessed as part of the 2023 review of NDIS costs, when data on ILC activities will be available.

Interface with mainstream services is not clear at an operational level

The Australian Government has entered into bilateral agreements with State and Territory Governments to delineate the types of services to be provided and funded by the NDIS and mainstream services. Schedule 1 of the *National Disability Insurance Scheme Rules (Supports for Participants) 2013* (Cwlth) sets out the rules to determine whether the NDIS or another system is most appropriate to fund specific supports for individuals.

COAG has accountability for the NDIS and the *National Disability Strategy,* and through its Disability Reform Council (DRC), receives reports and advice on progress and risks. While the principles agreed to by COAG on the boundaries between the NDIS and mainstream services are clear, greater clarity is required at the operational level. This will prevent duplication, gaps and cost shifting by the NDIA, and the Australian, State and Territory Governments.

The boundary issues are yet to be tested. However, the *National Disability Strategy* should be strengthened to include more detail around boundaries (based on challenges faced when seeking to operationalise boundaries), and greater accountability. At review points of National Agreements and National Partnership Agreements under the Intergovernmental Agreement on Federal Financial Relations, parties should agree to specific commitments and reporting obligations that are consistent with the Strategy. As the DSS said:

> Translating the National Disability Strategy into tangible results for people with disability, their families and carers is a major factor in successful implementation of the NDIS.

Adding a standing item to the agenda of each COAG council that is responsible for services that interface with the NDIS to discuss any gaps in service provision would also help build clarity around what services governments will provide, and ensure ongoing monitoring and solutions for potential future gaps. The Councils should put forward issues to be resolved and suggested actions to the DRC.

Concerns that some people with disability may be left without services

Many are concerned that, as disability support programs are rolled into the NDIS, people using these services (including those not eligible for the NDIS) may no longer receive continuity in support. This is a key risk to the financial sustainability of the NDIS — and one that the NDIA has little control over.

Mental health services are an area of particular concern. The National Mental Health Commission's report on Mental Health Programs and Services estimated that about 700 000 Australians experience a severe mental illness in any one year. According to the NDIA, about 64 000 people with primary psychosocial disability are expected to be eligible for individual packages in the NDIS at full scheme.

Clearly, there needs to be support for people with mental health illnesses outside of the scheme — a responsibility that remains (largely) with State and Territory Governments. However, governments are withdrawing their funding for a number of mental health support programs and using this funding to offset part of their contribution to the NDIS. At this stage, it is unclear what supports will be available for people with a mental illness who do not meet the NDIS eligibility criteria. This should be clarified as a matter of urgency.

The implications of this are significant. Not only is uncertainty distressing for those with mental illness, any gap in support places an additional call on the generosity of informal support. Gaps could also place pressure on the financial sustainability of the NDIS if they

encourage scope creep, or force those who are unlikely to meet the eligibility criteria to test their access for fear of having few supports should they not qualify for the scheme. Mental health and psychosocial disability are a key priority of the DRC, but more clarity is required.

While the Australian and State and Territory Governments have agreed to provide continuity of support for disability services outside the NDIS, in practice there is confusion and uncertainty about what services will continue to be provided and/or funded. Governments need to be clearer about how they will approach continuity of care, and transparent about what disability services they will continue to provide for people who are not eligible for the NDIS.

Gaps in disability services need to be quickly identified (possibly with the assistance of ILC and LACs) and managed, to ensure the sustainability of the overall scheme. The NDIA and the Australian and State and Territory Governments should report regularly to the DRC on boundary issues.

9 Market readiness

The market-based approach of the NDIS means that there will be significant changes in the way that supports are demanded by, and provided to, participants. This disruption of the disability supports market is designed to maximise the choice and control of participants, while also giving providers incentives to efficiently and effectively deliver the supports that participants want and need.

While the scheme will drive efficiencies, the increase in funding and considerable unmet need in the disability support sector means that the number of workers and providers will need to grow quickly over the transition period. For example, the NDIS workforce will need to more than double from 2014-15 to 2019-20. The scale, scope and capacity of providers will also need to expand substantially. As the success of the NDIS relies on providing the right supports to participants, market readiness will affect costs during transition and beyond.

Providers face challenges to be ready for the NDIS

To meet the needs of NDIS participants, there must be a significant increase in the quantity, quality, range and responsiveness of disability supports.

In making the transition to a market-based system for disability supports, providers are facing the prospect of workforce shortages and coming to grips with operating in a market that will, for some time, be characterised by price caps. The shift in the business model, from a block-funded to a fee-for-service environment, is highly challenging for many.

Prices are critical for market development and participant outcomes

Participants exercising choice and control will increasingly drive the price of disability supports. And these prices will drive providers to supply the supports that participants most value, and encourage competition and innovation among providers. Allowing the market to determine the price of supports is an important tenet of the NDIS — it will contribute to both participant outcomes and the financial sustainability of the scheme.

However, prices are currently regulated. The NDIA sets maximum prices ('price caps') for many of the supports provided by NDIA-registered providers to:

- ensure value for money for participants — as the price of supports may be bid up too quickly before the sector grows sufficiently to meet the increased demand
- encourage the market supply of disability supports.

In practice, the NDIA must balance these two objectives. If prices are set too high, this will encourage the supply of supports, but reduce the purchasing power of participants. If prices are set too low, this could lead to a shortage of particular supports. Striking the right balance is difficult. From a long-term perspective, price regulation should not linger for years, have excessive scope, nor skew the market (such as by benefiting some providers or participants over others).

The Commission heard from many stakeholders that the NDIA's pricing methodology has, in some cases, led to perverse incentives, poor participant outcomes and hindered market development — especially for supports required by participants with complex needs. According to the NDIA, existing providers (many who previously relied on block-funding) are finding it difficult to adjust to the fee-for-service model.

The NDIA, on completing its 2017-18 price review, commissioned McKinsey & Company to review its pricing approach. The report will be completed at the end of 2017.

The Commission agrees with the NDIA's findings from recent reviews that the communication, transparency and timeliness of the pricing process needs to be improved. Price regulation of NDIS supports should be administered by a body with relevant capabilities and necessary resources. Prices of supports should be regulated as narrowly and for the least time possible, as well as be:

- transparent, with wide public consultation and publicly available information, including all assumptions used in any pricing models
- more granular and targeted by setting prices for supports at the state and territory level, with an expectation that price signals could be set at a more disaggregated regional level where possible
- evidence-based, with the collection of data and public reporting on providers' characteristics and costs
- supported by clear and limited legislative authority

- timely (giving providers sufficient time to phase in changes and be responsive to market conditions) and reviewed on a regular basis
- used only when there is clear evidence that unregulated prices are likely to lead to inflation that would harm participants.

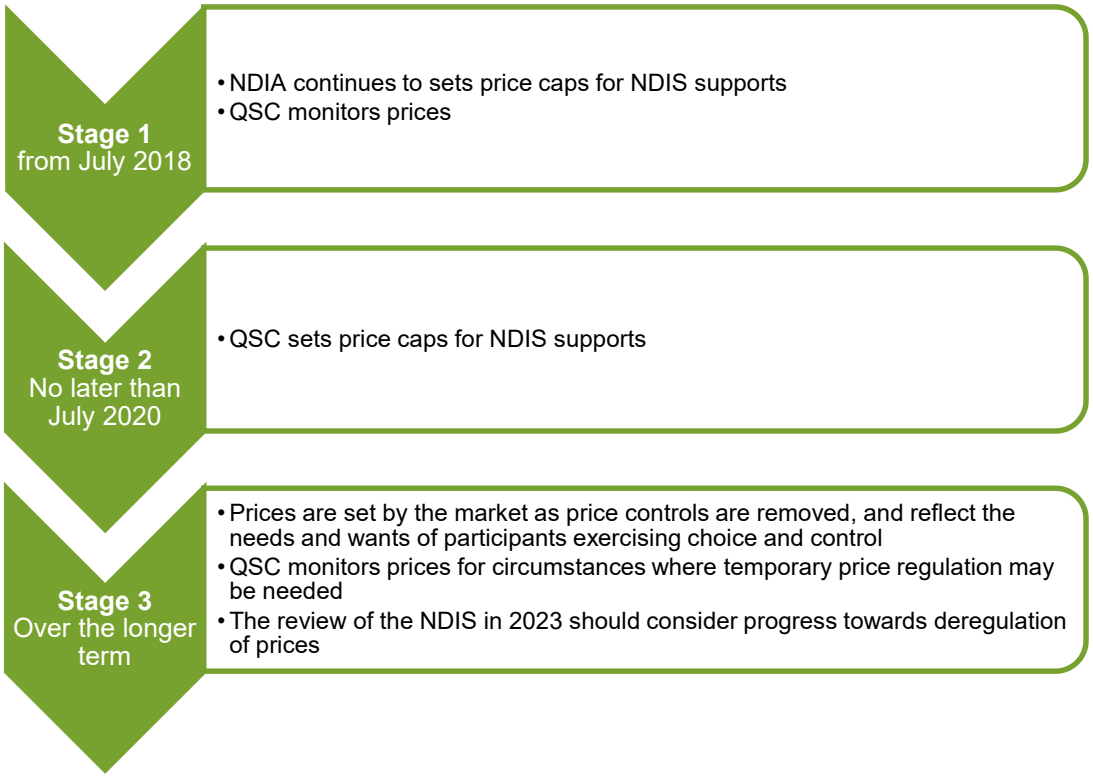
The Commission is concerned that while ever the price-setting mechanism is held within the NDIA, there is an incentive for it to be used to offset budget pressures. Prices should be set with market development as the primary focus. To better reflect the above principles, the Commission proposes moving towards the deregulation of prices in three stages (figure 7).

- The first stage reflects the current situation: the NDIA continues to set price caps for NDIS supports. But to provide additional oversight and improve the transparency of price-setting, the NDIS Quality and Safeguards Commission (QSC) should begin monitoring prices from its commencement in July 2018, particularly to highlight price settings it considers to be inconsistent with longer-term market development.
- The second stage (following the end of transition) addresses the greater need (see above) to ensure strong and competitive markets that provide a sufficient quantity of supports to meet the demand from 475 000 participants. To that end, the QSC should take over the role of price regulator no later than July 2020.
- The third stage is characterised by the longer-term removal of price controls by the QSC as markets for disability supports become more fully developed (which will occur at different times in different jurisdictions). The review of NDIS costs in 2023 should consider the state of market development including progress towards deregulation of prices. Following deregulation, there will still be need for the QSC to monitor prices to ensure that participant outcomes are being achieved through the ongoing provision of safe and quality supports.

It is undeniable that the supply response to the scheme is less than what will be required to deliver supports to participants.

The NDIA's cautious approach in setting prices was commensurate with the uncertainties around cost pressures early in the scheme, but the pace and growth of market development now needs to be accelerated. Vesting price regulation powers in the QSC will ensure that market development (and participant wellbeing) receives the focus that it needs, and reflects its increasing importance over time as the scheme rolls out.

Figure 7 **The PC's recommended path for NDIS price deregulation**



Without better oversight and transparency of price signals in the near term to achieve the required significant increase in supply, the benefits of the NDIS will not be fully realised. These concerns were raised by numerous stakeholders, including many of the governments funding the scheme. The Victorian Government, for example, said:

> It is important to separate the price-setting function from the NDIA and then clarify the role and accountability to be retained by the NDIA. Victoria considers that there is also an immediate need to consider areas where NDIS pricing may be inhibiting market growth or risking provider failure (particularly in areas or services in which there are thin markets). In some areas, the NDIA appears to have applied flawed assumptions to its calculation of prices. Examples include low allowances to train, supervise and recruit direct support staff, unrealistic assumptions around the amount of time staff need to spend undertaking non-client facing functions, and low assumptions around the proportion of overall costs devoted to overheads (particularly during the transition period). Victoria considers that these areas should be corrected as soon as possible.

Independent price monitoring and regulation will benefit participants, providers, and the community. Participants will be assured that quality and safety standards are considered in the pricing of NDIS supports. Providers will have greater certainty that price setting will be transparent and evidence-based. And the community can be confident that the funds they have contributed to the scheme will be spent in a way that best balances the needs of market development and the interests of participants.

Thin markets need more attention

When creating a new market for disability supports, there is a risk that, in some areas, or for some types of supports, the market (the number of providers or participants) will be too small to support the competitive provision of services ('thin market'). Thin markets are not new — they have been, and will continue to be, a persistent feature of the disability support sector.

In the absence of government intervention, there will be greater shortages, less competition, and ultimately poorer outcomes for participants. Participants at most risk are those who:

- live in outer regional, remote or very remote areas
- have complex, specialised or high intensity needs, or very challenging behaviours
- are from culturally and linguistically diverse backgrounds
- are Aboriginal and Torres Strait Islander Australians
- have an acute and immediate need (crisis care and accommodation).

The NDIA has not, to date, developed a Provider of Last Resort policy, or its Market Intervention Framework, and this has led to concerns about continuity of services. These policies should be published as soon as possible.

More flexible funding, service delivery and other measures tailored to specific circumstances are also needed. The NDIA should consider the widest range of approaches, including block-funding.

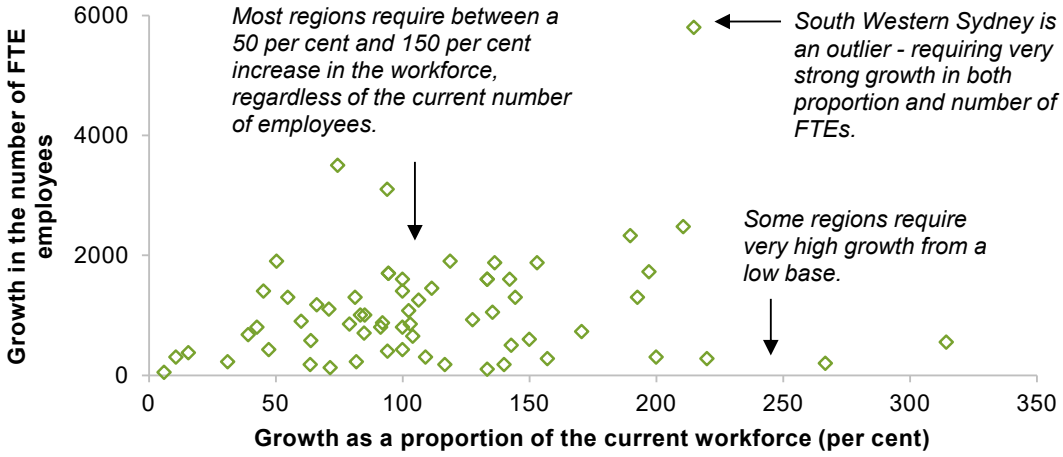
The NDIA should also collect and publicly release granular data, feedback and reports on thin markets, including when Provider of Last Resort arrangements are used. This will help inform the appropriateness and effectiveness of market interventions. Regardless of the approach chosen, there is a need for transparent reporting and evaluation of thin market arrangements, and collaboration between the Australian and State and Territory Governments.

The workforce is not growing fast enough

As the NDIS provides more individualised supports for people with disability, the workforce needed to provide those supports will need to both increase and become more diverse. There is broad consensus that the number of full-time equivalent positions will need to roughly double over the transition period — at a local level, some regions will need to triple their workforce or more to meet demand (figure 8).

Figure 8 **Variation in workforce growth required in different regions[a]**

Each dot represents the growth in the amount of full-time equivalent (FTE) employees needed relative to the current situation, both in terms of the number and proportion, between 2015-16 and 2019-20.



[a] The NDIA's market position statements provide 'low and high' estimates for the number of FTE disability workers at present and what will be needed in the future. To derive these estimates for growth, the midpoints of each range are used. No data are available for Western Australia. Regions are areas consisting of several local government areas.

Several policy changes are recommended to mitigate the potential workforce shortage over the short term, including:

- meeting the desires of many existing workers — who are qualified and experienced, and usually work part-time — to work additional hours
- trialling different approaches to help fund volunteer organisations to provide participant supports
- allowing for skilled migration where residual shortages remain persistent.

Building the workforce is a long-term exercise

While these measures will help to address workforce shortages in the transition period, more attention also needs to be paid to the longer-term development of the workforce.

The responsibility for workforce development is currently shared jointly between the DSS and the NDIA — with the former having 'oversight' of workforce development and the NDIA allocated the task of 'market steward'. The DRC also plays a role in workforce development issues, along with the relevant State and Territory Government departments.

The current fragmented landscape of roles and responsibilities for workforce development is understandable given the breadth and reach of the scheme, and the speed of implementation, but is unacceptable. The risk is that a fragmented workforce policy may

lead to inaction, or result in duplication or unnecessary programs at a time when the scheme can least afford it. While some progress is being made to better coordinate the activities of different jurisdictions, much more needs to be done.

A 'big tent' approach to workforce development remains appropriate, but the roles and responsibilities of different parties should be clarified and made public. This is a big task, and is not yet being given the attention it needs.

- State and Territory governments should have more responsibility for workforce development issues over the transition period, as they have the best experience of where there has been historically unmet need and the approaches best suited to solve such issues in particular jurisdictions.
- The Australian Government should retain oversight of the scheme, and focus on areas that affect the supply and demand of care workers from an economy-wide perspective, including the interaction of the NDIS with other care sectors (such as aged care) and monitoring trends in the supply of skilled workers through tertiary and vocational education.
  - The Australian Government should adjust immigration policy where necessary to address workforce shortages.
- The NDIA is best placed to provide more granular detail to governments on where supply gaps are emerging, or likely to emerge.
- Governments should also regularly consult with providers on emerging workforce policy issues, such as where the incentives of the scheme may be affected by other laws and regulations like minimum standards, conditions of State and Commonwealth awards, and training and development.

Over the long term, the workforce development responsibilities of State and Territory Governments will diminish as the NDIS is fully rolled out and supplants their existing disability support programs. Even then, State and Territory Governments should remain 'in the tent' when it comes to workforce policymaking given the interaction between the NDIS and other mainstream services.

Building the evidence base is also important

Existing data on the size and scope of disability care workers and the organisations they are employed by are poor, and not commensurate with the importance of the NDIS. The DSS (the agency currently tasked with market development oversight) said that 'a significant limitation to assessing the NDIS market readiness is the availability of market and workforce data'. To address this deficiency, the Australian Government should fund the collection of more fit-for-purpose data by the Australian Bureau of Statistics and the university sector.

Participants need help to make the most of the NDIS

The NDIS is about giving participants more choice and control over their supports. While some participants will be ready to manage and work with the NDIS to implement their plans, others will be less so, and may find it difficult to get the most out of the scheme. This in turn will reduce the overall benefits and financial sustainability of the scheme.

How ready participants are to make the most of their plan will depend on a number of factors, including: an individual's capacity; their network of informal carers and peers; the assistance provided under the NDIS; how ready the market is to provide supports; and the complexity of the scheme. As participants spend more time in the NDIS, there will also be some degree of 'learning by doing'.

However, some scheme participants are finding it hard to understand and interact with the NDIS, particularly because the scheme is a new way of allocating and supplying disability supports. There is a lack of useful information about providers and their services. Providing timely, accessible and useful information to participants about providers will help people with disability access their NDIS supports, and better exercise choice and control.

Supports provided in plans give some assistance to participants to implement their plans, including through support coordination (a key means to bolster the readiness of participants with complex needs). However, there is some evidence that support coordination is being provided to participants for only a fixed period of time. The NDIA should allocate support coordination based on need, rather than time.

Intermediaries can also help participants navigate the NDIS, as they can provide tailored supports to participants to manage their plans, including helping to pay providers and hire workers. Intermediaries are especially important for those who may struggle to deal with the administrative burden of managing their own affairs (while allowing participants to retain choice and control). They can also reduce scheme costs by reducing the administrative burden for the NDIA and aggregating participants' purchases of common supports.

However, the take-up rate of intermediaries to date has been slow. Only 11 per cent of participants in the transition period are using intermediaries. To encourage greater use of intermediaries, the NDIA should provide more information to participants and planners about the roles and use of intermediaries. Intermediaries should also be closely monitored to ensure that safeguards are in place to protect participants and providers. And the NDIA should continue to assess the capacity of participants to self-manage on a case-by-case basis.

Disability advocates also play an important role and help participants in a way that NDIS supports cannot. They can help participants get better plans, find supports, navigate the new scheme with its new jargon and complexities, and provide systemic advocacy about difficulties faced by people with disability. However, many State and Territory Governments have reduced or ceased funding for disability advocacy — rolling it into NDIS funding of supports instead. As advocacy remains important over the transition period, the Commission

recommends that funding be restored by jurisdictions that have ceased or reduced funding, and data collection and evaluation of disability advocacy be increased.

More effective government stewardship of the market is needed

As discussed above, there are substantial challenges developing the market supply of disability supports. While some progress is being made, there are still difficulties in growing the number of providers and the disability care workforce, as well as helping participants to become informed and effective consumers (figure 9). This is occurring at a time when the rapid pace of the rollout — and growth in demand for supports — is at its greatest. Based on experience to date, there will be a shortage of disability supports under the scheme.

Many of these challenges could have been anticipated. This highlights the need for more effective market stewardship by governments (including by the NDIA). As the Agency said:

> Market stewardship recognises that when governments implement policies to increase consumer choice and adopt market-based delivery, they must also oversee how the marketplace develops.

Just as providers, workers and participants need to change their approach to disability supports, so too must governments.

The responses from jurisdictions have varied, and their effectiveness is unclear. Although some of the variation reflects jurisdictional differences (including the rollout timetable), it also highlights the uncertainties around the roles and responsibilities of governments under the NDIS. In practice, this has led to gaps, duplication and shifting of responsibilities. This is a risk to the scheme, and to the wellbeing of participants and their families.

While the bilateral agreements provide some level of detail about 'who is responsible for what', more rigorous communication, public reporting and coordination of market stewardship activities are needed. The DRC should immediately clarify and publish the specific and practical delineation of market stewardship roles, responsibilities and accountability arrangements of Australian, State and Territory Governments. Where governments, their agencies and/or the NDIA are responsible for a market stewardship task, there should be clear and transparent reporting about the specific outcomes they are to achieve, the timeframe in which it is meant to occur, and progress towards that goal. Governments should also coordinate their market stewardship actions across all sectors, particularly with other care sectors and mainstream services.

Coordination among market stewards is important, but the release of timely, market-relevant data are also needed urgently. The Australian, State and Territory Governments should, with the NDIA and QSC, collect and publish disaggregated, tailored and forward-looking market data. This includes provider and workforce data, as well as qualitative information and feedback from liaison with market participants. A better evidence base would enable a deeper understanding of the market and in turn, inform risk-based market stewardship responses.

Figure 9 **The main actors, actions and Commission's recommendations affecting market readiness**

Key issue	Provider readiness: Price Signals	Provider readiness: Non-Price Signals	Workforce readiness	Participant readiness
Responsible stakeholders	Price regulator (currently NDIA)	Provision of market information (NDIA)	Coordination of workforce development activities by Governments, DSS and NDIA	Assistance in plans (NDIA)
Main current actions	McKinsey & Company price review initiated by the NDIA	Changes arising from the NDIA provider pathway review	Sector Development Fund Workforce action plan developed by DSS	Changes arising from the NDIA participant pathway review
Commission recommends	Principles-based pricing Independent price monitor and regulator (NDIS Quality and Safeguards Commission)	NDIA to release more frequent and granular data on participant demand NDIA to make public its Provider of Last Resort policy and Market Intervention Framework	Better coordination between governments, providers and the NDIA to develop the workforce Appropriate data collection Trialling use of volunteers	Implement objectives of the eMarketPlace Clarifying the supports that help participants Encouraging use of intermediaries Continue funding disability advocacy

All of the market readiness issues suggest that market stewardship needs improvement

Clarify and make public the roles and responsibilities for each party
Require transparent and regular reporting against outcomes
Collect and make public disaggregated, tailored and forward-looking market data
Coordinate market stewardship actions across all sectors

10 Governance

The governance arrangements for the NDIS are complex and reflect the shared responsibility of the scheme between the Australian and State and Territory Governments. While the NDIS is administered by an Australian Government Authority (the NDIA) under Commonwealth legislation and under the direction of an Australian Government Minister, it is designed and funded by the Australian, State and Territory Governments.

In 2011, the Commission recommended a single national scheme, and a single national agency, to provide disability care and support. The Commission considers that this is still the best model, and that Western Australia, the sole jurisdiction to remain outside the NDIS, should be in the national NDIS. The possibility of Western Australia joining the scheme is currently under consideration by the Western Australian Government.

NDIS rules

Under the current governance arrangements, State and Territory Governments play a significant role in setting NDIS policy. For example, while the Minister for Social Services is responsible for creating NDIS Rules, Category A Rules require unanimous agreement from the Australian Government and each host jurisdiction.

There have been cases where NDIS rules have taken considerable time to implement. The process for implementing or amending Category A NDIS Rules should be streamlined, to ensure that swift changes can be made in response to developments that threaten the financial sustainability of the scheme. The Commission does not recommend that the requirement for agreeing to Category A NDIS Rules be changed from unanimous agreement. Instead, the process should be changed to encourage timely agreement to Rules without diluting the control of State and Territory Governments. This could be done, for example, by requiring governments to state whether they agree or disagree to a proposed rule introduction or change within a certain amount of time. No response could be taken as agreement to the proposal.

The NDIA's operating costs and staff cap

The NDIA needs sufficient autonomy to manage the NDIS as an insurance-based scheme.

The NDIA is subject to a cap on operating costs. At full scheme the cap is set at 7 per cent of package costs. While capping operating costs could encourage efficiency, if the cap is set too low it could hinder the NDIA's ability to effectively manage the scheme. While similar types of schemes operate close to a 7 per cent average when they are close to maturity, they also typically have significant fluctuations in their annual operating expenses as a proportion of their overall expenses. A target of 7 to 10 per cent, with the expectation that the NDIA would sit at the bottom of this range, would give the NDIA the flexibility to smooth year-to-year fluctuations in spending, while still encouraging efficiency.

The NDIA also has a full scheme cap of 3000 directly employed staff. Capping staff levels could lead to poorer outcomes, especially early in the scheme's life when the agency is building capacity and institutional knowledge, and developing first plans for many participants. The number of employed staff (and in-house skills) required will depend on the model adopted to undertake planning, and is likely to change as the scheme matures. The NDIA, as a corporate Commonwealth entity, should be given the independence to determine the most effective and efficient number of staff to deliver the scheme.

Monitoring the performance of the NDIS

Performance reporting is important for ensuring outcomes are realised and that there is accountability when they are not. It is also an important component of the insurance approach. The performance of the NDIS is currently monitored and reported through a number of reports, including the quarterly report to the DRC and the Annual Financial Sustainability Report.

While the NDIA is still developing its performance reporting, there are some gaps in the framework and the reporting against the framework, especially around quality. As reporting on outcomes develops, evidence of good outcomes will be evidence of good quality plans, processes and experiences. However, this could take many years. In the meantime, reporting on measures and indicators of quality is needed, and should begin by June 2018.

There is also a need for improved public reporting of review processes. The NDIA should publicly report on the numbers of reviews, review timeframes, outcomes of reviews, and participant satisfaction with the review process. This would improve clarity, transparency and accountability around the effectiveness of the review process.

11 Funding

To ensure that the integrity of the NDIS' objectives are maintained, the funding arrangements for the NDIS need to provide funding certainty and allow the scheme to operate in line with insurance principles. This requires:

- sufficient funding for the NDIA to take a lifetime approach to participant supports
- predictable funding that gives people with disability (and their families and carers), and those that may acquire a disability later in life, certainty that they will receive reasonable and necessary supports over their lifetime
- incentives for the NDIA to efficiently and effectively operate the scheme
- incentives for governments to take a collaborative approach to mainstream interfaces and other disability services.

The current funding arrangements

In 2011, the Commission's preferred funding option was for the Australian Government to be the single funder of the NDIS. This option was preferred on the basis that it would:

- provide certainty and clear lines of funding responsibility
- avoid the inefficiencies of the Commonwealth-State 'blame game' that can afflict shared funding arrangements
- reflect the Australian Government's capacity to raise efficient and sustainable taxes of the magnitude required.[6]

The Commission also recommended that the Australian Government direct payments from consolidated revenue into a National Disability Insurance Premium Fund using a legislated formula that provided stable revenue to meet the actuarially-assessed reasonable needs of the NDIS and included funding for adequate reserves.

The funding arrangement for the NDIS (expected to cost $22 billion in 2019-20) is a pooled approach (this was the Commission's second, less preferred option), with funding from Australian and State and Territory Governments. In the first year of full scheme, the State and Territory Governments (assuming Western Australia joins the national scheme) will contribute a combined $10.3 billion to the NDIS, and the Australian Government will pay the remainder. The arrangements are governed by a range of bilateral agreements that are to be revisited every five years. The NDIA does not have a reserve to manage fluctuations in expenditure.

DisabilityCare Australia Fund arrangements should be phased out

A 0.5 percentage point increase in the Medicare levy provides some funding for the NDIS via the DisabilityCare Australia Fund (DCAF). The DCAF is managed by the Future Fund and is subject to management fees. A maximum of $9.7 billion over 10 years will be credited to the State and Territory Governments to partially reimburse their NDIS contributions, with the remainder available to the Australian Government (at least 75 per cent of the revenue).

The Australian Government's 2017-18 Budget also included plans to increase the Medicare levy by (a further) 0.5 percentage point and credit it to the yet to be established NDIS Savings Fund (alongside other redirected savings, contributions from NDIS underspends returned to the Australian Government, and recommitted funds from the Building Australia Fund and Education Investment Fund (subject to legislation)). The NDIS Savings Fund is a special account ring-fenced within consolidated revenue and is not subject to management fees.

6 This option was subject to the State and Territory Governments reducing their taxes to avoid increasing the tax burden on Australians beyond what is necessary to provide additional funding to the NDIS.

The DCAF arrangements will become less appropriate over time as State and Territory Government withdrawals become more frequent and the 'churn' of funds increases. The Commission recommends that the DCAF arrangements be discontinued after 2023-24[7] and that the Medicare levy funds for the NDIS be put into the proposed NDIS Savings Fund.

Escalation parameters

As the NDIS is designed to be a no-fault scheme that covers the entire population, the contributions of governments to the NDIS can be thought of as an 'insurance premium' paid by individuals through their taxes. The current Bilateral Agreements provide that the State and Territory Government contributions will increase by 3.5 per cent each year (the 'escalation parameters') until 2023, subject to the outcomes of this study.

The current escalation parameters of 3.5 per cent are based on the long-term annual projections of the consumer price index of 2.5 per cent and a net population growth rate of 1 per cent. The threshold issue for escalation parameters is whether or not State and Territory Government contributions at full scheme and beyond should keep pace with scheme costs or maintain existing real per capita contributions.

The argued benefit of State and Territory Government contributions tracking scheme costs is to give them some 'skin in the game' to control costs. However, there are a number of factors that contribute to increasing scheme costs, and most of these are not within the control of the State and Territory Governments. State and Territory Government tax bases are also less efficient than the Australian Government's, which means it is more costly for them to raise funds than it is for the Australian Government.

The Commission recommends keeping State and Territory Government NDIS contributions constant on a real per capita basis over time, as it is reasonable to expect that their tax revenue will grow with inflation and population.

On the basis of current projections of population and price growth post 2019-20, the currently agreed escalation parameters of 3.5 per cent are at the lower end of the likely range of values based on reasonable assumptions. An escalation parameter of 4 per cent would be more appropriate over the short to medium term, until they are reviewed in 2022-23.

Funding an insurance-based scheme

Insurance schemes typically prepare actuarial forward estimates of costs over a period of time and adjust their insurance premiums in line with long-term actuarial projections of future scheme costs. Premiums are usually set at a level to allow reserves to build up to manage year-to-year fluctuations in costs and to set aside money for claims not yet finalised.

7 Governments have not negotiated payments to the State and Territory Governments after 2023-24.

Having access to reserves also allows insurance companies to make upfront investments aimed at reducing scheme costs over the longer term.

For the NDIS to operate as an insurance-based scheme, the NDIA needs to have the autonomy to manage the lifetime risk of participant costs and to manage discrepancies between actual and estimated costs in any given year. The NDIA, rather than the Australian Government, is best placed to manage the costs of the scheme and risk of cost overruns because it has the best information to do so.

Increasing funding contributions in line with cost increases, with a buffer for risk, would provide the NDIA with sufficient certainty and flexibility to manage the costs of the scheme, rather than having to rely on injections of cash from the Australian Government (which should be rare in a well-run insurance scheme) under the current cost overrun arrangements. It would also provide greater certainty to governments about future contribution obligations.

Allowing the NDIA access to a pool of reserves could also result in improved lifetime outcomes for participants (as the NDIA could focus more on long-term investments) and provide assurance to the community that the scheme is insulated (to some extent) from the vagaries of the budget cycle. Governments should commit now to establishing a pool of reserves for the NDIA. The reserve entitlement should be calculated based on an actuarial and economic analysis of the optimal reserve amount and allowed to gradually accrue over time.

12 Data

The NDIA collects data on participants when they access the scheme, when plans are developed, at plan implementation and at plan review. At full scheme, there will be data on about 475 000 scheme participants. And while the longitudinal dataset to support actuarial analysis of the scheme will take time to build (little data are currently available), as one study participant said, 'the NDIA is building the most comprehensive population-based longitudinal database on disability in the world'.

The NDIA's information and communication technology system needs to be fit for purpose to undertake the longitudinal data analysis, reporting and monitoring required to support the insurance approach of the NDIS. And there are some issues with the current system not being capable of extracting all the information required. Progress on enhancing the information and communication technology needs to be monitored by the NDIA.

It is also imperative that access to the longitudinal dataset is made available to other researchers. The NDIA has a legislative basis for allowing others to use the NDIS data, but it is yet to establish policies for data sharing. A data sharing policy should be established.

But not all data relevant for assessing the effectiveness of the NDIS will be (or should be) collected within the scheme. A number of stakeholders raised concerns about data collections outside the NDIS discontinuing as State and Territory Governments wind down

disability support services. It is important that data are available to examine the interface between the NDIS, other disability supports and mainstream services. The Australian, State and Territory Governments should commit to the ongoing funding of the Survey of Disability, Ageing and Carers and an expanded Disability Services National Minimum Data Set.

Recommendations and findings

How is the scheme tracking?

FINDING 2.1

The scale and pace of the National Disability Insurance Scheme (NDIS) rollout to full scheme is highly ambitious, and will not be delivered as scheduled in terms of participant intake. The rollout schedule risks the National Disability Insurance Agency (NDIA) not being able to implement the NDIS as intended and it poses risks to the financial sustainability of the scheme. The NDIA is cognisant of these risks.

FINDING 2.2

The Productivity Commission supports the National Disability Insurance Agency's (NDIA's) approach to projecting scheme costs and the decision to delay integrating data from the trial and transition period to date. As such, the Commission has not revised its own projections of scheme costs.

However, it is imperative that new data are incorporated into the NDIA's assessment of longer-term costs as soon as possible. The Commission's assessment is that, in the absence of major new data reliability issues, there should be sufficient data for the NDIA to update the estimates of scheme costs on the basis of scheme experience for the 2017-18 Annual Financial Sustainability Report.

FINDING 2.3

The National Disability Insurance Scheme, at the end of trial, came in under budget. But of concern to the Productivity Commission is that this was in large part because not all committed supports were used (in 2015-16 the utilisation rate was 76 per cent). While lower than expected levels of utilisation means lower scheme costs, it also implies poorer outcomes for participants.

Based on trial and transition data, scheme costs are broadly on track compared to the National Disability Insurance Agency's (NDIA's) long-term modelling. At this stage, early cost pressures (such as greater than expected numbers of children in the scheme) are being more than offset by lower than expected levels of utilisation.

The NDIA has put in place initiatives to address emerging cost pressures. It is too early to assess the effectiveness of these initiatives.

Scheme benefits

FINDING 3.1

Early evidence suggests that the National Disability Insurance Scheme is improving the lives of many participants and their families and carers. Many participants report an increase in the amount of support provided, more choice and control over the supports they receive, improvements in their quality of care, greater independence and an increase in overall wellbeing.

FINDING 3.2

Not all participants are benefiting from the National Disability Insurance Scheme. The groups at risk of having a less positive experience include those with psychosocial disability, complex and multiple disabilities, and language and cultural barriers, as well as people with disability transitioning into the community from the criminal justice system, the homeless and the socially isolated.

RECOMMENDATION 3.1

The National Disability Insurance Agency should collect and publish data on whether or not participants eligible for individualised supports through the National Disability Insurance Scheme have employment restrictions. Data should be collected in a format similar to data collected on employment restrictions by the Australian Bureau of Statistics Survey of Disability, Ageing and Carers.

Scheme eligibility

RECOMMENDATION 4.1

When determining that an individual is eligible for individualised supports through the National Disability Insurance Scheme under the disability requirements, the National Disability Insurance Agency should collect data on which of the activity domains outlined in section 24 of the *National Disability Insurance Scheme Act 2013* (Cwlth) are relevant for individuals when they enter the scheme.

RECOMMENDATION 4.2

The National Disability Insurance Agency should remove the Performance Indicator Target placed on Early Childhood Early Intervention partners that seeks to ensure that less than 50 per cent of children who connect with the partner are referred for access to the National Disability Insurance Scheme.

RECOMMENDATION 4.3

The National Disability Insurance Agency should make public a process for changing the conditions listed in List A and List D of the operational guidelines on access to the National Disability Insurance Scheme, including identifying under what circumstances a change in the lists may be considered.

RECOMMENDATION 4.4

The National Disability Insurance Agency should implement a psychosocial gateway. The gateway should be the primary pathway that people with psychosocial disability enter the National Disability Insurance Scheme.

The gateway should:

- use specialised staff
- operate on a face-to-face basis to the greatest extent possible
- consider models of outreach to engage people with psychosocial disability who are unlikely to approach the scheme
- provide linkages to both clinical and non-clinical services and supports outside the scheme
- collect data on both entrants into the scheme and people linked to services and supports outside the scheme.

Scheme supports

RECOMMENDATION 5.1

The National Disability Insurance Agency (NDIA) should implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review.

If required, the Australian Government should amend the *National Disability Insurance Scheme Act 2013* (Cwlth) to enable the NDIA to implement such a process.

RECOMMENDATION 5.2

The National Disability Insurance Agency should:

- review its protocols relating to how phone planning is used
- provide clear, comprehensive and up-to-date information about how the planning process operates, what to expect during the planning process, and participants' rights and options
- ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre-planning with participants.

RECOMMENDATION 5.3

The National Disability Insurance Agency should ensure that planners have a general understanding about different types of disability. For types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or more use of industry knowledge and expertise.

Boundaries and interfaces with the NDIS

FINDING 6.1

It is a false economy to have too few resources for Information, Linkages and Capacity Building, particularly during the transition period when it is critical to have structures in place to ensure people with disability (both inside and outside the National Disability Insurance Scheme) are adequately connected with appropriate services.

RECOMMENDATION 6.1

Funding for Information, Linkages and Capacity Building (ILC) should be increased to the full scheme amount of $131 million for each year during the transition.

The effectiveness of the ILC program in improving outcomes for people with disability, the adequacy of its funding, and its impact on the sustainability of the National Disability Insurance Scheme should be reviewed as part of the next COAG agreed review of scheme costs in 2023. The ILC budget should be maintained at a minimum of $131 million per annum until results from this review are available.

RECOMMENDATION 6.2

The Australian, State and Territory Governments should make public — through the COAG Disability Reform Council (DRC) — their approach to providing continuity of support and the services they intend to provide to all people with disability (including the value of supports and number of people covered), beyond supports provided through the National Disability Insurance Scheme. Arrangements for continuity of support should be made clear before full scheme implementation.

The National Disability Insurance Agency should report annually to the DRC on boundary issues as they are playing out on the ground, including identifying service gaps and actions to address barriers to accessing disability and mainstream services for people with disability. The reporting should be used for ongoing monitoring, evaluation and improvements.

RECOMMENDATION 6.3

Each COAG Council with responsibility for a service area that interfaces with the National Disability Insurance Scheme (NDIS) should have a standing item on its agenda to address how these services interface with NDIS supports. The standing item should cover service gaps, duplication and other boundary issues, including ways to improve outcomes for people with disability. Each Council should put forward issues and proposed solutions to the Disability Reform Council for action.

At review points of National Agreements and National Partnership Agreements under the *Intergovernmental Agreement on Federal Financial Relations*, parties should agree to specific commitments and reporting obligations that are consistent with the *National Disability Strategy*. The Agreements should be strengthened to include more details around how boundary issues are being dealt with, including practical examples.

RECOMMENDATION 6.4

If the medical and general accident streams of the National Injury Insurance Scheme are not implemented, then State and Territory Governments should bear the additional costs borne by the National Disability Insurance Scheme because of the absence of these streams.

Provider readiness

FINDING 7.1

In a market-based model for disability supports, thin markets will persist for some groups, including some participants:

- living in outer regional, remote and very remote areas
- with complex, specialised or high intensity needs, or very challenging behaviours
- from culturally and linguistically diverse backgrounds
- who are Aboriginal and Torres Strait Islander Australians
- who have an acute and immediate need (crisis care and accommodation).

In the absence of effective government intervention, such market failure will result in greater shortages, less competition and ultimately poorer participant outcomes.

RECOMMENDATION 7.1

The National Disability Insurance Agency should address thin markets by:

- considering a range of approaches, including block-funding
- publicly releasing its Provider of Last Resort (POLR) policy and Market Intervention Framework discussed in the *NDIS Market Approach: Statement of Opportunity and Intent* as a matter of urgency
- collecting and making publicly available disaggregated data, feedback and reports on thin markets, including when POLR arrangements are used.

RECOMMENDATION 7.2

Bilateral agreements regarding the full rollout of the National Disability Insurance Scheme should only include in-kind funding arrangements for services that are required to ensure continuity of support for existing clients. For in-kind services that persist past transition, a timetable for when they will be 'cashed out' should be included in bilateral agreements.

Pricing of disability supports

FINDING 8.1

The National Disability Insurance Agency's approach to setting price caps to date has hindered market development by discouraging the provision of some disability supports. In some cases, it has led to poor participant outcomes, especially for those with complex needs. The benefits of the National Disability Insurance Scheme will not be fully realised if the Agency continues with its current pricing approach.

RECOMMENDATION 8.1

The body responsible for regulating the price of supports under the National Disability Insurance Scheme should have relevant capabilities and the necessary resources to set price caps in a manner that is:

- transparent, with wide public consultation and publicly available information, including all assumptions used in any pricing models
- evidence-based
- supported by clear and limited legislative authority
- independent
- timely, particularly in giving providers sufficient time to phase in changes and be responsive to market conditions.

RECOMMENDATION 8.2

The Australian Government should amend the *National Disability Insurance Scheme Act 2013* (Cwlth) to require the National Disability Insurance Scheme Quality and Safeguards Commission (QSC), upon its commencement in 2018, to monitor, review and report on the price caps for scheme supports set by the National Disability Insurance Agency (NDIA). This should include appropriate funding for the QSC to undertake price monitoring of scheme supports, and to continue the business characteristics and benchmarking study currently undertaken by National Disability Services and the University of Western Australia.

The Act should require the NDIA to provide any relevant data and information that is required by the QSC in its price monitoring functions. The NDIA should make public a summary of the report of the 2017 McKinsey & Company price review upon completion, and provide the full report to the QSC.

RECOMMENDATION 8.3

The Australian Government should amend the *National Disability Insurance Scheme Act 2013* (Cwlth) to transfer the National Disability Insurance Agency's (NDIA) power to set price caps for scheme supports to the National Disability Insurance Scheme Quality and Safeguards Commission (QSC) by no later than 1 July 2020. The Act should require the NDIA to provide any relevant data and information that is required by the QSC in its price regulation functions.

Prices should only be regulated as narrowly and for as short a time as possible. As part of its price regulation functions, the QSC should:

- collect, de-identify and publicly release data on providers' characteristics, including the price, profits, costs and quality of services
- set price caps for supports at least at a state and territory level, which should be made public no less than 60 days before prices take effect
- comprehensively review and make public its price model on at least an annual basis. This review should be transparent, have wide public consultation, be evidence-based and evaluate the effectiveness of prices in meeting clearly defined objectives
- determine when to deregulate prices for supports, with particular regard to the type of support and region.

Progress towards price deregulation should be considered by the independent review of scheme costs in 2023.

Workforce readiness

FINDING 9.1

The disability care workforce will not be sufficient to deliver the supports expected to be allocated by the National Disability Insurance Agency by 2020.

RECOMMENDATION 9.1

The roles and responsibilities of different parties to develop the National Disability Insurance Scheme (NDIS) workforce should be clarified and made public by the beginning of 2018.

- State and Territory Governments should rely on their previous experience in administering disability care and support services to play a greater role in identifying workforce gaps and remedies tailored to their jurisdiction.
- The Australian Government should retain oversight of workforce development, including how tertiary education and aged care policy interact and affect the development of the workforce.
- The National Disability Insurance Agency should provide State and Territory Governments with data and analyses held by the Agency to enable those jurisdictions to make effective workforce development policy.
- Providers of disability supports should have access to a clear and consistent mechanism to alert the National Disability Insurance Agency, the NDIS Quality and Safeguards Commission, and the Australian, State and Territory Governments about emerging and persistent workforce gaps.

RECOMMENDATION 9.2

The National Disability Insurance Agency should publish more detailed market position statements on an annual basis. These should include information on the number of participants, committed supports (disaggregated at a level of detail consistent with the guides used to set price caps), existing providers and previous actual expenditure by local government area.

The Australian Government should provide funding to the Australian Bureau of Statistics to regularly collect and publish information on the qualifications, age, hours of work and incomes of those working in disability care roles, including allied health professionals.

RECOMMENDATION 9.3

The Australian Government should adjust immigration policies where necessary to address National Disability Insurance Scheme workforce shortages.

RECOMMENDATION 9.4

Some volunteer organisations are finding it difficult to provide supports to eligible scheme participants. There is merit in the National Disability Insurance Agency:

- considering whether volunteer organisations should be funded to cover both the initial costs of connecting participants with volunteers and ongoing costs of volunteer management. The Agency should consider whether this is best done through line items for scheme participants or through a more direct funding arrangement with volunteer organisations
- trialling different funding arrangements to cover ongoing costs of volunteer management and collecting data on the outcomes of participants that use such services to better evaluate the costs and benefits of volunteer organisations providing scheme supports over the longer term.

RECOMMENDATION 9.5

The National Disability Insurance Agency should collect data on the number of participants who make use of paid informal carers to deliver scheme supports, including the costs associated with such payments and their length of use.

RECOMMENDATION 9.6

The National Disability Insurance Agency should:

- ensure planners take into account the amount of respite care that is reasonable and necessary under an individualised support package, based on the amount of informal care that is expected to be provided by informal carers
- label short-term accommodation supports provided in participants' plans in a way that makes it clear that these supports can be used for respite
- better inform participants and their informal carers that core supports provided in individualised support packages can be used to fund additional in-home care or support in shared facilities to provide respite
- include specific measures to ensure a supply of respite services in its provider of last resort policies.

Participant readiness and market stewardship

RECOMMENDATION 10.1

The National Disability Insurance Agency should:

- clarify to scheme participants and the community the role of support coordinators in relation to Local Area Coordinators, plan managers, mainstream services and advocates
- allocate support coordination to participants in their plans on the basis of need (and not for a fixed time period) in determining whether it is a reasonable and necessary support, pursuant to section 34 of the *National Disability Insurance Scheme Act 2013* (Cwlth).

RECOMMENDATION 10.2

The National Disability Insurance Agency should provide accessible information to participants and the public about the providers available in the market and indicators of participant satisfaction with those providers. This information should be updated in as close to real-time as possible, and be consistent with the stated objectives of the eMarketPlace discussed in the *Integrated Market, Sector and Workforce Strategy*. It should be provided no later than 1 July 2018.

RECOMMENDATION 10.3

The National Disability Insurance Scheme Quality and Safeguards Commission, upon commencement, should closely monitor the operation of intermediary services under the National Disability Insurance Scheme, and make changes to safeguarding rules and codes of conduct as necessary to ensure that intermediaries act in the best interests of participants.

The National Disability Insurance Agency should provide clear and timely information about the option for participants to self-manage their plans, and the role that intermediaries can play to assist them to undertake different tasks on their behalf. The Agency should continue to assess the capacity of participants to self-manage on a case-by-case basis, consistent with the provisions of the *National Disability Insurance Scheme Act 2013* (Cwlth).

RECOMMENDATION 10.4

The Australian, State and Territory Governments should continue to fund disability advocacy organisations. State and Territory Governments should fund disability advocacy to 2019-20 by an amount that at least matches the per capita contribution of disability advocacy funding announced by the Australian Government.

The Australian, State and Territory Governments should also collect data from funded disability advocacy organisations about people with disability who use their services, and their outcomes. This data should be in a format that can be linked with data held by the National Disability Insurance Agency, and be made publicly available. The Department of Social Services should undertake an independent evaluation of advocacy funding at the beginning of 2020 to inform future funding arrangements, and thereafter periodically evaluate disability advocacy. These reports should be made public.

FINDING 10.1

The supply of disability supports in the short to medium term will not be able to meet participant demand resulting from the National Disability Insurance Scheme. This is due to a combination of factors, including rapid intake of the scheme, difficulties faced by participants to navigate the new markets for disability supports, difficulties by providers to adjust quickly to a new market-based model of service delivery, and underdeveloped market stewardship.

RECOMMENDATION 10.5

The COAG Disability Reform Council should immediately clarify and make public the roles and responsibilities of the Australian, State and Territory Governments with respect to market stewardship (those actions required to define and support the effective functioning of sustainable and enduring markets for participants and providers). This should include clear and transparent reporting of the specific actions and outcomes they are to achieve (including costs, benefits and risks), timeframes and progress towards goals.

The Australian, State and Territory Governments should:

- with the National Disability Insurance Agency and the National Disability Insurance Scheme Quality and Safeguards Commission, collect and make publicly available disaggregated, tailored and forward-looking market data, including provider and workforce data on supply gaps
- coordinate their market stewardship actions across all sectors, particularly with other care sectors and mainstream services.

Governance

RECOMMENDATION 11.1

The *National Disability Insurance Scheme Act 2013* (Cwlth) should be amended to change the process for agreeing to Category A Rules to reduce the time it takes to implement or amend those rules.

The amendment should not change the requirement that there be unanimous agreement among the Australian Government and the host jurisdictions for implementing or amending Category A Rules.

RECOMMENDATION 11.2

At full scheme, the annual operating budget for the National Disability Insurance Agency should be set within a funding target of 7–10 per cent of package costs with the expectation that, on average, it would sit at the lower end of the band.

The National Disability Insurance Agency should be required, in its annual report, to state the reasons why it has not met this target in any given year.

RECOMMENDATION 11.3

The Australian Government should remove the cap on staff employed directly by the National Disability Insurance Agency.

RECOMMENDATION 11.4

The Western Australian Government and Australian Government should put in place arrangements for Western Australia to transition to the National Disability Insurance Scheme. Any decision to join the national scheme should be made public as soon as possible.

RECOMMENDATION 11.5

The National Disability Insurance Agency should publicly report on the number of unscheduled plan reviews and reviews of decisions, review timeframes, outcomes of reviews and stakeholder satisfaction with the review process.

RECOMMENDATION 11.6

The *NDIS Quality and Safeguarding Framework* and associated regulatory arrangements should be examined as part of the first five-yearly review into National Disability Insurance Scheme costs in 2023.

RECOMMENDATION 11.7

The National Disability Insurance Agency (NDIA) should continue to develop and expand the performance reporting against the *Integrated NDIS Performance Reporting Framework*, including on outcomes, and Local Area Coordination and Information, Linkages and Capacity Building activities.

The NDIA should also fill gaps in its performance reporting, including reporting on plan quality (such as participant satisfaction with their plans and their planning experience, plans completed by phone versus face-to-face, and plan reviews). This work should be made a priority. The NDIA should begin reporting on measures and indicators of quality by June 2018.

The *Integrated NDIS Performance Reporting Framework*, and any additional reporting outside this framework included in the Quarterly report to the COAG Disability Reform Council (DRC), should be regularly reviewed by the DRC and refined as needed.

RECOMMENDATION 11.8

The National Disability Insurance Agency should better balance participant intake, the quality of plans and participant outcomes. This rebalancing should be explicitly tied to quality indicators that are publicly reported on (as per recommendation 11.7).

RECOMMENDATION 11.9

The Australian, State and Territory Governments should immediately start planning for a changed timetable for participant intake for the National Disability Insurance Scheme.

In doing so, the Australian, State and Territory Governments should ensure that adequate continuity of support arrangements are in place and assess whether additional resources are required to ensure the scheme meets its objectives. The issue of resourcing disability services under the changed timetable should be dealt with by the Treasurers and Ministers responsible for the disability portfolio in each jurisdiction, at the next COAG Disability Reform Council meeting.

Funding arrangements

RECOMMENDATION 12.1

The DisabilityCare Australia Fund (DCAF) should be discontinued after 2023-24. All the Medicare levy funds hypothecated for the National Disability Insurance Scheme (NDIS) should be put in the proposed NDIS Savings Fund.

The reimbursement arrangements that currently apply under the DCAF should not be continued after 2023-24. If necessary, the impact of such reimbursements should be reflected directly in reduced contributions from the State and Territory Governments.

RECOMMENDATION 12.2

From full scheme, the escalation parameters that determine the growth of State and Territory Government financial contributions to the costs of the National Disability Insurance Scheme should be set on the basis of population growth and inflation. This will maintain constant real per person contributions from the State and Territory Governments.

The Commission's assessment of projections of population and inflation over the period 2019-20 to 2023-24 suggests the escalation parameters should be set at 4 per cent, rather than the currently agreed 3.5 per cent.

The escalation parameters should be reassessed for the period beyond 2023-24, at 5 yearly intervals, based on the most contemporary projections of population and inflation at that time. The funding shares among the States and Territories should also be rebased according to the most contemporary census population data available at that time.

FINDING 12.1

If funding contributions to the National Disability Insurance Scheme increase in line with projected scheme costs and there is an actuarially-assessed buffer for risk, then cost overruns in a mature scheme will only occur where cost increases are sudden and difficult to predict.

RECOMMENDATION 12.3

From full scheme, the Australian Government should explicitly factor projected increases in scheme costs, based on the provision of reasonable and necessary supports, into the calculation of its contributions to the National Disability Insurance Scheme.

If cost overruns occur from full scheme, they should be funded by the Australian Government.

RECOMMENDATION 12.4

Governments should commit now to providing a pool of reserves for the National Disability Insurance Agency. The pool should build up gradually over time, with the target amount based on an actuarial and economic analysis of the optimal level of reserves.

Data and evidence

RECOMMENDATION 13.1

Australian, State and Territory Governments should commit, by June 2018, to fund (on an ongoing basis) the Australian Bureau of Statistics Survey of Disability, Ageing and Carers, so it can be conducted every three years.

RECOMMENDATION 13.2

The Australian, State and Territory Governments should agree to expand the data collection for the Disability Services National Minimum Data Set to include supports to people with disability that are provided or funded by governments outside the National Disability Insurance Scheme (NDIS).

The data collected should include services provided to NDIS participants, but not provided by the NDIS.

A decision on the data to be collected should be made by June 2018, with the broader data to be included in the 2018-19 Disability Services National Minimum Data Set.

FINDING 13.1

There are benefits from allowing researchers to have access to National Disability Insurance Scheme unit record data. Access could be provided by creating a de-identified longitudinal dataset and by allowing approved researchers access to bespoke and more detailed data sets on a case-by-case basis.

FINDING 13.2

The National Disability Insurance Agency should adopt a risk-based approach to sharing and release of data. A risk-based approach could include:

- open data that are able to be publicly released because they are non-sensitive
- a synthetic dataset that is more disaggregated but also non-sensitive, that is readily provided to researchers
- secure sharing of more sensitive data to researchers in an environment such as SURE
- better sharing of data with other relevant agencies such as the Australian, State and Territory Governments, with secure access and storage procedures put in place.

There are likely to be benefits, particularly in the early years of its operation, from drawing on the capability and expertise of more mature organisations such as the Australian Institute of Health and Welfare and Data61.

RECOMMENDATION 13.3

The National Disability Insurance Agency (NDIA) should engage with stakeholders on how data access will be operationalised. By July 2018, the NDIA should issue a statement outlining the organisation's goals for data sharing and an intended timeline for operationalising data sharing by the NDIA.

1 About this study

The National Disability Insurance Scheme (NDIS) is a new scheme designed to change the way that support and care are provided to people with permanent and significant disability. It is currently being rolled out across Australia and is expected to be fully implemented in all states and territories by mid-2019.

This study is a review of NDIS costs. It looks at the sustainability of scheme costs in light of the benefits and impacts of the scheme on the lives of people with disability, and Australians more generally. The study will help inform the final design of the scheme.

Some background to the study

In 2011, a Productivity Commission inquiry into *Disability Care and Support* found that Australia's system of disability supports was inequitable, underfunded, fragmented, inefficient and gave people with disability little choice and no certainty of access to appropriate supports (PC 2011, p. 5). The Commission recommended that a national disability insurance scheme be established to change the way that support and care are provided to people with significant disability, and to provide insurance cover to all Australians in the event of such a disability. The recommendation was based on the finding that such a scheme would generate substantial community-wide benefits, including improving the lives of people with disability and their families and carers.

The Commission's recommendation was accepted by Australian governments and on 7 December 2012, COAG signed an Intergovernmental Agreement for the launch of the NDIS (COAG 2012b). In the Heads of Agreement between the Australian Government and the State and Territory Governments, it was agreed that the Productivity Commission would review NDIS costs in 2017, to inform the final design of the scheme ahead of its full rollout. The terms of reference for this study were received on 20 January 2017.

1.1 About the NDIS

The NDIS is based on the premise that individuals' support needs are different, and those participating in the scheme should be able to exercise choice and control over the services and support they receive. The objectives of the NDIS (as outlined in the *National Disability Insurance Scheme Act 2013* (Cwlth) (NDIS Act)) include:

- supporting the independence and social and economic participation of people with disability

- providing reasonable and necessary supports, including intervention supports
- enabling people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports
- facilitating the development of a nationally consistent approach to the access to, and the planning and funding of, supports for people with disability
- promoting the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community
- raising community awareness of issues that affect people with disability.

The NDIS operates under the NDIS Act, and is administered by the National Disability Insurance Agency (NDIA). Funding for the NDIS is shared by the Australian and State and Territory Governments.

The NDIS provides individualised supports to assist people with permanent and significant disability to participate in economic and social life.[8] This report refers to people who are eligible for individualised supports as 'participants' of the scheme.

For each participant, the NDIS funds 'reasonable and necessary' supports related to their disability. Reasonable and necessary supports are those that help participants live as ordinary a life as possible, including care and support to build skills and capabilities, so that they can engage in education, employment and social and community activities.

Supports are also available to those who meet early intervention criteria. This covers cases where early intervention can significantly improve outcomes and is cost effective. The focus on early intervention reflects the lifetime, insurance-based approach of the scheme.

Individuals eligible for the scheme are assessed, and individual support packages are developed and funded. Access, planning and payments are managed by the NDIA. (In Western Australia, arrangements are different, but intended to be consistent with the NDIS (Porter, Barnett and Faragher 2017).)

The individualised supports provided to participants account for the vast majority of scheme costs and therefore references to 'the scheme' (including in this report) often refer to these supports.

However, the NDIS is broader than just supports for eligible participants. Information, linkages and capacity building (ILC) services are also provided under the NDIS to help all people with disability (not just scheme participants), and their families and carers, with information and referrals to community and mainstream services (including health, education, employment, justice, transport and housing) (NDIA 2016b). ILC will also

[8] Permanent and significant disability is defined in this report as a disability that permanently and substantially reduces a person's functional capacity or psychosocial functioning. This is in line with the eligibility criteria contained in the NDIS Act (s. 24).

facilitate greater social cohesion by promoting awareness and acceptance of disability in the wider community.

More detail on the scheme, including eligibility criteria, planning processes and governance arrangements, is provided throughout this report.

The NDIS is part of a broader system of support

The NDIS is part of a wider disability system. It is one component of the broader *National Disability Strategy 2010–2020*, which was endorsed by COAG in February 2011 and provides a ten-year national policy framework for improving the lives of Australians with disability, their families and carers (COAG 2011; DSS 2016c).

Only a proportion of people with disability will become scheme participants and receive individualised supports. There are approximately 4.3 million people with disability in Australia (figure 1.1). Once fully implemented, the NDIS will provide individual packages to about 475 000[9] people — those people with a permanent and significant disability.

Supports for people with disability (both NDIS participants and non-NDIS participants) are also provided through other Australian and State and Territory Government funded disability services and mainstream services, such as health and education.

1.2 The benefits of the NDIS

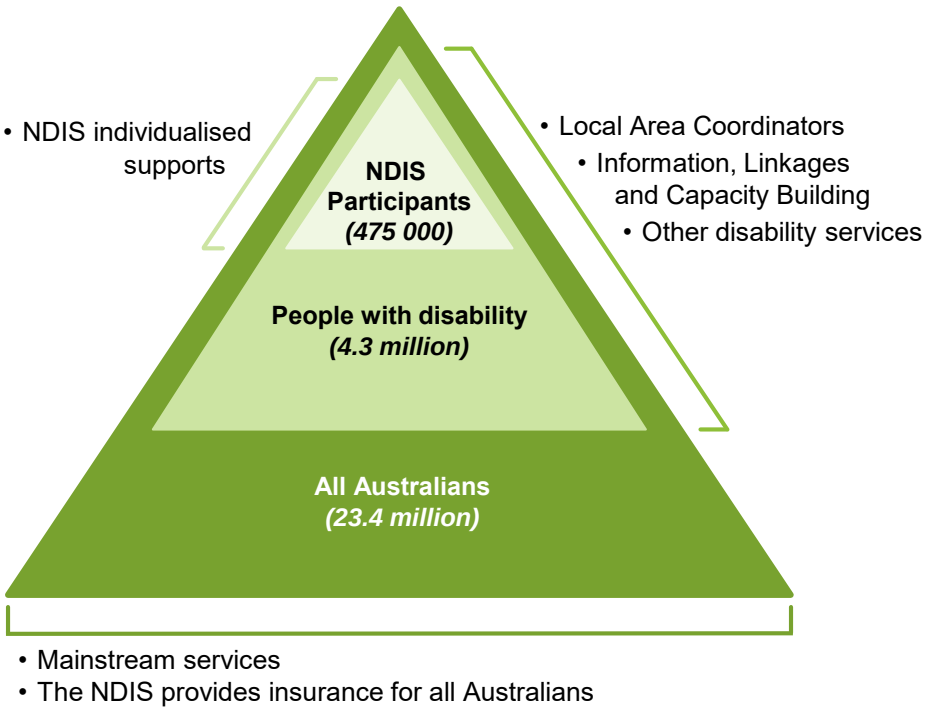
The Commission recommended a national disability insurance scheme in 2011 on the basis of the substantial net benefits it would generate in the long term from:

- improved wellbeing for people with disability and their families and carers through increased care and support, and more choice and control over the supports they receive. This was identified as the area of largest benefit with more, and better targeted, support for participants leading to greater social participation and independence
- efficiency gains in the disability sector — through increased competition and innovation, and better value for money
- savings to other government services — by better supporting people with disability and reducing their reliance on mainstream services
- increased economic participation for people with disability — by overcoming obstacles to employment for those with disability through direct interventions, like school leaver employment programs, and through changes to community attitudes. The Commission estimated that employment of people with disabilities could increase by 100 000 by 2050 (catching up to OECD rates), resulting in $8 billion in additional gross domestic product in that year alone

9 460 000 participants under the age of 65 years and 15 000 aged 65 years and over (chapter 2).

- increased economic participation for informal carers — the Commission estimated that an additional 7500 carers could re-enter the workforce (PC 2011).

Figure 1.1 **The NDIS is part of a broader system of supports[a]**



[a] Number of Australians and those with disability are based on 2015 data. NDIS participants are the projected number of people eligible in 2020.

Sources: Commission estimates based on unpublished NDIA data; ABS *(Disability, Ageing and Carers, Australia: Summary Findings, 2015, Cat. no. 4430.0)*.

A new approach to disability care and support

The scheme is designed to change the way that participants and disability support providers interact, and the way that supports are funded. Two of the key changes from previous approaches include a more market-based, person-centred approach to care and support, and a scheme based on insurance principles.

A more market-based approach aims to create incentives that better provide participants with the quantity, quality and variety of services they desire in an efficient way. It is expected to overcome many of the previous system's shortcomings (table 1.1), including by providing participants more choice and control over their supports and services, and encouraging innovation by service providers through increased competition. The market will, nevertheless, continue to have significant government oversight, as in other administered markets such as health and education.

Table 1.1 **Intended effects of the NDIS on the disability services system**

Features of pre-NDIS disability services system	*Features of a more market-based system*
• Largely 'block-funded', with funding provided in advance of service delivery and little freedom to innovate.[a]	• Predominantly fee-for-service paid on invoice. In principle, prices for services are set by the competitive market, and there is innovation by service providers attracting and retaining consumers.
• Services often limited and priorities for families in immediate crisis, rather than for early intervention. Consumers have little control over the services they receive and limited choice of provider.	• Funding to meet the reasonable and necessary support needs for each NDIS participant. Consumers have choice and control regarding the services received and providers used.
• The primary relationship is between the service provider and the funder, with consumers often described as 'passive' recipients of services.	• The primary relationship is between the consumer and service provider. Intermediaries and access to information about provider quality, performance and pricing help consumers exercise choice.
• Providers are subject to various statutory provisions (at all levels of government) regarding quality. The system is complex, difficult to navigate and not well integrated nationally.	• Compliance with a national quality framework. A nationally consistent and navigable system.
• High transaction costs for both consumers and providers.	• Lower transaction costs for consumers and service providers. There is adequate depth and resilience in the market to underpin financial sustainability.

[a] Block funding refers to the process where governments purchase a 'block' of services from a provider, which is to be delivered to clients who meet certain criteria, or are referred to those providers as part of an individualised plan.

Sources: Adapted from ANAO (2016, p. 20), which is based on analysis by PC (2011); DRC (2015a); and NDIA presentations on the market transition.

As an insurance-based scheme, the NDIS takes a lifetime approach to a participant's support needs and life goals (box 1.1). It is intended to provide assurance to both those with permanent and significant disability, and those who may acquire such disability in the future, that they will receive the support they require. In other words, there is essentially no cap on funding — anyone who meets the eligibility criteria is guaranteed to receive funding for supports and services. The scheme also focuses on early intervention investment in people with disability so that their outcomes can be improved later in life, and costs minimised over the long term, even if that involves more spending upfront. The insurance-based approach also allows for ongoing monitoring and refinement of the scheme.

This contrasts with the previous system which operated on an annual capped amount and did not tailor supports to individuals, leading to short-term planning, limited choice, higher long-term support needs, unmet demand and adverse outcomes for some (PC 2011).

Box 1.1 **The NDIS is an insurance-based scheme**

The insurance approach of the NDIS takes a long-term view of the total cost of disability in order to improve participant outcomes and meet the future costs of the scheme. Key elements of the approach include:

- universal coverage by pooling risk across all Australians and taking the risk of disability support costs away from individuals
- creating an innovative and competitive market for disability support, through which participants can exercise choice and control over the planning and delivery of their supports
- a long-term view of the total future social cost of disability for all people who are insured and yet to be insured
- the NDIA — in its role as the social insurance manager — managing the total cost of disability over a participant's lifetime and incentivising short-term investment in participants to reduce long-term costs.

The NDIA identifies four principles for the way that the insurance approach is operationalised.

1. Actuarial estimates of long-term costs — updated to reflect the experience of the scheme, and used to help ensure the scheme is financially sustainable and that the scheme is continuously improved.
2. A long-term view of funding requirements — takes a lifetime view of participant needs and seeks early investment and intervention for people in order to maximise their independence and social and economic participation, and reduce their support requirements in the long term.
3. Investment in research and innovation — to encourage and build the capacity and capability for innovation, outcome analysis and evidence-based decisions on early intervention.
4. Investment in community participation and building social capital — to make the community accessible and inclusive for people with disability, and provide participants and non-participants with necessary supports outside the NDIS, through mainstream services, ILC initiatives and education programs.

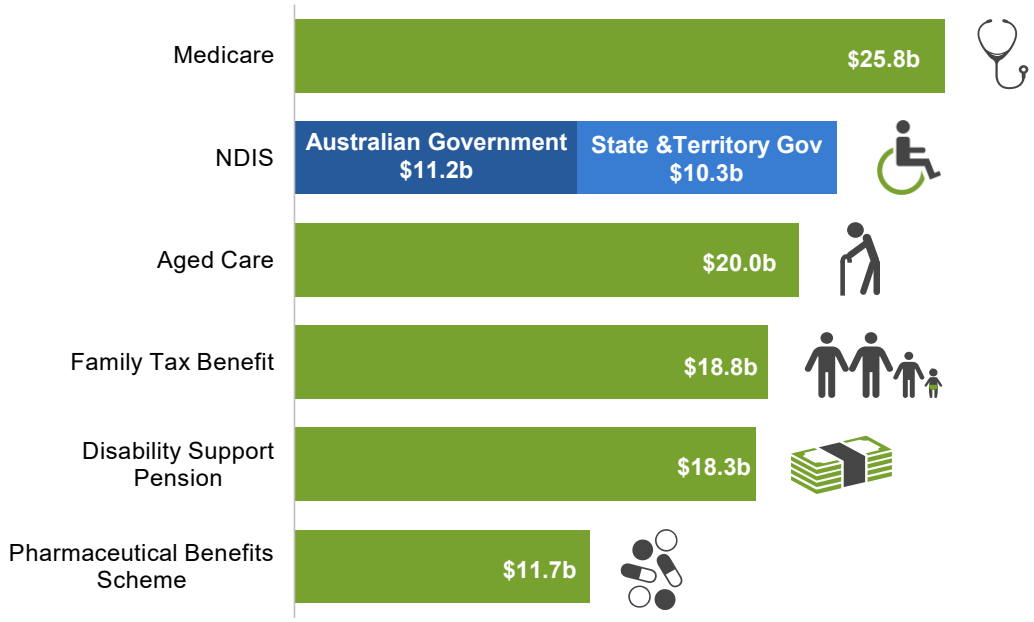
Source: NDIA (sub. 161, pp. 22–26).

1.3 The NDIS is a major reform

The NDIS is a major reform. As the NDIA (2016i, p. 7) said, the scheme is 'on a scale not previously contemplated in Australia and is designed to address un-met need'. The NDIS will be the largest social reform since the introduction of Medicare. At a currently estimated annual cost of about $22 billion when fully implemented, government expenditure on the NDIS will exceed that on aged care and will be almost double that spent on the Pharmaceutical Benefits Scheme (figure 1.2).

At full rollout, the NDIS is expected to cover 475 000 people with disability. This is almost 200 000 more people than were covered under the previous system (NDIA 2016i, p. 8). To meet this increased demand, the disability workforce will need to more than double (chapter 9).

Figure 1.2 **Projected NDIS expenditure compared with other Australian Government programs, 2019–20[a]**



[a] The NDIS amount is based on Department of Social Services modelling and is sourced from the 2016-17 Australian Government budget (the 2017-18 budget estimate excludes the cost of the Western Australian scheme).

Source: Australian Treasury (2016, 2017c, 2017d).

Introducing a scheme of this scale and nature is a challenging task and it is inevitable that it will take many years before the scheme is fully established and operating smoothly. The enormity and significance of the task was acknowledged by many study participants. For example, the ACT Disability, Aged Carer and Advocacy Service said:

> The NDIS is monumental reform for Australia: a grand scheme (akin to the introduction of Medicare) that has the potential to make vast differences in the life experiences of an array of people with disability, their families and carers both now and in decades to come. (sub. 87, p. 1)

Richard Madden, from the Centre for Disability Research and Policy at University of Sydney, said:

> The NDIS has been introduced quickly, and involves a large increase in public expenditure, and inevitably some uncertainty as long standing support arrangements change. The change effort has been huge for all involved. Inevitably, there have been issues to be addressed, and some delay in ambitious timetables. These issues, while important, must not detract from the achievements made and the opportunities that exist. (sub. 101, p. 3)

And the National Mental Health Commission said:

> … the NDIA has been given an extremely difficult task. Implementing a reform of the scale and nature of the NDIS was always going to be challenging; implementing it with a curtailed timetable, reduced resourcing and under shared accountability arrangements where different governments have different expectations. (sub. PP319, p. 5)

There is overwhelming support for the scheme

While many stakeholders commented on the scale and complexity of the reform, there is an extraordinary level of commitment to the success and sustainability of the NDIS (and to preserving the core principles of the scheme as set out by the Commission). This commitment is shared by governments, people with disability and their families and carers, providers of disability services and disability advocates (box 1.2). For example, Mental Health of Young People with Developmental Disabilities said:

> The NDIS is a ground-breaking social reform that is to be commended and supported. … Designing the NDIS as an insurance scheme with benefits paid to individuals is an empowering move. For too long people with disabilities have not been able to exercise control over their lives as able-bodied and minded Australians do. 'Choice and control' is the right of every person with disabilities and that of their primary carers. (sub. PP269, p. 2)

It is also acknowledged that 'making the scheme work' is not just the responsibility of the NDIA, but also of governments, providers and participants (and their families and carers). As the Australian Disability Discrimination Commissioner said:

> Yes — the NDIS is big, it is complex, and it changes everything, but it is the change that we need. And when we think about what life might be like for people with disability without the NDIS, I think it becomes clear that it is the change we cannot afford to prevent. … ensuring the sustainability and success of the NDIS is not only the responsibility of the NDIA or its board — it is the responsibility of all governments, service providers, participants, their families and carers. If we want real and lasting change for people with disability, we cannot absolve ourselves of our responsibility to make the NDIS work. (McEwin 2017)

Box 1.2 There is overwhelming support for the NDIS

Australian Federation of Disability Organisations:

> We want to begin … by emphasising our unwavering support for the NDIS. AFDO and its members regularly hear from people with disability and their families about the difference the NDIS is making to their lives. People who now have the dignity of appropriate and timely support, the opportunity to be more involved in their communities, the chance to move out of home, the economic freedom of a new job. These are the kinds of differences the NDIS is making. (sub. 180, p. 6)

Anglicare Australia:

> Anglicare Australia strongly believes that the establishment of the NDIS is a major achievement. Our member agencies are already witnessing the transformative power of the scheme for participants, and finding that reconfiguring services to reflect their needs and aspirations is creating opportunities to reimagine and create better outcomes in people's lives. (sub. 157, p. 4)

Women with Disabilities Victoria:

> WDV is a strong supporter of the NDIS. We agree with its fundamental principles, including a human rights approach, choice and control for participants and a clear focus on outcomes for individuals. (sub. PP282, p. 3)

JFA Purple Orange:

> … the NDIS is a major, once-in-many-generations opportunity to invest in the life chances of people living with disability, to achieve a fair go, so that people living with disability take their rightful place as valued active members of Australian community life and the economy. (sub. 186, p. 4)

National Disability Services:

> The principles on which the NDIS is founded remain compelling and inspiring. Doubling the funding for disability support to rectify the chronic under-supply of services, choice and control for people with disability and their families, an insurance approach that focuses on early intervention and building the capacity of individuals and families and increased equity across Australia. (2016, p. 3)

Occupational Therapists Australia:

> OTA is a strong supporter of the NDIS and the scheme's focus on providing individualised support for participants with informed choice and control over their plans. Occupational therapists worked across all NDIS launch sites and contributed to the design and implementation of the scheme during its trial period. They are continuing to support participants as the scheme transitions to full rollout. (sub. PP285, p. 2)

Scope Australia:

> Scope is fully committed to the implementation of the National Disability Insurance Scheme. The Scheme creates a paradigm shift in social policy and recognises the rights of all Australians to live an ordinary life. It has enhanced the lives of more than 60,000 participants and their families and for the first time fully recognises the rights of people with a disability to live their lives as empowered and equal citizens. (sub. 72, p. 29)

Northern Territory Government:

> The NT Government is a strong supporter and advocate of the NDIS which will support Territorians with disability achieve life goals through choice and control. (sub. PP359, p. 9)

New South Wales Government:

> The NSW Government is a strong advocate of the National Disability Insurance Scheme (NDIS). The improvement in the lives of people with disability, as outlined by the Productivity Commission (PC) in its 2011 inquiry report into Disability Care and Support, is a goal embraced by NSW. (sub. 60, p. 2)

Transitional issues can become entrenched problems

It is no surprise, given the size, speed and complexity of the reform, that there are transitional issues with the rollout of the NDIS. All major reforms are followed by a (sometimes protracted) period of disruption and adjustment. Flourish Australia, while strongly supporting the NDIS, said it:

> … as with any reform of such a substantial scale, there can be unintended consequences, implementation issues and uncertainty, especially during the transition phase. We are particularly mindful of the impact of this on the people we support. (sub. 74, p. 1)

Most transitional issues are expected to be ironed out as the scheme rollout is completed and the scheme matures. And the NDIA said that resources are being devoted to addressing implementation issues:

> The NDIS is still in its infancy and delivering the Scheme will evolve and improve over time. The NDIA is intent on learning from experience and improving systems, processes and practices as quickly as possible to ensure the success of the Scheme. (sub. 161, p. 16)

> Work to improve the participant and provider pathways … is well underway and, in close consultation with stakeholders, is focusing on reforms that will make processes more responsive and flexible to participant and provider needs, and more focused on outcomes across participant lifetimes. (sub. PP327, p. 10)

However, if transitional issues are not dealt with quickly and effectively, they can become entrenched problems that endure in the longer term and affect the success and sustainability of the scheme. As Blind Citizens Australia said:

> Blind Citizens Australia recognises the NDIS represents the single largest reform Australia has seen since the introduction of Medicare. As such, it is understandable that there are still a number of operational and interfacing difficulties that remain outstanding. The challenge is in ensuring these matters are promptly responded to and resolved. (sub. PP351, p. 14)

1.4 The Commission's approach to the study

This study is a review of NDIS costs. The Commission was asked to look at:

- the sustainability of scheme costs, including current and future cost pressures, and how to manage any potential cost overruns
- whether jurisdictions have the capacity to deliver disability care and support services as the scheme expands
- how the NDIS impacts on, and interacts with, mainstream services
- whether efficiencies have been achieved within the scheme
- whether there are any issues with scheme design, including the application of market and insurance principles, in ensuring the best possible outcomes for people with permanent and significant disability

- funding and governance arrangements, including financial contributions, risk-sharing, and the 'escalation parameters', which define the annual increase in funding required by different jurisdictions.

Costs are one side of the equation — benefits are just as important

A number of stakeholders expressed concern that the Commission would focus on costs and not take into account the intent of the scheme and the potential impact that it could have on the lives of people with disability (box 1.3). As the Australian Federation of Disability Organisations said:

> A focus on costs should not be at the expense of a focus on outcomes for the very people the scheme is intended to support. Any decisions made in the interests of ensuring sustainability should also be consistent with improving outcomes for people with disability. (sub. 180, p. 6)

Box 1.3 Stakeholders said the focus should not be solely on costs

Anglicare Australia:

> … measures of the financial sustainability of the NDIS should not be narrowly held and applied solely within the scheme itself. Although such measures are of course essential, questions regarding the overall worth of the scheme that capture the cost and benefit to Australian society should be included … (sub. 157, p. 21)

Community Mental Health Australia:

> … [CMHA] believes that the Commission in assessing whether or not the NDIS is financially sustainable must investigate how the scheme is being implemented and how this is being managed. (sub. 11, p. 2)

Australian Blindness Forum:

> The financial sustainability of the NDIS should be defined and measured by the standard that all people with disability can access and participate in the community. (sub. 48, p. 17)

New South Wales Government:

> Any review of costs and sustainability isn't necessarily about minimising short term costs. Costs must be considered in relation to the objectives of the NDIS (reasonable and necessary support; choice and control; increased social and economic participation). (sub. 60, p. 9)

Victorian Government:

> The PC rightly highlights the cost risks for the NDIS, as financial sustainability is one of the central tenets of the scheme and crucial for it to operate as intended. However, Victoria considers that the risks of the scheme should be conceived more broadly and over a longer time horizon; successful implementation of the scheme must consider participant outcomes, use an insurance based approach and give greater consideration to market development. (sub. PP298, p. 5)

SDN Children's Services:

> SDN believes that a drive for financial sustainability must not be disconnected from a drive for quality, effective practices. (sub. 73, p. 2)

Autism Aspergers Advocacy Australia:

> Maybe 'sustainability' is the wrong notion. It is more about benefit versus cost, and people having a reasonable standard of living in our community. (sub. 178, p. 36)

While the focus of this study is on scheme costs, costs cannot be considered in isolation of the benefits. The Commission's approach (consistent with the *Productivity Commission Act 1998* (Cwlth)) is to examine costs in light of the benefits and impacts of the scheme on the lives of people with disability, and Australians more generally, using a wellbeing framework (figure 1.5). This is consistent with the insurance approach of the NDIS, which is about 'maximising outcomes for participants and their families/carers at the lowest possible sustainable cost' (NDIA, sub. 161, p. 26). It is also consistent with the objectives of the NDIS (choice and control, independence, social and economic participation, reasonable and necessary support), which are seen by the Commission as integral to the analysis of scheme costs.

What are the factors driving scheme costs?

Assessing the sustainability of scheme costs, including current and future cost pressures, involves examining the factors that drive scheme costs. Key factors include:

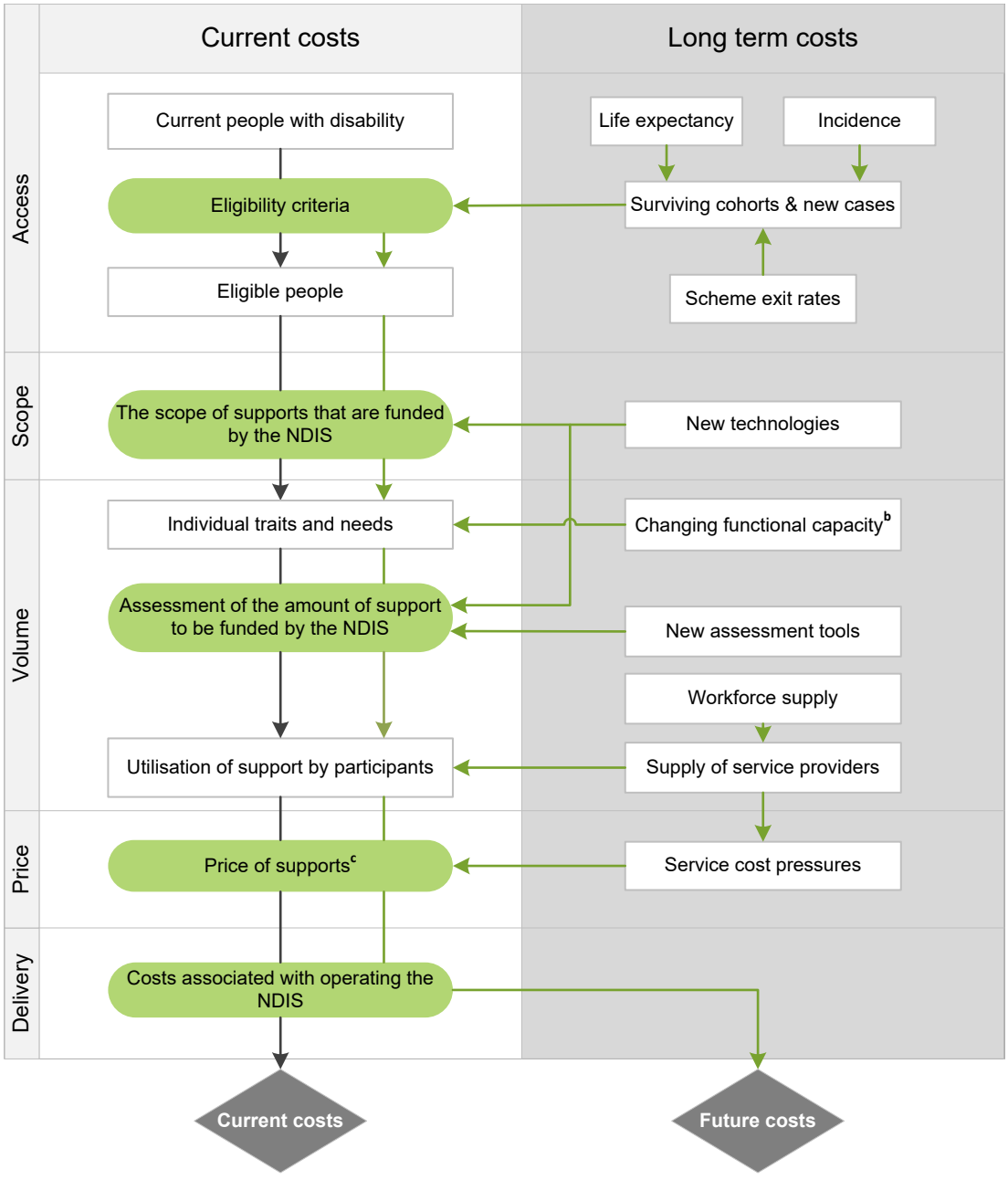
- access — the number and profile (age, sex, disability type, disability severity) of participants in the scheme
- scope — the scope of supports provided to participants in the scheme
- volume — the quantity of supports in a participant's plan and the proportion of supports in a plan that are utilised by a participant
- price — the price paid for supports under the scheme
- delivery — the costs associated with operating the scheme (figure 1.3).

Scheme culture will also be an important driver of costs. Moving away from the welfare culture of current disability systems to one of seeking reasonable and necessary supports and managing down the total cost of disability over a participant's lifetime (in line with an insurance approach) will be critical for the financial sustainability of the scheme. As noted by Bruce Bonyhady, the former Chair of the NDIA Board:

> Importantly, the NDIS cannot be allowed to be turned into a Centrelink-type entitlement model, because under this approach costs would continually escalate. (sub. 100, p. 2)

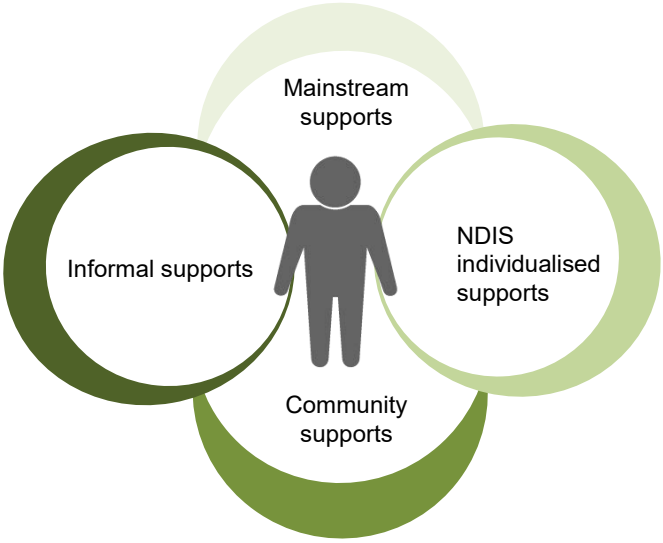
Other support systems can also affect scheme costs. The NDIS, as a person-centred approach to providing disability supports, relies on supports and services outside of the NDIS (including informal, community and mainstream supports) to be in place to help people with disability to live ordinary lives (figure 1.4). If these supports are not available, people with disability could seek NDIS funding to fill the gap, and this could pose risks to scheme costs.

Figure 1.3 **What drives scheme costs?[a]**



[a] Green cells denote cost drivers that the NDIA and/or governments have *direct* control over. Grey cells are cost drivers that can only be *indirectly* influenced by the NDIA and governments. [b] This includes changes in participants' functional capacity attributable to early intervention. [c] Price caps of disability supports are currently set by the NDIA.

Figure 1.4 **A person-centred approach relies on supports beyond the NDIS**



Source: Adapted from NDIA (sub. 161, p. 22).

Sustainability — interpreted as financial sustainability

The Commission interprets scheme sustainability to mean 'financial sustainability'. This is in line with the NDIS Act. Under the Act, the NDIA manages, advises and reports on the financial sustainability of the NDIS. While financial sustainability is not defined or listed as one of the explicit objectives of the Act, the Act (s. 3) does state that 'regard is to be had to … the need to ensure the financial sustainability of the National Disability Insurance Scheme'.

The insurance approach to the scheme and financial sustainability are inextricably linked. For a commercial insurer, financial sustainability is about balance sheet adequacy — there needs to be enough capital to meet some proportion of future expected liabilities by way of cash claims (as set out in prudential standards by the Australian Prudential Regulation Authority) (NDIA 2016h).

However, the financial risks inherent in the NDIS are unique. The NDIS is currently funded on a cash-flow basis — annual contributions meet the cash claims expense — so a balance sheet approach to financial sustainability is not applicable (though there are good reasons for moving closer to funding arrangements that better reflect insurance principles — chapter 12). And because there is no annual capped amount (as there was in previous disability support systems), the financial risk associated with satisfying all valid claims for reasonable and necessary support needs to be managed. As the NDIA explained:

> … unlike traditional disability systems, it is not open to the NDIA to refuse to fund reasonable and necessary supports for a participant who has been found to be eligible on the basis that the

'budget has been exhausted'. The NDIS, therefore, faces significant financial risks in the same way that an insurer does and these risks must be managed. Indeed, the NDIS Act explicitly requires the Agency to manage the financial risk that goes with a regime under which any valid claim has to be satisfied. However, the NDIS is still concerned with people rather than claims, and outcomes as well as financial result. (2016h, p. 6)

In light of this, the NDIA defines financial sustainability for the NDIS as:

- the scheme is successful on the balance of objective measures and projections of economic [and] social participation and independence, and on participants' views that they are getting enough money to buy enough high-quality goods and services to allow them reasonable access to life opportunities — that is, reasonable and necessary support; and
- contributors think that the cost is and will continue to be affordable, under control, represents value for money and, therefore, remain willing to contribute. (2016h, p. 18)

Based on the NDIA's definition, achieving financial sustainability requires continuous monitoring of both participants' outcomes and costs. It is not about minimising costs or maximising benefits, but rather balancing the two in a way that ensures there is a net benefit over time. As the NDIA put it:

> … while cost efficiency will be of prime importance to an insurer it will not be the sole focus of the NDIS. Rather, good participant outcomes will be an ongoing objective and, so, finding the right balance between participant outcomes and cost will be critical. (2016h, p. 12)

And as pointed out by the New South Wales Government, financial sustainability must be considered against a long-term (not a short-term) view of costs:

> The lifetime costs for supporting participants must be considered and an investment approach taken. Early intervention principles are appropriate (including beyond just early childhood), and may increase costs in the short term before delivering lower lifetime costs. The alternative is immediate cost reductions that deliver worse social or economic outcomes for participants or the need for acute responses later in life: this is not an improvement to financial sustainability.
>
> … Financial sustainability must be considered with reference to a suite of indicators, with a long-term view, and with consideration of broader impacts elsewhere. (sub. 60, pp. 9–10)

The Department of Social Services supported the NDIA's definition of financial sustainability, and said that:

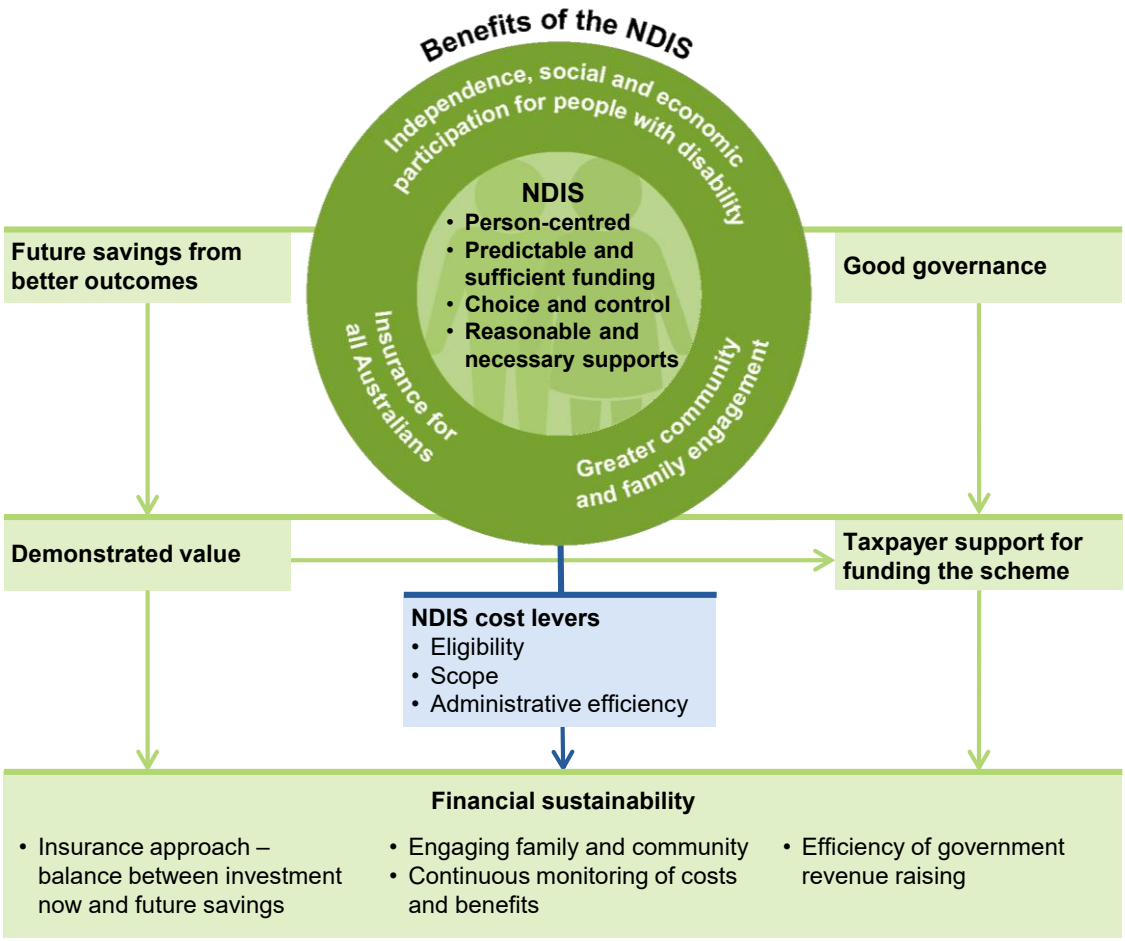
> Considerations of NDIS sustainability need to weigh the success of the Scheme in improving economic and social outcomes and the value-for-money proposition for contributors. (sub. 146, p. 17)

As outlined above, financial sustainability is a difficult concept to define in a unique scheme like the NDIS, but the Commission supports the definition used by the NDIA. The definition provides a clear link between scheme costs, benefits and support from taxpayers.

A wellbeing framework for considering costs and benefits

The Commission examined scheme costs and the financial sustainability of the scheme in light of the benefits to people with disability and Australians more generally using a wellbeing framework (figure 1.5).

Figure 1.5 **Wellbeing framework for considering costs and benefits**



The NDIS aims to improve not only the lives of current scheme participants, but also of future participants. This will only be the case if the scheme is financially sustainable. Financial sustainability is also essential if scheme participants are to consistently receive reasonable and necessary care while they remain in the scheme. Cost overruns could jeopardise the level of care and support participants receive, or result in a return to some of the less desirable features of the previous system (including, for example, an inequitable rationing of support services).

While the NDIS is sometimes described as an 'uncapped scheme', the ultimate cap — and test of financial sustainability — is taxpayers' continuing willingness to pay for it. Unlike

other insurance schemes that rely on premiums to fund costs, the NDIS will only be funded as long as taxpayers consider it is a good use of taxes. Taxpayers' willingness to fund the NDIS will depend on their perception of value for money in terms of:

- people with disability experiencing better lives as a result of the scheme
- the scheme making it easier for families and carers to play a supporting role
- the way the scheme invests in people with disability
- the confidence taxpayers have that the NDIS will be available to cover their care needs (or those of their loved ones) should a disability be acquired in the future
- the supports that are funded (and the evidence base to support what is funded)
- efficiency gains and cost savings in the disability support system and other government services.

Cost overruns could lead to pressure to reduce the scope and certainty of care and supports provided under the NDIS, or require governments to provide more funding at the expense of other programs.

The NDIA's actuarial estimates of long-term costs (which reflect the experience of the scheme and management responses to cost pressures) play an important role in demonstrating to the Australian community that the scheme represents value for money.

Perceptions about the effectiveness of governance arrangements for the NDIS are also important. For example, the community expects planning processes to be in line with the objectives of the scheme and services to meet quality standards. Governments also need to demonstrate that the funds for the NDIS are dollars well spent from a limited tax revenue bucket, and that funding the scheme is not to the detriment of other important expenditures.

Assessing the financial sustainability of the NDIS also involves looking at interrelated systems. This includes, but is not limited to, the efficiency and effectiveness of the NDIA, the readiness of participants, the readiness of providers, and the integration of the NDIS with mainstream services. Only a system that is integrated and holistic in its focus will bring the benefits to people with disability that the scheme is expected to deliver.

It is still early days

While significant benefits are expected to result from the new system of disability care and support, the Commission is aware that, like any major reform, it will be many years before the full extent of the benefits are realised or reflected in objective measures.

Even once the scheme is fully implemented, the transition to a mature market will be gradual, and participants, carers and providers will need time to adjust to the new system. According to an Australian National Audit Office report (ANAO 2016, p. 19), the disability services

market under the NDIS is expected to take up to ten years to develop, and perhaps longer in some market segments. The NDIA, in its Market Approach Statement 2016–2019, said that:

> Developing a strong, contestable marketplace for disability supports is a long term project. All stakeholders in the marketplace will require time to build capability, confidence and systems to support the market mechanisms. Participants, possessing greater consumer power, are learning to make choices and explore different service options. Providers are building an understanding of their customer base and preferences, positioning service offers and transforming their operations. (2016k, p. 12)

And, because the scheme is not yet fully rolled out and there are some transitional issues, the experience to date may not be reflective of the underlying long-term outlook. (Chapter 2 discusses in more detail the limitations of the trial and transition data.)

1.5 A guide to this report

This report outlines the Commission's findings and recommendations on NDIS costs. In conducting this study, the Commission drew on a range of evidence. It consulted widely, including with NDIS participants, advocacy groups, peak bodies, service providers, disability care and support workers and academics. It also met with Australian and State and Territory Government departments and agencies, including extensive liaison with the NDIA and the Department of Social Services. There have also been a number of other reviews of various aspects of the NDIS since the trial began and the Commission drew on these where relevant.

The Commission released an issues paper for this study on 22 February 2017 and a position paper on 14 June 2017. The Commission used the information and evidence provided in the 372 submissions and 185 brief submissions it received in response to these papers (a full list of submissions and consultations is provided in appendix A). The Commission wishes to thank study participants for their input.

Structure of this report

The next two chapters look at how the scheme is performing. Chapter 2 examines how scheme costs are tracking and chapter 3 looks at the evidence, to date, on scheme benefits.

Chapters 4 and 5 discuss two of the key cost drivers for the scheme — eligibility (which determines the number of participants in the scheme), and what supports scheme participants receive (as determined by the rules relating to support coverage and the planning process). Chapter 6 looks at how the NDIS interfaces with non-NDIS disability services and mainstream services and the ways in which this impacts on the financial sustainability of the scheme.

Chapters 7 to 9 look at the supply side of the equation. Chapter 7 assesses whether providers will be able to meet demand for disability services; chapter 8 examines price caps for the NDIS; and chapter 9 considers workforce issues. Chapter 10 looks at whether participants can successfully engage with the scheme.

The last three chapters of the report cover governance arrangements (chapter 11), funding (chapter 12) and data and evidence (chapter 13).

2 How is the scheme tracking?

Key points

- Tracking scheme costs and participant outcomes (and making adjustments in response to scheme experience) is critical to ensuring that the National Disability Insurance Scheme (NDIS) achieves its objectives and is financially sustainable.
- The speed of the launch and the scope of the trial phase meant that some aspects of the NDIS were being developed during trial, including assessment tools and ICT systems.
- To reach the estimated 475 000 participants at full scheme, the National Disability Insurance Agency (NDIA) will need to approve hundreds of plans a day — in 2018-19, about 500 plans will need to be approved and hundreds more reviewed, each day.
  - The intake of participants is already falling behind the expected pace, indicating that the bilateral estimates are unlikely to be met.
- It is inevitable that there will be transitional issues with the rollout of the NDIS given the size, speed and complexity of the reform, but already there are signs that a focus on meeting the bilateral estimates risks the NDIA not being able to implement the NDIS as intended.
  - The focus on getting participants into the scheme has come at the expense of the quality of plans. Some key planning supports for participants are not in place and this has affected participant readiness.
- The NDIA's projection of full scheme costs ($22 billion) is broadly consistent with the Commission's 2011 modelling.
- While the transition experience should inform estimates of full scheme costs, the NDIA considers that, at this early stage, the data have too many limitations to update assumptions on prevalence rates and package costs.
  - In the absence of any new major data reliability issues, there should be sufficient data for the NDIA to update the estimates of scheme costs on the basis of scheme experience for the 2017-18 Annual Financial Sustainability Report.
  - The Commission did not revise its own projections of scheme costs. This is because it broadly agrees with the NDIA's approach to projecting scheme costs and the decision to delay integrating data from the trial and transition.
- Based on trial and transition data, NDIS costs are broadly on track with the NDIA's long-term modelling. While there are more children entering the scheme than expected, this is more than offset by lower levels of utilisation than expected. But while lower than expected levels of utilisation means lower scheme costs, it also implies poorer outcomes for participants.
  - In the first three quarters of 2016-17, the scheme experienced higher than expected package costs, but this improved in the last quarter.
- The NDIA has put in place initiatives to address emerging cost pressures, including the Early Childhood Early Intervention approach and the use of reference package data in the planning process to reduce variability in the level of support provided to participants.

Tracking scheme costs and participant outcomes is critical to ensuring that the National Disability Insurance Scheme (NDIS) achieves its stated objectives and is financially sustainable over the longer term. In 2011, when the Commission estimated full scheme costs for a national disability insurance scheme, it said that insights from the early experience of the scheme should be used to provide a more precise estimate of the long-term scheme costs, given the uncertainties at the time around the costings of the scheme (PC 2011, p. 932).

The National Disability Insurance Agency (NDIA) estimates that at full scheme about 475 000 participants will have individualised supports and the scheme will cost $22 billion in the first year of full operation (NDIA 2016a, p. 18, 2017y, p. 6). The number of participants is higher than what is reported in the NDIA's publications because the NDIA only reports the number of scheme participants under the age of 65 years.[10]

These estimates are consistent with the Commission's 2011 estimates of scheme costs (discussed further below). For this study, the Commission did not update its estimate of long-term scheme costs, however, it did review the NDIA's updates and improvements to the Commission's 2011 estimates. At this stage there are too many limitations with the early scheme data to update the modelling assumptions (though early scheme data can be used to assess where cost pressures may be emerging).

The first section (section 2.1) of this chapter looks at the NDIS rollout schedule. Section 2.2 looks at the assumptions that drive the NDIA's long-term estimates of scheme costs. Section 2.3 provides an overview of scheme participants and costs to date, and looks at how they compare with the NDIA's assumptions.

2.1 The rollout of the scheme so far

The NDIS was trialled from 2013 in different jurisdictions across Australia. Trials commenced in New South Wales, Victoria, South Australia and Tasmania in July 2013 (table 2.1). The trial sites varied in size and scope. For example, the trial sites in:

- South Australia and Tasmania covered the whole jurisdiction but were restricted to certain age groups (children aged 0–14 years for South Australia and 15–24 years in Tasmania)
- Victoria and New South Wales were limited geographically (the Barwon and Hunter regions) but had no age restrictions (apart from the NDIS-wide restriction that participants must be aged under 65 years to enter the scheme).

The transition to full scheme began in all States and Territories in July 2016, with the exception of Western Australia (which began transitioning to a locally administered, but nationally consistent NDIS in July 2017). The Bilateral Agreements between the Australian and State and Territory Governments set out the timeframes for the transition in each

[10] The NDIA projects that in 2019-20, the NDIS will include 460 000 participants under the age of 65 years and 15 000 participants aged 65 years and over. The NDIA reports 460 000 participants in its publications.

jurisdiction, including quarterly estimates of the number of participants who will enter the scheme. Jurisdiction-specific Heads of Agreements signed by the Australian and the State and Territory Governments outline that the full scheme is scheduled to be rolled out nationally by 2019-20, with the timeframes for the transition to differ across jurisdictions (NDIA ndb) (table 2.1).[11]

Table 2.1 **NDIS transition arrangements by jurisdiction**

	Trial period			Transition to full scheme			Full scheme
	2013-14	2014-15	2015-16	2016-17	2017-18	2018-19	2019-20
NSW	Hunter area trial		Early transition in Nepean Blue Mountains area (children aged 0–17 years)	Transition to full scheme (by region)		Full scheme	
Vic	Barwon area trial			Transition to full scheme (by region)			Full scheme
Qld				Transition to full scheme from July 2016 (by region). Early transition from January 2016 in Townsville, Charters Towers and Palm Island			Full scheme
SA	Statewide trial (children aged 0–14 years)			Transition to full scheme (by age and region)		Full scheme	
Tas	Statewide trial (people aged 15–24 years)			Transition to full scheme (by age)			Full scheme
NT		Barkly region trial		Transition to full scheme (by region)			Full scheme
ACT[a]		Territorywide trial		Full scheme			
WA[b]		Perth Hills area trial		Transition to locally administered NDIS			
		MyWay trial					

[a] The Bilateral Agreement for the NDIS launch between the Australian Government and the ACT Government notes that from 2016-17, the ACT will be in 'transition to full scheme'. This transition has been categorised as 'full scheme' because all residents who meet the eligibility criteria will have access to the scheme. [b] In February 2017, the Australian Government and Western Australian Government signed a Bilateral Agreement for a nationally consistent, but locally administered, NDIS.

Sources: Adapted from ANAO (2016, p. 79); NDIA (ndb); Porter, Barnett and Faragher (2017).

The speed of participant intake is creating problems

In 2011, the Commission recommended that the NDIS commence in July 2014 in two geographic regions (PC 2011, p. 938).[12] With the benefit of hindsight, the schedule recommended by the Commission was highly ambitious and was unlikely to have been met.

[11] The Bilateral Agreements covering the trial phase (signed between 2012 and 2014) included the planned intake of participants and the balance of cash and in-kind contributions to the scheme. A second set of Bilateral Agreements cover the arrangements for transitioning the NDIS to full scheme. These were signed in 2015 and 2016. The ACT reached full scheme at the completion of the trial period so a second bilateral agreement was not required.

[12] The Commission also recommended that the scheme would be national by July 2015 and reach full scheme by 2018-19.

But the scheme was launched a year earlier than even that ambitious timetable, and the scope of the trials was broadened significantly. The changed timing and scope of the trials compressed the planning phase for the scheme and exacerbated some of the issues faced by the scheme. Some aspects of the scheme were being built and tested over the trial, for example:

- the NDIS commenced without an assessment tool to help determine reasonable and necessary supports and had to build one over the first three months of operation (NDIA, sub. 161, p. 3). The Commission acknowledged that there was no ideal assessment tool for the NDIA to use, but also said that the scheme should not be delayed in the absence of 'perfect' tools (PC 2011, pp. 338–339)
- the ICT system used during trial was an interim system that would not scale to full scheme (NDIA, sub. 161, p. 3). The new system, put in place in 2016 for full scheme, has also had a number of issues (chapter 13).

A review of the capabilities of the NDIA described the Agency as being 'like a plane that took off before it had been fully built and is being completed while it is in the air' (Whelan, Acton and Harmer 2014, p. 7).

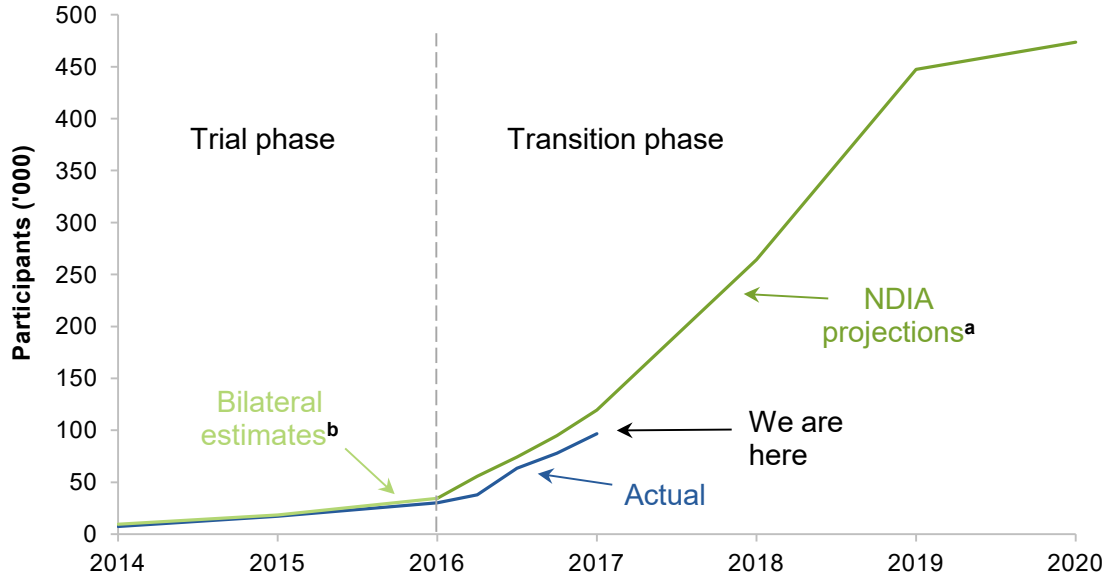
The participant intake schedule is highly ambitious given the magnitude of the reform. To reach the estimated 475 000 participants at full scheme by 2019-20, the NDIA will need to approve hundreds of plans a day (figure 2.1). In the June 2017 quarter, the NDIA approved about 15 000 plans, or roughly 165 plans a day (NDIA 2017y, p. 13). In 2018-19 (the final year of transition), NDIA modelling indicates that about 500 plans will need to be approved, and hundreds more reviewed, each day.

As JFA Purple Orange (sub. 186, p. 7) said the NDIS transition arrangements 'mean a tsunami of new participants will be processed into the scheme over the next two years'. Associate Professor Helen Dickinson of the Public Service Research Group at the University of New South Wales (2017) also recently commented that 'this vast reform is being implemented at break-neck speed'.

The NDIA is already struggling to keep up with the participant numbers included in the Bilateral Agreements — at the end of June 2017, there were 97 000 participants with approved plans, which was just 83 per cent of the bilateral estimates (table 2.2).[13] If the number of people approved to enter the scheme but awaiting a plan (26 000) are added to scheme participant numbers, then the bilateral estimates have only just been reached.

[13] The 97 000 participants with an approved plan reported by the NDIA includes 6 314 children who have entered the Early Childhood Early Intervention pathway but who *do not* have an approved plan. It also includes participants aged 65 years and over (however, the bilateral estimates only include participants aged 0 to 64 years).

Figure 2.1 **Growth in number of participants in the scheme[a]**



[a] Scheme participant projections are based on projections prepared by the Scheme Actuary for the NDIA's 2015-16 Annual Financial Sustainability Report using data at 30 June 2016. The Commission adjusted the projected number of participants for the four quarters of 2016-17 to be consistent with the bilateral estimates reported in the latest NDIA quarterly report. [b] Bilateral estimates based on the NDIA's quarterly reports.

Source: Commission estimates based on NDIA (2016a, 2017y).

Table 2.2 **NDIS participants and bilateral estimates**

	Participant cohort with approved plans[a]				*Bilateral estimate*[b]	*Per cent of estimate*
	Existing disability service clients	*New*	*ECEI*[c]	*Total*		
End of 2015-16	15 308	14 973		30 281	34 545	88
End of 2016-17 Q1	20 652	17 214		37 866	54 811	69
End of 2016-17 Q2	37 715	23 489	2 267	63 471	73 070	87
End of 2016-17 Q3	47 703	27 857	2 439	77 999	93 385	84
End of 2016-17 Q4	58 400	32 238	6 134	96 772	116 555	83

[a] This includes participants who at one point had an approved plan but who have since exited the scheme. [b] The bilateral estimates presented in this table are for participants aged 0–64 years. [c] ECEI denotes the number of children who have entered the Early Childhood Early Intervention pathway but who *do not* have an approved plan.

Source: NDIA (2017y, p. 17).

The NDIA, commenting on the bilateral estimates before the Commission's position paper, said:

> The transition to full scheme commenced on 1 July 2016 and immediately there were problems. The new systems and process, coupled with the scale of intake and issues with the ICT portals saw the NDIA fall behind both in terms of the bilateral estimates and the quality of the participant and provider experience.
>
> The NDIA was able to recover against the bilateral estimates, but problems emerged during this time with the quality of plans and concerns were expressed about aspects of the planning process and the impact on the participant experience. These are matters that the NDIA is now actively addressing. (sub. 161, p. 4)

There also appears to be fewer clients in existing programs transitioning to the NDIS than the national minimum data set suggested, and compared with the estimated number of transitioning participants in the Bilateral Agreements (noting that the numbers in the Bilateral Agreements are estimates, not hard targets). The NDIA said:

> The original estimates of the expected presentation rate were based on demographic data available at the time (e.g. geography, age and the scope and nature of the previous State and Territory client bases). The early Transition experience indicates that other 'real-time' factors are also determinants of the actual participant presentation rate (e.g., participant readiness to join or phase into the Scheme, and difficulties contacting participants due to multiple sources of contact data of varying quality). (sub. PP327, p. 10)

Despite the lower than expected participant intake to date, at this stage the NDIA has not revised the overall expected number of participants in full scheme (sub. 161, p. 76). It has, however, indicated that the lag associated with participants presenting to the scheme is likely to persist (sub. PP327, p. 10).

If the current trend continues, it will take an additional year (2020-21) before all 475 000 participants will be in the scheme (though this delay could be longer if the scheme falls further behind the bilateral estimates when the participant intake ramps up in 2017-18, or if participants do not apply to enter the scheme as soon as they are eligible — something that is already being observed in some jurisdictions).

It is the Commission's view that the current timetable for participant intake will not be met.

Transition to full scheme is a unique stage in the life of the scheme

Given the size, speed and complexity of the reform, it is inevitable that there will be transitional issues with the rollout of the NDIS. It needs to be recognised that the scheme is still in its infancy and it will take time to get it right. A number of study participants noted that the transition period is a unique period in the life of the scheme. The Australian Federation of Disability Organisations, for example, said:

> We acknowledge that there have been many issues during trial and the transition to full scheme implementation. But we also recognise that this is a unique period in the life of the NDIS. Never

> again will the scheme have to grapple with the multiple challenges posed by bringing in a large number of participants in such a short period of time. Once this period of transition is over, growth will be limited to a small number of new participants. AFDO understands that there are significant operational challenges in ensuring hundreds of thousands of people enter the scheme in a short period of time. (sub. 180, p. 8)

Mental Health Australia also said:

> The Transition period is a unique period in the life of the NDIS. Never again will large numbers of people be required to move into the Scheme in such a short period of time. Difficulties were to be expected given the numbers of people involved and the complexity of the task at hand. (sub. PP321, p. 19)

But already there are signs that the rollout schedule is compromising the NDIA's ability to implement the NDIS as intended, and risking the financial sustainability of the scheme — and the number of participants entering the scheme is only just starting to ramp up. Many of the concerns raised with the Commission in this study relate to the rollout schedule and the risks of focusing on participant numbers (box 2.1). The NDIA is also aware of the risks, noting that:

> … bilateral estimates can and do impact upon the way in which the Scheme is delivered. This can put sustainability at risk and impact on the way in which early intervention and investment initiatives are implemented in the short term. It may also have adversely impacted the quality of plans. (sub. 161, p. 109)[14]

While the NDIA has been set a challenging task of generating plans for tens of thousands of participants each quarter, it is important that it also undertakes the planning process in a way that achieves the objectives of the scheme (chapter 5).

A further problem resulting from the participant intake schedule is that parts of the supporting infrastructure that are essential to the objectives of the scheme are not operating as intended. For example, Local Area Coordinators (LACs), which play a key role in delivering information and linking individuals to disability services, were supposed to be 'on the ground' in rollout areas six months before participants joined the scheme (chapter 5). But this did not occur and some areas were still without a LAC months after they joined the scheme. The need to meet bilateral estimates also resulted in LACs being asked to divert resources away from Information, Linkages and Capacity Building (ILC) tasks to undertake planning-related activities. ILC is important for containing scheme costs and reducing reliance on individualised supports (chapter 6).

[14] The NDIA rightly notes that actual participant numbers lagging behind bilateral estimates does not in itself present 'a risk to the financial sustainability of the Scheme' as fewer participants equates to lower costs (NDIA, sub. PP327, p. 10). However, a focus on the meeting the bilateral estimates at the expense of plan quality does have the potential to increase scheme costs in the long term.

Box 2.1 Risks from the rollout schedule are highlighted

House with No Steps:

> … the Scheme has aggressive ramp-up targets. These are putting pressure on the NDIA's capacity to develop quality plans for participants. Unfortunately, the need to achieve high growth in participant numbers appears to be outweighing considerations of plan quality and consistency. (sub. 104, p. 5)

Community Mental Health Australia:

> If the focus purely becomes about signing as many people up as quickly as possible and preventing cost-overruns, then the intent of what the NDIS was actually meant to deliver starts to become lost. (sub. 11, p. 2)

Maurice Blackburn Lawyers:

> We believe the roll-out timeline of the NDIS is highly ambitious and increases the serious risk of inadequate delivery of services to participants. It also poses significant financial risks to the scheme as a whole. (sub. 58, p. 6)

Blind Citizens Australia:

> While we understand the agency is under intense pressure to meet the targets that have been agreed upon under the bilateral agreements between state and territory governments, meeting these targets should not come at the expense of the basic rights and freedoms of people with disability. (sub. 130, pp. 2–3)

Australian Federation of Disability Organisations:

> The need to bring in a large number of participants into the scheme to meet bilateral targets has during transition led to practices which have not always been consistent [with] the original vision of the scheme. (sub. 180, p. 5)

Young People in Nursing Homes Alliance:

> Trying to meet the very demanding targets in the bi-lateral agreements has been torturous for both the scheme and for its partners. The NDIS has had to divert resources away from core commitments to manage these urgent imperatives … (sub. 187, pp. 26–27)

Plan Management Partners:

> … the volume of plans to be completed in order for the scheme to achieve its milestone rollout targets is ultimately generating more work for LACs and plan reviewers due to the variability in quality of resultant plans. (sub. 126, p. 11)

Catholic Social Services Australia:

> The speed of the NDIS rollout will put considerable pressure on processing participants' eligibility, assessment and planning. This pressure will be exacerbated by annual plan reviews that are required for those already in the scheme. (sub. 166, p. 7)

The Department of Social Services:

> … there are risks arising from the scale and pace of roll-out that has potential to place strain on the NDIA, and on agreed transition timeframes. (sub. 146, p. 24)

Mental Health Australia:

> At this time, the NDIA is being judged on volume, on time and on budget. … In the headlong rush to meet both time and volume commitments outlined in bilateral agreements, as the CEO of the [NDIA] recently conceded, insufficient attention appears to have been paid to quality … Processes that are ill-suited to people with psychosocial disability are compromising outcomes for individuals. Consequently, the vision of the Scheme and public confidence in its effectiveness are undermined. (sub. PP321, p. 19)

The NDIA (sub. 161, p. 16) acknowledged that its 'systems and processes are not at peak efficiency and are not ideal in terms of dealing with the speed and scale of the intake challenge'. Also that:

> While the NDIA remains committed to meeting the bilateral estimates, it recognises that the systems and processes that underpin delivery must continue to improve to meet the scale of the challenge while delivering appropriate high quality individual outcomes. The achievement of the bilateral estimates must be done in a manner that maintains the commitment in all jurisdictions to quality, safety, improved outcomes and sustainability. (sub. 161, p. 16)

The rollout schedule has also meant that the market for disability care and support (including providers, workers and participants and their families) has had very little time to adjust to the new scheme (chapters 7–10). As One Door Mental Health said:

> The speed with which the roll-out has occurred has placed significant financial strain on providers, particularly small providers, as a result of needing to move from the relative stability of block-funding arrangements to the uncertainty of unknown revenue through fee-for-service. (sub. 179, p. 11)

Without time to allow for the demand side to become better informed and active, and for the supply side to adjust and grow, there is a risk that participants will be unable to use their supports, either because the services are simply not there, or because participants are not sufficiently well equipped to navigate the scheme.

A number of participants agreed with the Commission's assessment of the risks to the scheme from the ambitious participant intake schedule. For example, Legal Aid NSW said:

> In our experience, the timing and pace of the NDIS rollout has led to poor outcomes for many participants. The focus on participant numbers has compromised the quality of the planning process, and often, participants are left frustrated and dissatisfied with their plans. (sub. PP245, p. 3)

Queensland Government:

> The Queensland Government agrees that the timeframes are ambitious and shares concerns regarding the NDIA's ability to implement the scheme as intended including its ability to manage the increased workload as it approaches full scheme rollout. (sub. PP345, p. 3)

And Catholic Social Services Australia said:

> CSSA agrees with the Commission's finding that the speed of scheme rollout has put considerable pressure on the capacity of the NDIA … leading to compromises in the planning process, lack of support for participants and inadequate communication with providers. (sub. PP278, p. 2)

The NDIA, in response to the Commission's position paper, re-emphasised that the Agency is actively working to mitigate the risk associated with the participant intake schedule. The

NDIA noted the planning process as the most pressing challenge to scheme rollout and stated that significant work is being undertaken to improve the scheme's operation.

> The quality of participant outcomes is the NDIA's primary consideration relative to the speed of the rollout. (sub. PP327, p. 10)

Chapter 5 makes recommendations designed to improve the quality of the planning process. Chapter 11 explores whether additional changes are required to mitigate the risks that the rollout schedule presents to the sustainability of the scheme.

FINDING 2.1

The scale and pace of the National Disability Insurance Scheme (NDIS) rollout to full scheme is highly ambitious, and will not be delivered as scheduled in terms of participant intake. The rollout schedule risks the National Disability Insurance Agency (NDIA) not being able to implement the NDIS as intended and it poses risks to the financial sustainability of the scheme. The NDIA is cognisant of these risks.

2.2 Projections of scheme costs

One of the NDIA's insurance principles is to develop actuarial estimates of long-term costs (chapter 1). Actuarial estimates are compared with the actual scheme experience, so that the NDIA can identify cost pressures, and track and monitor responses put in place to address those pressures.

However, estimating future scheme costs presents a number of challenges. For example, while there is information on the number of potential participants who are currently receiving support from existing State and Territory Government programs, there are only survey data (which are subject to sampling error) on the number of potential participants not receiving support from government programs.

There is also uncertainty about the support needs of potential participants. While there are comprehensive data on the catastrophic injuries that are covered by compensation schemes (mostly spinal cord, brain and burn injuries), for most disabilities, comprehensive data on the level of funding required to achieve good long-term outcomes are not available. The NDIA has constructed reference packages for different disabilities with the help of expert reference groups (chapter 5). These packages will be refined over time as data are collected from the NDIS on the effectiveness of different supports and their cost.

In 2011, the Commission estimated a national disability insurance scheme would cover 411 000 participants at a gross cost of $13.6 billion at full scheme (PC 2011) (box 2.2).

Box 2.2 The Commission's modelling approach in 2011

In its 2011 report on *Disability Care and Support*, the Commission estimated that a national disability insurance scheme would cover 411 000 participants and would have a gross cost of $13.6 billion (and a net cost of $6.5 billion) at full scheme. The costings were based on three calculations:

- the number of people who would be eligible for the scheme
- the level of support that these people would require
- the average per person cost associated with each level of support — four types of support were costed: care and support; aids and appliances; home modifications; and transport.

No single data source contained all the information required.

- The primary data source for numbers of people and level of support was the 2009 ABS Survey of Disability, Ageing and Carers. The number of participants entering with psychosocial disability was calculated by consulting with experts who had previously examined the prevalence of enduring psychiatric disability.
- A variety of sources were used to estimate the average per person costs for different types of support, including data from the Victorian Transport Accident Commission, the New South Wales Lifetime Care and Support Scheme, and the Multiple Sclerosis Longitudinal Study.

The Commission also estimated that when the scheme matured (around 2050), the *net* cost would be $4.4 billion. The long-term savings were attributable to assumptions regarding early interventions and community capacity building (for example, more people with disability are able to live in the community with intensive supports rather than in supported accommodation).

A further offset of about $720 million was assumed when the national injury insurance scheme matured.

The Commission recognised that there were significant uncertainties about the cost estimates because of the nature and quality of the data, and undertook a number of sensitivity analyses to explore these uncertainties.

Source: PC (2011, pp. 748–780).

The NDIA (2017y, p. 6) projected that by 2019-20 the NDIS will cover 475 000 participants and cost about $22 billion each year.[15] These estimates are broadly consistent with the Commission's 2011 modelling after taking into account inflation (including the effects of pay rises awarded to social and community services workers by the Fair Work Commission in 2012), population changes, and costs associated with participants aged 65 years and over (who enter the scheme prior to 65 years) (box 2.3).

[15] Both the Commission's and the NDIA's projections of scheme costs include Western Australia. While the gross cost of the NDIS is estimated to be $22 billion in 2019-20, the scheme is expected to reduce the funding required for a range of government programs. A review by the Australian Government Actuary in 2011 estimated these offsets to be about $11 billion (NDIA, sub. 161, p. 29).

Box 2.3 Comparing the NDIA's estimates and the Commission's 2011 estimates

While the NDIA uses a different methodology to that used by the Commission in 2011 to estimate costs, the differences in projected costs are mainly attributable to incorporating population projections, industry-specific wage increases and costs associated with participants aged 65 years and older (table below).

Population

Between 30 June 2012 and 30 June 2020, Australia's residential population aged under 65 years is projected to increase by 12 per cent. Applying this increase to the Commission's estimate of 411 250 scheme participants (aged under 65 years) results in 461 000 participants aged under 65 years — this is in line with the 458 368 participants estimated by the NDIA. Incorporating population projections adds about $1.5 billion to the Commission's estimates of scheme costs.

Wage increases in the disability sector

In February 2012, the Fair Work Commission found that employees in the community and disability sectors were underpaid compared to public service workers doing similar jobs. The subsequent Equal Remuneration Order applies adjustments ranging from 23 per cent (for employees at the lowest level) to 45 per cent (for employees at the highest level) in nine instalments between December 2012 and December 2020. These adjustments are applied on top of increases from the annual wage review undertaken by the Fair Work Commission.

The NDIA's modelling of scheme costs assumes that average cost of care in the disability sector will increase 29 per cent between 30 June 2014 and 30 June 2020. If Australian Government Actuary assumptions regarding cost increases from the Department of Social Services' funding model are applied between 2011-12 and 2013-14, the total increase in average costs to 2020 is 44 per cent. The NDIA assumptions imply an increase in average costs from $31 183 to $45 018 per participant. These cost increases would add about $6.4 billion to the Commission's estimates of scheme costs.

Participants aged 65 and older

The NDIA modelling projects that there will be 15 000 participants aged 65 years and over in 2019-20 and that they will add an extra $1.09 billion to scheme costs (with an average cost of $71 000 per participant). The Commission's 2011 estimates of costs did not include participants 65 years and over on the basis that they did not represent a net increase in costs to the Australian Government (as their support was funded under the aged care system).

	Participant numbers	*Scheme costs ($b)*
Productivity Commission estimates 2011[a]	**411 250**	**12.82**
Population projections to 2019-20	49 544	1.54
Inflation in disability sector (wages)	..	6.38
Participants aged 65 years and older	15 285	1.09
Updated Productivity Commission estimates	**476 079**	**21.84**
NDIA projections for participants[b]	**473 653**	**21.76**
Difference (%)	2 426 (0.5%)	0.08 (0.4%)

a Excluding operating costs and offsets associated with the National Injury Insurance Scheme and assumed efficiency dividends. **b** Excluding operating costs ($1.5 billion), offsets associated with the National Injury Insurance Scheme ($0.7 billion) and assumed efficiency dividends ($0.3 billion). **..** Not applicable.

Sources: Commission estimates; NDIA unpublished estimates; PC (2011); Fair Work Australia (2012).

The NDIA's methodology is more refined than that used by the Commission in 2011 (the NDIA gave the Commission its long-term cost projection model used to produce the 2015-16 Annual Financial Sustainability Report). The key differences between the NDIA's model and the Commission's 2011 model are:[16]

- participant numbers are modelled for 14 separate disability groups (apart from psychosocial disability, there was no distinction between disabilities in the Commission's 2011 modelling)
- average package costs assumptions are based on reference package data developed by expert reference groups (the Commission in 2011 used data from injury and accident schemes that operate in Australia)
- epidemiological data on incidence and mortality rates for different disabilities were used to model participant numbers over time (the Commission did not explicitly model entry and exit rates in 2011).

Some key assumptions behind the NDIA's cost projections

There are a number of key assumptions that drive the NDIA's long-term projections.

- *Prevalence and incidence rates* — the estimate of participant numbers at full scheme (prevalence) is derived using the ABS Survey of Disability, Ageing and Carers and epidemiological data. Estimates of entry (incidence) and exit rates used to make long-term projections also use these data.
- *Long-term prices* — inflation of 4.3 per cent per year is assumed in the short term based on current wage rates (including the Social, Community, Home Care and Disability Services Award), with a long-term assumption of 4 per cent per year.
- *Utilisation* — there is no explicit assumption regarding underutilisation in the NDIA's projections. The projections assume that participants are allocated, and completely spend, a reference package of supports (the expected level of support required by participants given their age, disability and level of function).
- *Early intervention and early investment* — the NDIA's projections assume that early investment will reduce costs by 0.35 per cent per year. This assumption was originally developed for the Commission's modelling in 2011.
- *Technology* — advances in technology can both increase and decrease costs. The NDIA does not make any assumptions about the effect of technological advances on scheme costs.

[16] The Commission understands that further improvements to the modelling approach will be made for the 2016-17 Annual Financial Sustainability Report.

Participants aged 65 years and over

The proportion of NDIS costs that is attributable to participants aged 65 years and over will increase over time. The NDIA's modelling projects that in 2029-30, almost 20 per cent of scheme costs will be linked to participants aged 65 years and over compared to about 5 per cent in 2019-20 (table 2.3). This suggests that the share of total NDIS funding provided by the Australian Government will increase substantially over time as it is responsible for the funding of all participants aged 65 years and over (and all Indigenous participants aged over 50 years). This does not necessarily mean that there will be a sizable net cost to the Australian Government, as it also has primary funding responsibility for the aged care system (chapter 6).

Table 2.3 **NDIS costs attributable to participants aged 65 years and over**

Year	*Scheme costs (all participants)*	*Scheme costs (65 years and over)*[a]	*Proportion of total costs (65 years and over)*
	$b	$b	Per cent
2019-20	22.3	1.2	5.2
2024-25	30.6	4.1	13.4
2029-30	40.9	8.2	19.9
2039-40	70.2	19.3	27.5
2049-50	113.6	34.1	30.0

[a] This includes operating costs associated with participants aged 65 years and over.

Source: Unpublished NDIA modelling estimates.

The magnitude of the projected increase in the costs associated with participants aged 65 years and over is influenced by a number of assumptions relating to ageing in the scheme, including:

- the exit rates of participants aged 65 years and over, which can be disaggregated into:
  - mortality exit rates — these are based on epidemiological data and are disability specific
  - exit rates for participants entering the aged care system. Participants are assumed to enter the aged care system (and exit the NDIS) when they enter residential aged care (chapter 6).[17] These exit rates are based on (limited) data on the rates of transition to residential aged care and are disability specific
- the average package costs for participants aged 65 years and over:

[17] NDIS participants aged 65 years and over can choose to transition to the aged care system or remain in the NDIS. However, the financial incentives are such that there is little incentive for participants to make this transition (chapter 6). When a scheme participant enters residential aged care, they cease to be an NDIS participant.

- average package costs for those aged 65 years and over are assumed to be higher than for participants aged 55–64 years for about half of the primary disability groups — in 2019-20, the difference is assumed to be 20 per cent
- for the disability groups just identified, average package costs for older participants are also assumed to increase at a faster rate (an additional 1 per cent above economic inflation for every year between 2019-20 and 2044-45) than for participants aged under 65 years (i.e. in 2044-45, average package costs are an *extra* 25 per cent higher than for participants aged under 65 years, or 50 per cent higher in aggregate).[18]

More on utilisation rates…

Utilisation rates during the transition period are likely to remain significantly lower than the utilisation rate expected at full scheme. While data integrity issues make it difficult to develop precise projections on support utilisation at full scheme (2019-20), trial and transition data suggest a utilisation rate of about 75–85 per cent is plausible by the end of the transition phase (section 2.3).

Beyond 2019-20, utilisation rates are expected to rise as the market for supports matures. However, they are unlikely to reach 100 per cent — the NDIA noted that experience in other schemes suggests a utilisation rate of between 80 and 95 per cent could be expected (NDIA, sub. 161, p. 70).

Future updates to the projections of scheme costs

The NDIA has made some adjustments to their long-term cost projections using some trial data, but it has not made more extensive changes to cost projections based on all trial and transition data. Early scheme data deviate from some of the assumptions included in the NDIA's projections (section 2.3), but these data have too many limitations to update assumptions about prevalence and package costs. The data also reflect a period of the scheme prior to management responses implemented by the NDIA to address early cost pressures (discussed below).

As a number of study participants noted, it could be some time before conclusions can be made about the financial sustainability of the scheme. For example, the Victorian Government said:

> The Review is being undertaken at a very early state in the transition to full scheme and the market is at an early stage of its development — too soon to arrive at any conclusions about the scheme's ongoing costs or sustainability.
>
> It may be several years before total costs and lifetime costs are known. Little data is currently available and further experience is required to understand how the application of insurance principles can vary costs over a participant's lifetime. (sub. PP298, p. 1)

[18] The aggregate difference is 50 per cent not 45 per cent (20 per cent plus 25 per cent) due to compounding.

The New South Wales Government also said:

> Transition experience should inform estimates of full scheme costs, but must not be automatically extrapolated. Costs during transition must be considered with reference to the expected costs during this period (not with reference to full scheme costs). (sub. 60, p. 10)

The NDIA indicated that as the scheme rolls out, the transition data collected will be used to better inform estimates of full scheme costs, and to assess the effectiveness of the NDIA's responses to address cost pressures — in its latest quarterly report, the NDIA said that it is undertaking ongoing work to 'verify the longer-term cost of the NDIS based on scheme experience to date' (NDIA 2017y, p. 6).

It is imperative that new data are incorporated into the assessment of longer-term costs as soon as possible. Given the low levels of utilisation that the scheme has experienced in the transition to date (section 2.3), and the fact that underutilisation is likely to continue in the short to medium term (with funding implications), it is particularly important that utilisation assumptions are incorporated into the modelling. In the absence of any major data reliability issues, there should be sufficient scheme data to update estimates of scheme costs based on scheme experience for the 2017-18 Annual Financial Sustainability Report.

From time to time, the NDIA's costings of the scheme may need to be updated to reflect policy changes that alter the scope of the NDIS. For example, changes to the scope of the National Injury Insurance Scheme would impact on the cost of the NDIS and need to be reflected in the estimates of scheme costs (chapter 6).[19] It is important that any policy changes are incorporated quickly into the NDIA's costing of the scheme and that the changes attributable to the policy change are clearly articulated to preserve the public's confidence in the scheme's financial sustainability.

The Commission did not revise its own projections of scheme costs. This is because the Commission broadly agrees with the NDIA's approach to projecting scheme costs and the decision to delay integrating data from the trial and transition (but stress that these data should be incorporated as soon as practicable). It is the Commission's view that the NDIA's projections of scheme costs should inform the Australian Government's budget estimates for the NDIS (chapter 12).

In any case, point estimates of total scheme costs do not tell the whole story. Financial sustainability is about both costs and benefits, and risks to financial sustainability cannot always be easily modelled, or identified from scheme data. A long-term focus, both within and outside the NDIS, is therefore important. While the NDIA is responsible for monitoring scheme costs and responding to the cost pressures that it can control, all governments have a responsibility to ensure the success of the scheme and its financial sustainability.

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[19] Another example is the cost risk around specialist school transport services. If Governments decide that the NDIS should cover the costs of specialist school transport services, this would add between $300–$600 million each year to the cost of the scheme. This is a cost risk being considered by the NDIA, but it is not included in the Agency's cost modelling or financial sustainability reporting for the full scheme. (NDIA, sub. PP370, p. 10)

FINDING 2.2

The Productivity Commission supports the National Disability Insurance Agency's (NDIA's) approach to projecting scheme costs and the decision to delay integrating data from the trial and transition period to date. As such, the Commission has not revised its own projections of scheme costs.

However, it is imperative that new data are incorporated into the NDIA's assessment of longer-term costs as soon as possible. The Commission's assessment is that, in the absence of any major data reliability issues, there should be sufficient data for the NDIA to update the estimates of scheme costs on the basis of scheme experience for the 2017-18 Annual Financial Sustainability Report.

2.3 Key insights from trial and transition data

While it is early days, there are some insights from the early experience of the NDIS (from trial and transition data — July 2013 to June 2017). This section looks at participant characteristics, package costs, and utilisation of supports. These three factors determine the year to year costs incurred by the NDIA on individualised supports.

Trial and transition data need to be interpreted with caution

The first point to note is that data from the trial and transition phase need to be interpreted with caution. This is because:

- differences in trial sites and phasing schedules mean that the data cannot necessarily be used as a guide to anticipate full scheme experience (for example, the average level of committed support by a jurisdiction will reflect the trial cohorts for each jurisdiction)
- early scheme data are often subject to small sample sizes — minimal weight should be placed on disaggregated results where sample sizes are small
- the number of scheme participants in a region is likely to be an underestimate of the full scheme number because it takes time for potential participants to approach and gain access to the scheme. (On the other hand, the number of exits due to successful early intervention are likely to be lower in the first years of the scheme as it can take some years for the benefits of early intervention to accrue.)
- it can be difficult to determine whether observed cost pressures are transitional or whether they are likely to persist
- during transition, about 20 per cent of committed support is expected to be provided in-kind (Australian, State or Territory Government programs delivered under existing block-funding arrangements) (DSS, sub. 146, p. 22) and these supports tend to be more expensive than standard supports (NDIA, sub. 161, p. 101)

- data integrity may impact on the analysis, arising in part as a result of the NDIA transitioning to a new ICT system in July 2016. Some concern remains, despite the NDIA making manual adjustments where known data integrity concerns exist.

What do the early data tell us about participants?

At the end of the trial phase in June 2016, the number of participants with an approved plan (30 281) was 83 per cent of bilateral estimates (36 307) (NDIA 2016b, p. 42). (There were another 5400 participants who had been determined as eligible, but who did not yet have an approved plan.)

At the end of June 2017 (the most recent quarterly report), an additional 86 000 people had been found eligible for the scheme. This took the total number of scheme participants who had ever been active to 122 065 (NDIA 2017y, p. 15). About 97 000 active participants have an approved plan (NDIA 2017y, p. 15).

Participants by disability

Almost two-thirds of current scheme participants either have an intellectual disability (37 per cent) or autism (29 per cent) as their primary disability (figure 2.2). Psychosocial disability is the next most common disability, accounting for about 6 per cent of scheme participants.[20]

Participants with disabilities such as stroke and multiple sclerosis tend to be older, while participants with autism and other sensory/speech disabilities are relatively young (figure 2.2).

Most participants with autism enter the scheme under early intervention requirements (and early intervention is most effective at younger ages). In recent years there has been an increase in the number of autism diagnoses — likely in part due to a growing awareness of autism and more sensitive screening tools leading to higher prevalence rates for younger ages (Gothe-Snape 2017).

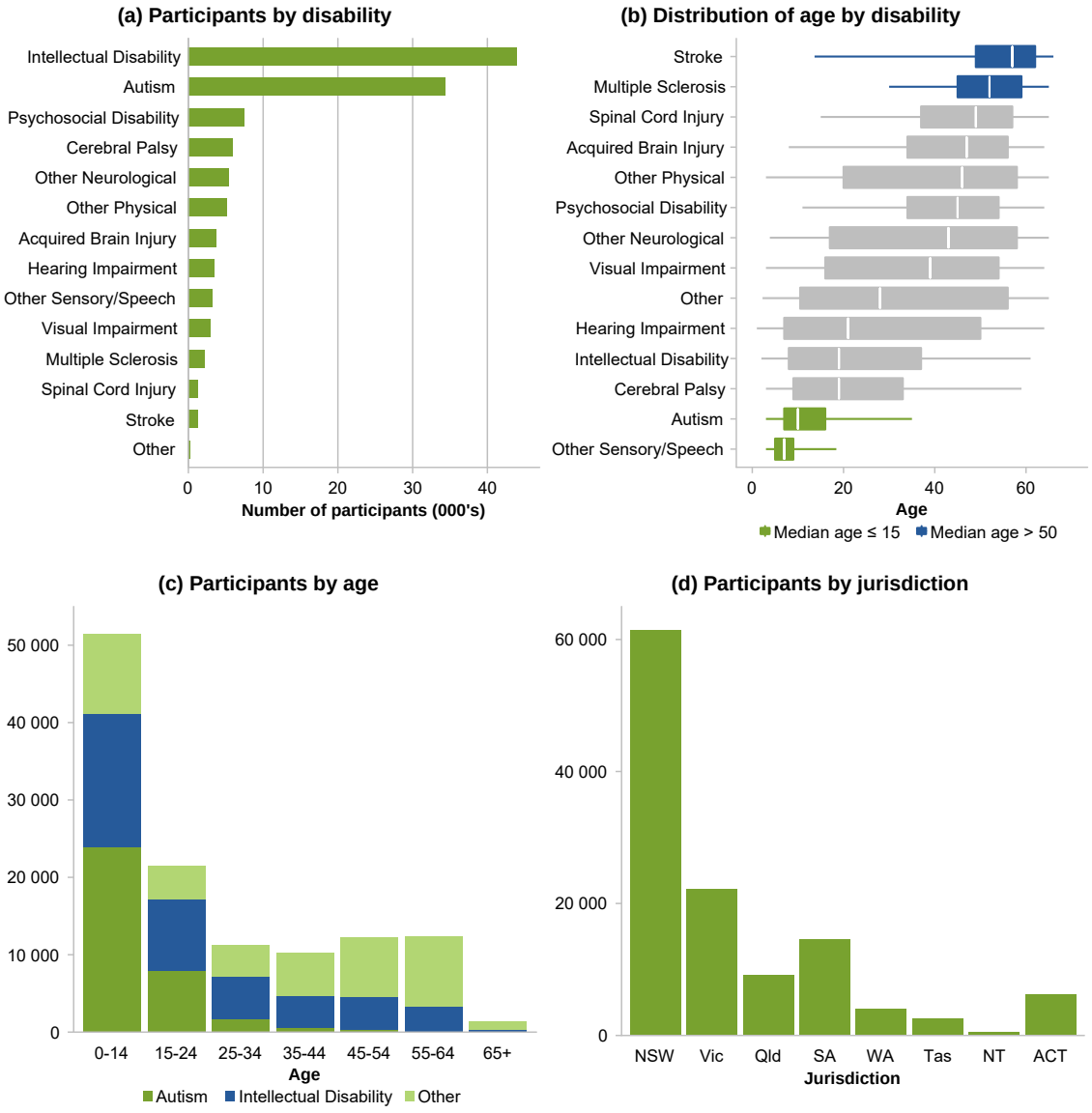
Disability-specific prevalence rates at the Barwon and Hunter trial sites broadly match those assumed in the NDIA's long-term modelling for all but the largest disability groupings (box 2.4) (figure 2.3). Prevalence rates were higher than the NDIA's long-term modelling assumptions for:

- autism, where prevalence rates were significantly higher in both trial sites (the NDIA implemented initiatives in response, discussed below)

[20] In addition, about 4 per cent of participants have a psychosocial disability that is not considered their primary disability (NDIA, sub. 161, p. 82).

- intellectual disability, where prevalence rates were much higher in the Barwon region, but not the Hunter region. The higher prevalence rate for intellectual disability in the Barwon region was most pronounced in participants aged under 18 years.

Figure 2.2 **Some insights: NDIS participants[a,b,c]**



[a] All figures include data on active eligible participants at 30 June 2017. [b] Figure (b) shows box plots of the distribution of the age of participants for different disability groups. The vertical line represents the median age of participants with that disability and the box shows the interquartile range (quartiles 1 and 3). The box plot tails show the 2.5 and 97.5 percentiles. [c] In figure (d), the number of participants in Western Australia includes the Perth Hills NDIS trial site, but not the Western Australia NDIS MyWay trial.

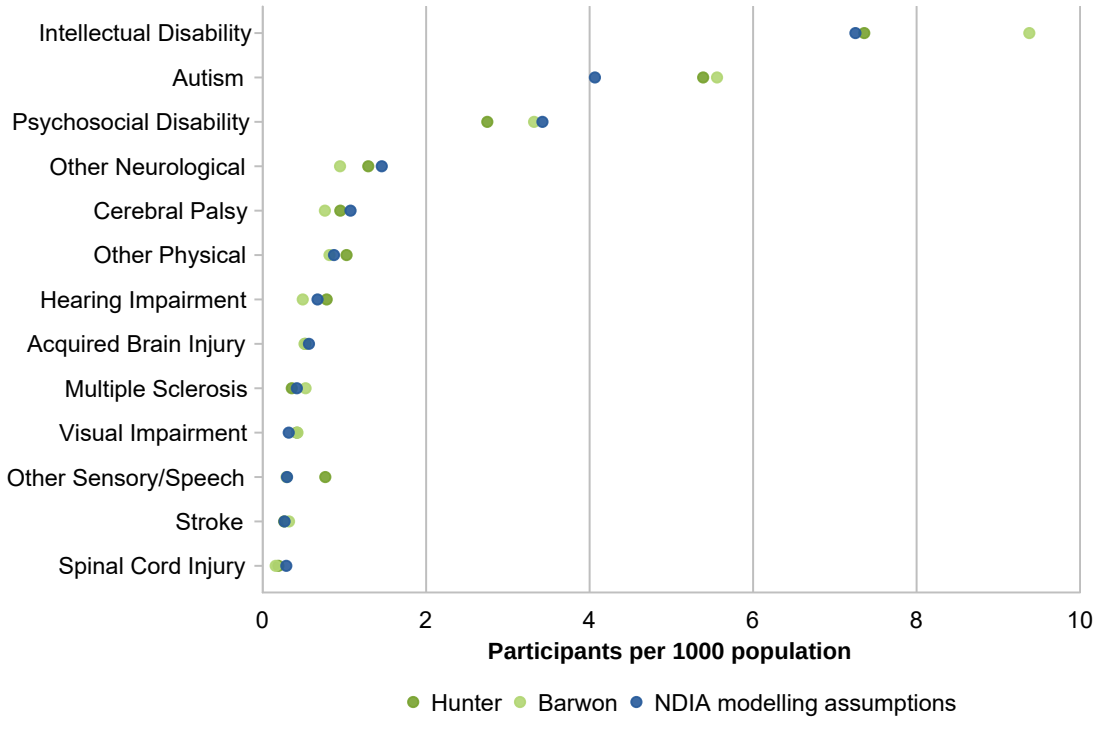
Source: Commission estimates based on unpublished NDIA data.

Box 2.4 Calculating prevalence rates

It is difficult to assess how participant numbers are tracking compared to the NDIA's long-term modelling assumptions, as it takes time for potential participants to approach and gain access to the scheme. To address this issue, the Commission used data from the Barwon and Hunter trial sites. Both these sites have been in operation since July 2013 and are open to everyone under the age of 65 years.

One significant limitation of this approach is that these trial sites may not be representative of the broader Australian population. Another limitation is that the NDIA has found that participants are continuing to approach the scheme at mature trial sites at a rate that is above that expected if only participants with newly acquired disabilities were approaching the scheme (though this latter factor would suggest prevalence may be even higher relative to the modelling assumptions than the numbers so far collected would indicate). Similarly, the number of exits from the scheme due to successful early intervention is likely to be lower than would be expected at full scheme, as it can take some years for the benefits of early intervention to accrue.

Figure 2.3 Prevalence rates by disability — trial compared to the NDIA's long-term estimates[a]



a Prevalence rates for a region are calculated as the number of active eligible participants with the selected disability per 1000 of the population aged 0–64 years at 30 June 2016. Data on the population for the Barwon and Hunter trial regions were sourced from the 2016 ABS Census of Population and Housing.

Source: Commission estimates based on unpublished NDIA data.

There is a lot of uncertainty around the number of participants with psychosocial disability at full scheme.

- Modelling work undertaken by the Department of Health (sub. 175, p. 4) in 2016, using the National Mental Health Service Planning Framework, estimated that about 92 000 people (18–64 years) have severe and complex psychosocial disorders that would closely align with the NDIS eligibility criteria for individualised supports.
- David McGrath Consulting estimated that 'approximately 289 000 people with a severe mental illness will need individualised, intensive 'NDIS-like' community supports in any 12-month period' in work conducted for Mental Health Australia in 2015 (Mental Health Australia, sub. 155, p. 10).
- The NDIA (2016b, p. 26) expects there will be about 64 000 participants with a primary disability of psychosocial disability in the scheme in 2019-20. According to the NDIA, at this stage of the rollout, the number of participants with psychosocial disability is tracking broadly in line with the modelling assumptions in mature trial sites (Scheme Actuary 2016).

Estimating the number of people with psychosocial disability eligible for the scheme is difficult because a robust and comprehensive database from which to draw is lacking. However, given there are a range of estimates prepared by stakeholders and agencies, it is essential that the methodology used is fully transparent, so that the estimates can be assessed and considered in relation to projections of numbers of participants with psychosocial disability at full scheme.

Participants by age

The largest share of participants in the scheme are children aged 14 years and under (about 51 000 or 43 per cent of total participants at the end of June 2017) (figure 2.2). About 47 per cent of children in the scheme have autism, and 33 per cent have an intellectual disability (including developmental delay).

The number of children in the scheme is higher than originally expected — this is even after accounting for the fact that the number of children in the scheme is skewed by the South Australian trial site, which was only for children.

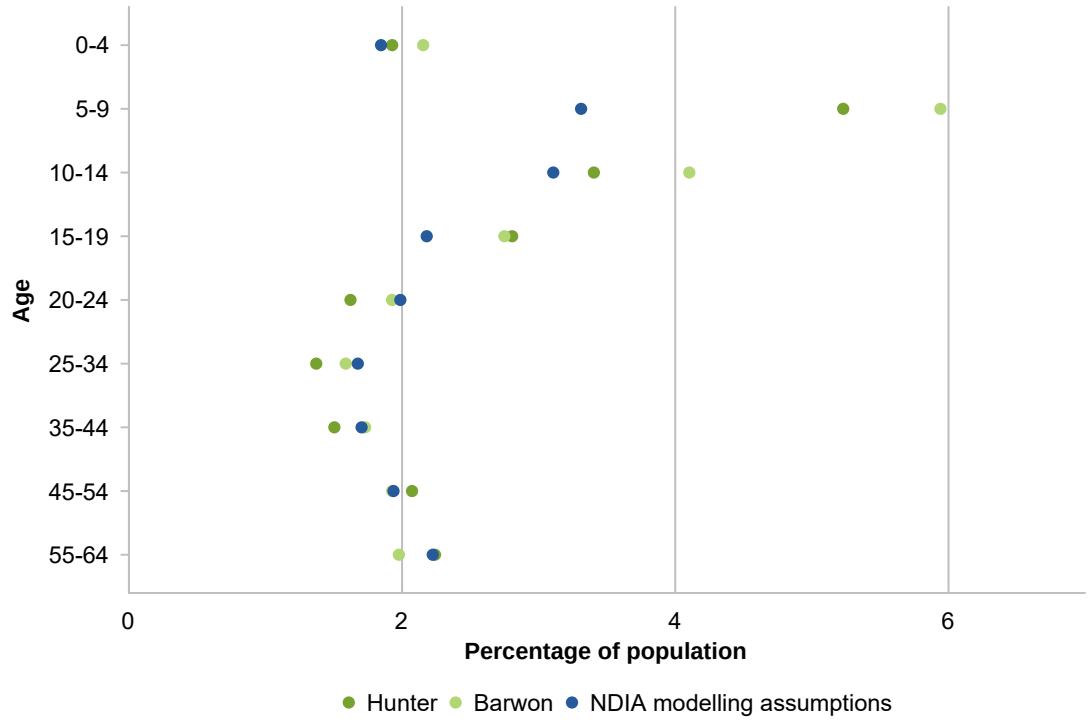
An analysis of the experience of trial sites by the NDIA (sub. 161, p. 78) found that the prevalence rates for children aged 0 to 6 years:

- exceeded the Commission's 2011 estimates in South Australia, Barwon and the ACT trial sites
- were in line with the Commission's 2011 estimates in Western Australia and the Hunter trial sites.

Looking at the data from the Barwon and Hunter trial sites, the Commission reached a similar conclusion. The largest gaps between actual and expected prevalence rates (based on the

NDIA's long-term modelling) are for children aged 5–9 years followed by children aged 10–14 years and young people aged 15–19 years. There are larger gaps for the Barwon region than the Hunter region (figure 2.4).

Figure 2.4 **Prevalence rates by age group — trial compared to the NDIA's long-term estimates[a]**



[a] Prevalence rates for a region are calculated as the number of active eligible participants in a given age group per 1000 of the population in the age group at 30 June 2016. Data on the population for the Barwon and Hunter trial regions was sourced from the 2016 ABS Census.

Source: Commission estimates based on unpublished NDIA data.

Participants by level of function

Participants are assessed for their level of functional capacity when they enter the scheme (box 2.5). Level of function data have been collected since July 2016 and data are available for almost 85 000 participants. At the end of June 2017, of those participants who have been assessed:

- 38 per cent had a high level of function
- 38 per cent had a medium level of function
- almost a quarter had a low level of function.

Box 2.5 Assessing level of function

As part of the planning process, the NDIA assesses each participant's level of function. This is one of many pieces of information that it uses to develop plans to help participants progress towards their personal goals and aspirations.

The National Disability Insurance Agency currently uses different assessment tools for 11 key disability types and the World Health Organisation Disability Assessment Schedule version II (WHODAS II) (for adults) and the Paediatric Evaluation of Disability Inventory-Computer Adaptive Test (PEDI-CAT) (for children) where no specific tool is identified. The scores of each assessment tool are mapped to a scale of 1 (high functional capacity) to 15 (low functional capacity), which provides a common measure across different types of disability.

To simplify its analysis, the Commission aggregated levels of function into three groups: high (levels 1–5), medium (levels 6–10) and low (levels 11–15).

Source: NDIA (sub. 161, p. 10).

Compared to the NDIA's long-term modelling assumptions, the distribution of participants by level of function to date is more heavily weighted towards the medium and low levels of function. This difference reflects, in part, the scheme's phasing schedules — participants with the greatest support needs are typically the first to enter the scheme in a region (figure 2.5). This is supported by the fact that the distribution of level of function for mature trial sites (Barwon and Hunter) is closer to the modelling assumptions.[21] (The distribution of level of function for the Hunter trial site is not expected to match modelling assumptions as it included a number of large residential facilities.)

That said, scheme costs will be higher than estimated if the early distribution of participants with lower levels of function persists at full scheme.

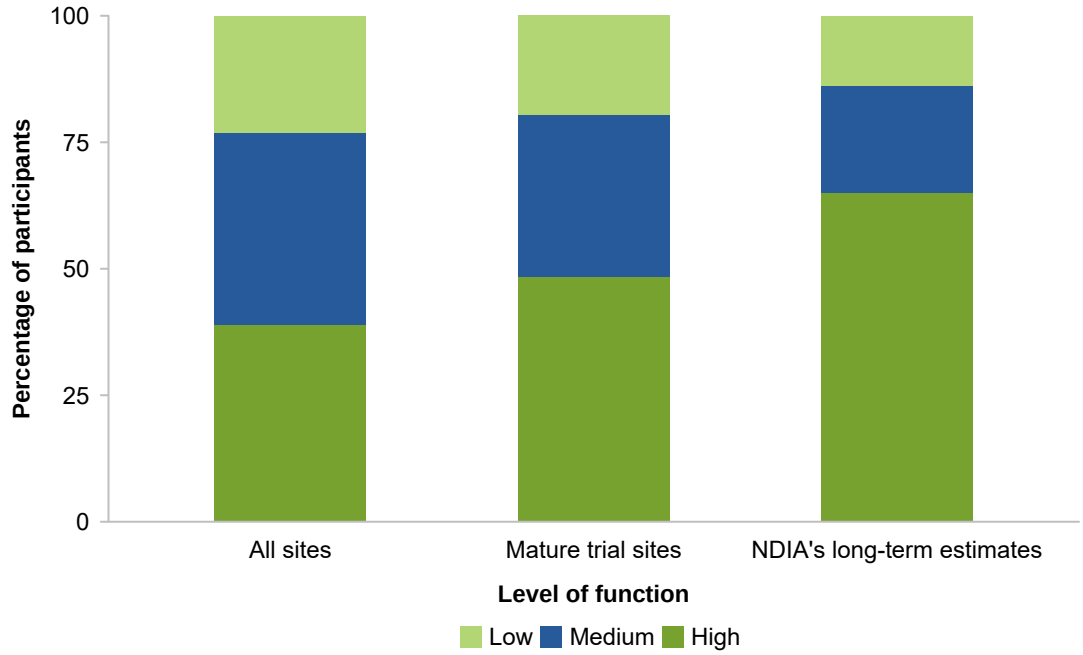
Participants by jurisdiction

About half of current NDIS participants are located in New South Wales (figure 2.2) — in comparison, the state accounts for 32 per cent of Australia's total population. This overrepresentation is because New South Wales had two trial sites while other jurisdictions had one. New South Wales is also further along the transition to full scheme (New South Wales is scheduled to reach full scheme by July 2018 — a year earlier than all the jurisdictions except South Australia and the ACT) (table 2.1).

[21] Data on level of function have not yet been collected for all trial participants.

Figure 2.5 **Distribution of participants by level of function compared to the NDIA's long-term estimates[a]**

At 30 June 2017



[a] 'All sites' denote all eligible scheme participants at 30 June 2017 for whom level of function data are available. 'Mature trial sites' denotes all eligible scheme participants at 30 June 2017 who were trial participants at the Barwon and Hunter trial sites and for whom level of function data are available. 'NDIA's long-term estimates' denote the distribution of level of function implicitly assumed in the NDIA's projections of scheme costs.

Source: Commission estimates based on unpublished NDIA data.

Participants by Indigenous and CALD status

The number of NDIS participants who identify as Aboriginal and Torres Strait Islander is broadly in line with estimates of disability prevalence for Aboriginal and Torres Strait Islander Australians. Aboriginal and Torres Strait Islander people represent 3 per cent of the population (ABS 2017a), and estimates of disability prevalence range from between 1.5 to 2 times the prevalence of the non-Indigenous population (ABS 2016a, 2016b; AIHW 2016). The NDIS data indicate that about 5 per cent of NDIS participants identify as Aboriginal and Torres Strait Islander.

However, some caution is warranted as it is not clear how the rollout schedule has influenced the number of Aboriginal and Torres Strait Islander participants in the scheme and there are some factors that may make it difficult for the NDIS to engage with Aboriginal and Torres Strait Islander people (many Aboriginal and Torres Strait Islander people with disability are reluctant to identify as people with disability and have only had a limited interaction with the disability service system (FPDN 2016)).

The NDIA does not report the number of culturally and linguistically diverse (CALD) participants as the data are not currently collected. That said, in the June 2016 quarterly report, the NDIA found that 4 per cent of participants in the trial were classified as CALD and that this was lower than expected (though again it is difficult to account for possible phasing schedule impacts) (NDIA 2016p, p. 34).[22]

The NDIA (2016t, p. 3) has developed a CALD strategy to support people from CALD backgrounds in accessing the services of the NDIS. CALD participants also have difficulties interacting with the planning process (chapter 5).

What do the early data tell us about package costs?

The scheme, at the end of the trial, came in under budget — there was a surplus of about 1.5 per cent of the funding envelope over the three years. However, this was in large part because not all committed supports were used (discussed further below).

The level of committed support (or a participant's package cost) is the dollar amount of support in a participant's plan. However, it is not necessarily the amount of support that a participant receives — there are a range of reasons why supports may be underutilised (discussed below). Over the course of the trial, the average annualised package cost was $36 049.[23] This is slightly below long-term modelling assumptions of average package costs ($38 360 in 2015-16 dollars).

However, making this comparison is of limited value because it does not account for the composition of participants included in the trial. Notably, the trial included a higher proportion of children (who typically receive less funded support than other participants because they receive more informal care). While participants with lower levels of function typically entered the scheme first during the trial — which would increase package costs — this was more than offset by the number of children entering the scheme.

To address this limitation, the Commission compared annualised package costs to the reference package amounts for each participant where level of function data were available. Reference packages represent the average expected package amount for a participant given their age, disability and level of function, and are a building block for the NDIA's modelling of scheme costs (box 2.6). Importantly, the package cost of a single participant is *not* expected to be equal to the reference package amount (factors such as scope for informal support and requirements for aids are important inputs into a participant's plan and can

[22] The NDIA (2017y, p. 7) identifies a participant as CALD if their country of birth is not Australia, New Zealand, the United Kingdom, the United States of America, Canada or South Africa, or their primary language spoken at home is not English.

[23] This figure excludes the cost of three large residential centres — Stockton and Kanangra (in the Hunter trial site) and Colanda (in the Barwon trial site) — which include a high concentration of high-cost participants in one geographical area. The average annualised package cost increases to $39 065 when they are included (NDIA 2016b, p. 46).

generate large differences between individual packages and reference package amounts), but package costs can be compared to reference packages at an aggregate level.

Box 2.6 Reference packages — fundamental to assessing financial sustainability, not individual packages

To acquit the study's terms of reference, it is necessary to examine the assumptions of the NDIA's financial sustainability modelling, and to consider the reference packages used to project costs for different cohorts of people with different disabilities over the long term.

Reference packages form a key part of understanding long-term costs, and whether the scheme is 'on track' in aggregate. That said, reference packages (and the data presented in this chapter) should not be conflated with what an individual might expect to receive in an individualised funded package at any given time. This is because a package received by an individual is determined by much more than a reference package (chapter 5), and the reference package amount does not account for an individual's particular goals, nor what supports may be reasonable or necessary in a particular individual's circumstances.

Comparing annualised package costs to the reference package amounts is further complicated by participants in Shared Supported Accommodation (SSA). SSA is accommodation for people who require specialist housing solutions and intensive support needs. SSA is designed for participants with extreme functional impairment. As such, package costs for participants in these facilities are substantially higher than other scheme participants (typically about $200 000).

At the end of June 2017, 8 per cent of participants with plans approved from July 2016 were in SSA. While the Commission's estimates include participants in SSA, there are reasons why the package costs of these participants may be lower as the scheme matures.

- There are a number of participants with relatively high levels of function in SSA who will potentially require significantly less support if they receive appropriate capacity building supports early in their lives.
- SSA services are currently delivered under in-kind arrangements and as such are likely to be priced on the high side. State and Territory Governments determine the price of in-kind services (chapter 7).

There are also some data integrity issues around data on committed supports for the transition period linked to the use of the NDIA's ICT system. The NDIA has made adjustments to the data provided to the Commission (and to the data that the NDIA publishes to meet its reporting requirements) to address a number of the identified issues.

For its position paper, when it compared annualised package costs with reference package amounts, the Commission found that the average annualised cost of packages was higher

than expected given the characteristics of participants ($60 000 compared to $56 000) for the period 1 July 2016 to 31 March 2017.[24]

However, after including data for the June 2017 quarter, the average annualised cost of packages has decreased and is now in line with expectations given the characteristics of participants ($54 000 compared to $55 000). A large part of this change can be attributed to the noticeable decrease in the proportion of participants who are in SSA that has occurred over this time period (11 per cent compared to 8 per cent).[25]

Packages by disability

Scheme participants with spinal cord injuries have the highest annualised average level of committed support ($114 000), followed by those with cerebral palsy and acquired brain injury (both $91 000) (figure 2.6). If participants in SSA are excluded, the averages fall to $109 000, $72 000 and $71 000 respectively.

There is significant variation in the amount of committed support received by participants with high-cost disabilities. The distribution of committed support for these disabilities is skewed towards some very high-cost participants, many of which are in SSA (figure 2.6). Disabilities with lower average levels of committed support (like autism and visual and hearing impairment) exhibit less variation in costs. Some participants with high-cost packages may have comorbidities that increase the level of support required, but are classified into a single disability group for reporting purposes.

Average annualised package costs are significantly lower than the NDIA's long-term modelling assumptions for seven of the high-level disability groupings (figure 2.7). However, package costs for participants with intellectual disability (the most common disability grouping) and visual impairments are higher than long-term modelling assumptions (though the number of participants with visual impairment is much lower than the number with intellectual disability so the aggregated impact is much lower). Average annualised package costs are broadly in line with long-term modelling assumptions for the remaining disabilities.

Packages by level of function

As expected, the average annualised package cost is highest for participants with the lowest level of function (figure 2.8). The average level of committed support for plans associated with low levels of function is almost $110 000, just over four times the amount for participants with high levels of function (about $26 000).

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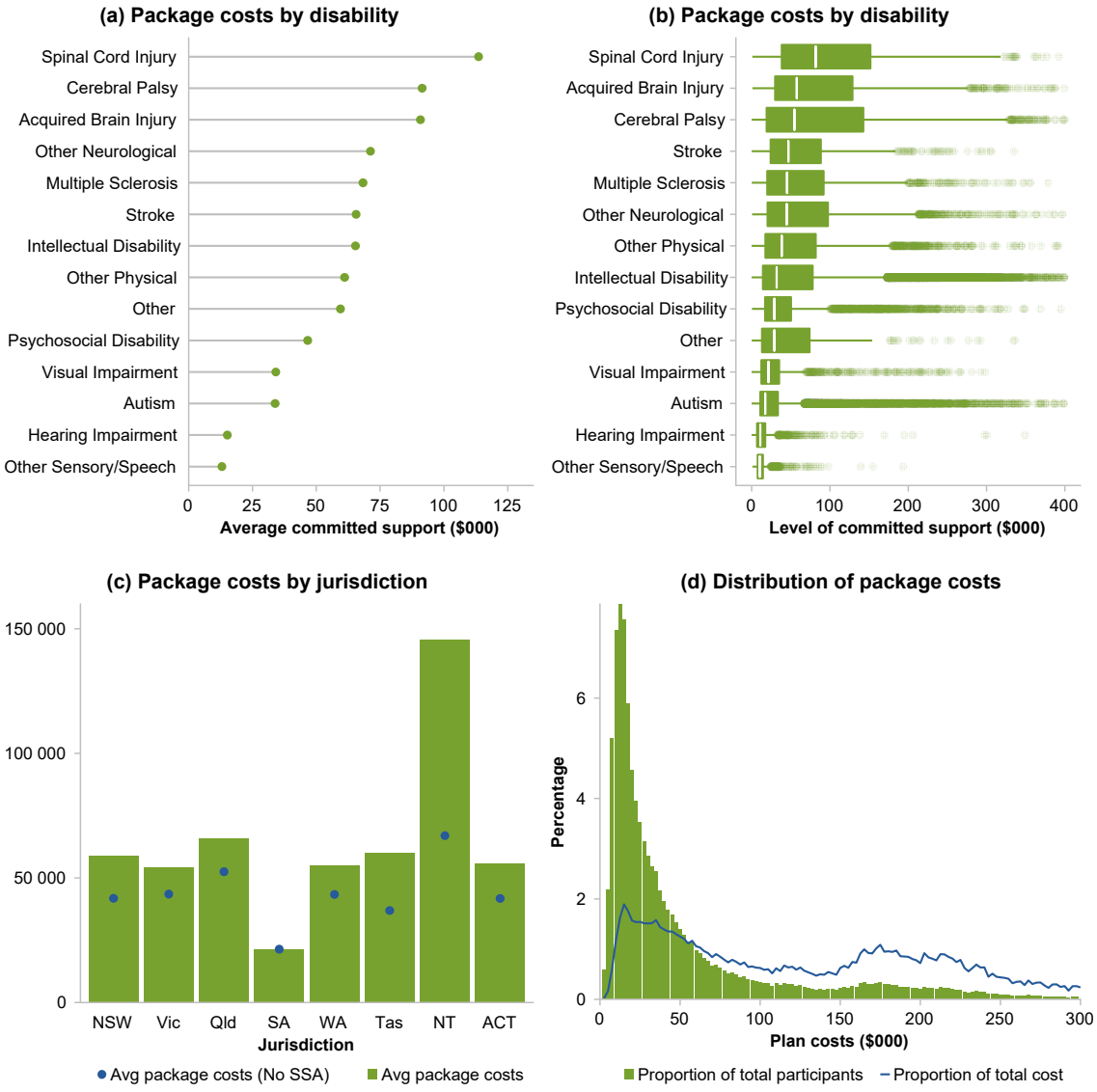
[24] Unless otherwise stated, the Commission has used plans effective after 1 July 2016 when analysing package costs.

[25] This trend brings the proportion of scheme participants who are in SSA towards the NDIA's long-term estimates of SSA prevalence (about 7 per cent).

Figure 2.6 **Some insights on annualised package costs[a,b,c]**

Plans effective from 1 July 2016

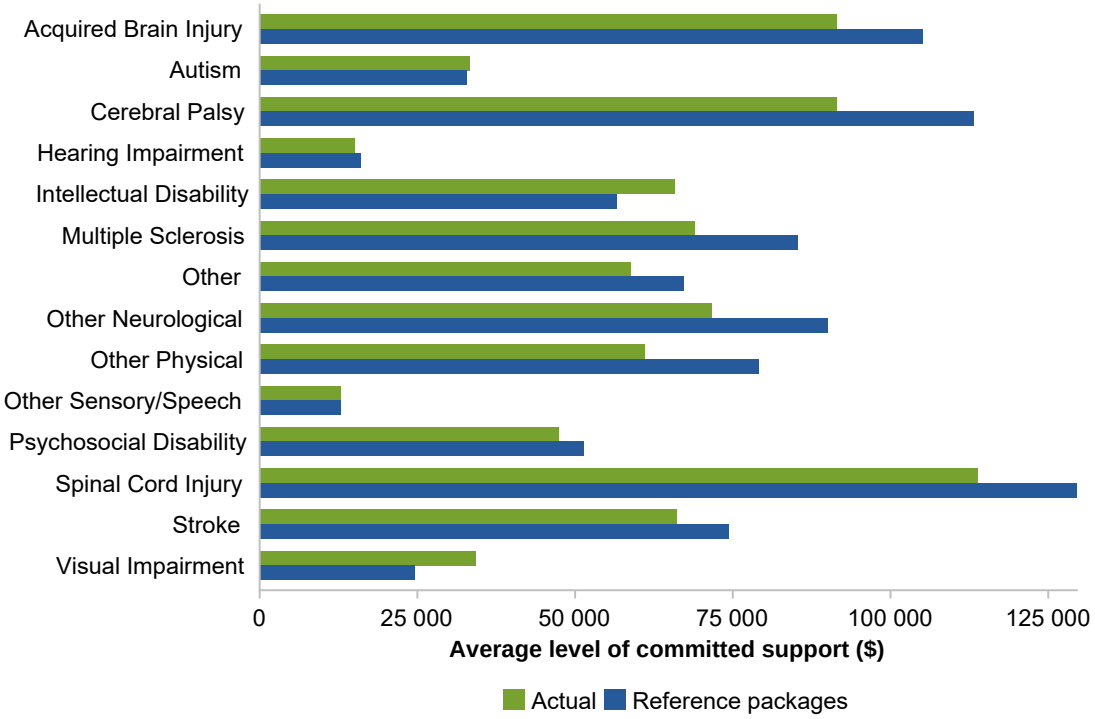


[a] For participants with multiple plans over the time period, the latest plan is used. [b] Figure (b) shows box plots of the distribution of the level of committed support for different disability groups. The white dash represents the median and the box shows the interquartile range (quartiles 1 and 3). The box plot tails show the minimum and maximum observations (though points that deviate by more than 1.5 times the interquartile range from the box are considered outliers and are denoted by a dot point). [c] In figure (c), Western Australia includes the Perth Hills NDIS trial site but not the WA NDIS MyWay trial.

Source: Commission estimates based on unpublished NDIA data.

Figure 2.7 **Average annualised level of committed support compared to reference packages, by disability[a,b,c]**

Plans effective from 1 July 2016



[a] Reference packages are the average package cost assumed in the NDIA's long-term modelling based on age, disability and level of function. They *are not* what an individual should expect to receive in an individualised funded package at any given time. [b] For participants with multiple plans over the time period, the latest plan is used. [c] Reference packages are linked to assessment tools. Therefore, participants who are assessed using the generalised assessment tools (including all participants with psychosocial disability) are linked to a 'generalised' reference package.

Source: Commission estimates based on unpublished NDIA data.

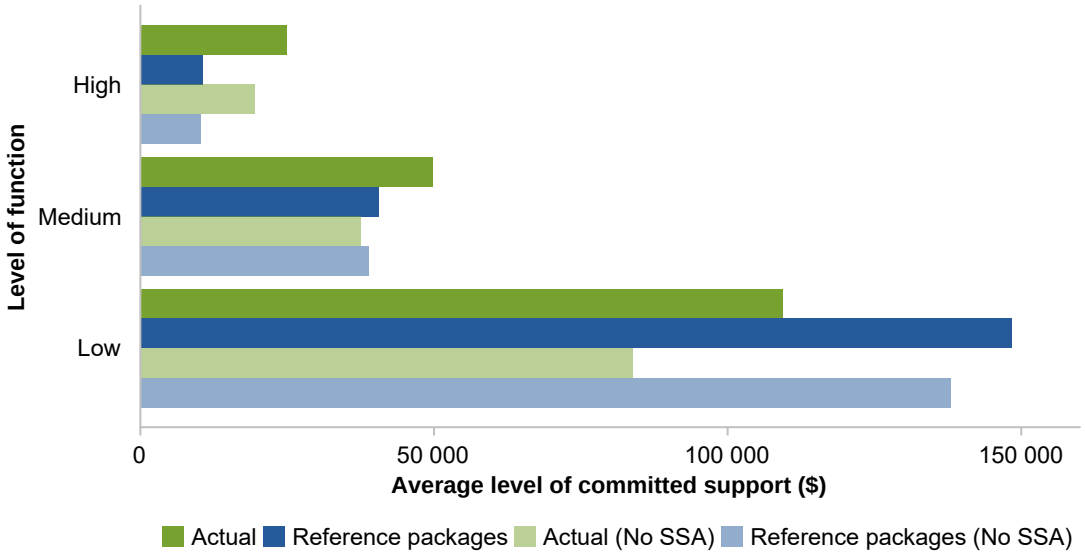
There are significant differences between average annualised packages costs and the NDIA's long-term modelling assumptions by level of function (figure 2.8).

- The average level of committed support for participants with low levels of function (who require more support) is less than expected (about $109 000 compared to $148 000). One explanation for this result may be that reference packages are underestimating the amount of informal support provided by families and carers.
- The average level of committed support for participants with medium levels of function is higher than modelling assumptions ($50 000 compared to $41 000).
- Participants with high levels of function (who require less support) are obtaining higher value packages on average than the modelling assumes ($25 000 compared to

$11 000).[26] The NDIA suggested that fewer participants than expected entering the scheme with small package amounts (less than $10 000) is in part due to problems with planning processes (NDIA 2016a, p. 40).

Figure 2.8 **Average annualised level of committed support compared to reference packages, by level of function[a,b]**

Plans effective from 1 July 2016



[a] Reference packages are the average package cost assumed in the NDIA's long-term modelling based on age, disability and level of function. They *are not* what an individual should expect to receive in an individualised funded package at any given time. [b] For participants with multiple plans over the time period, the latest plan is used.

Source: Commission estimates based on unpublished NDIA data.

Participants in SSA are a significant driver of average costs for the high and medium levels of function cohorts (figure 2.8). Given that SSA is designed for people with low levels of function, this suggests issues with how SSA was managed in the past. Historical experience suggests that investing in capacity building supports early to keep participants with high and medium levels of function out of SSA is critical for minimising scheme costs in the future.

Packages by jurisdiction

Participants in the Northern Territory have the highest average package costs ($150 000) followed by those in Queensland ($66 000). Participants in South Australia have the lowest average package costs ($21 000) (figure 2.6(c)).

[26] The average annualised package cost for participants with high levels of function ($29 000) only includes participants for whom reference package data are available. The average annualised package cost is $31 000 when all participants with high levels of function are included.

The average package cost differences are driven by the phasing schedules.

- About 39 per cent of Northern Territory participants with an approved plan are in SSA with an average package cost of $320 000.[27]
- The NDIS only began operating in Queensland at the beginning of 2016 and therefore has a disproportionate number of participants with low levels of function.
- Because of the scope of the South Australian trial, almost all the scheme participants in that state are children who generally have lower levels of committed support than older participants.

The distribution of total committed supports

The distribution of committed supports is heavily weighted to low cost packages with the most common package costing between $10 000–$15 000 (figure 2.6(d)).

The distribution of committed supports weighted by total cost of packages is flatter, peaking at $10 000–$15 000 and $175 000. The second of these peaks is attributable to participants in SSA. High cost participants account for a significant proportion of scheme costs — the top 20 per cent of packages (those over $80 000) account for 62 per cent of total committed supports.

Types of support provided

Most (over half) of the committed supports are earmarked to help scheme participants with their daily life — support for daily activities (box 2.7) (figure 2.9).[28] Social and community programs make up about 19 per cent of committed support and supports to improve daily living skills about 13 per cent. Employment supports make up about 2 per cent of committed support (discussed further in chapter 3).

[27] Scheme participants in SSA in the Northern Territory tend to be in the most complex types of SSA.

[28] Participants have some control over how they allocate their support budget depending on the support category (that is, they do have some scope to deviate from the support described in their plan).

Box 2.7 Types of support

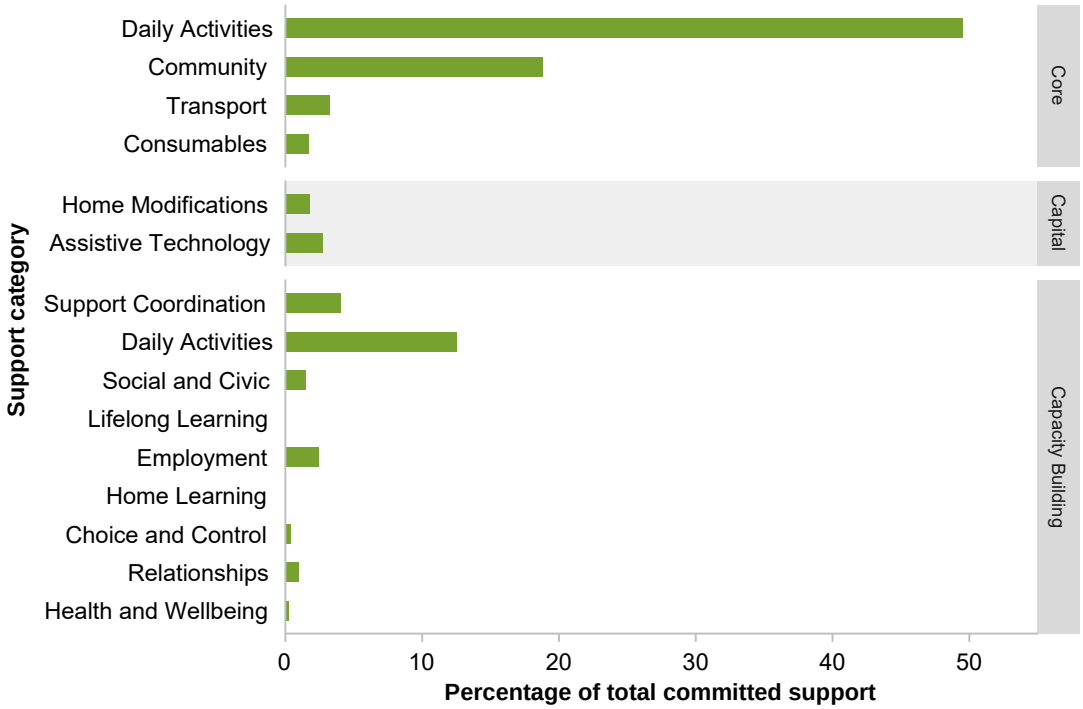
Supports provided under the NDIS fall into one of fifteen *support categories,* which in turn can be grouped into three *support purpose categories*:

- Core supports — support that enables participants to complete activities of daily living, and enables them to work towards their goals and meet their objectives.
- Capital supports — an investment, such as assistive technologies, equipment, home or vehicle modifications, and funding for capital costs associated with specialised housing.
- Capacity building supports — support that enables participants to build their independence and skills.

Source: NDIA (2016o).

Figure 2.9 Committed supports provided by support category[a]

Plans effective from 1 July 2016



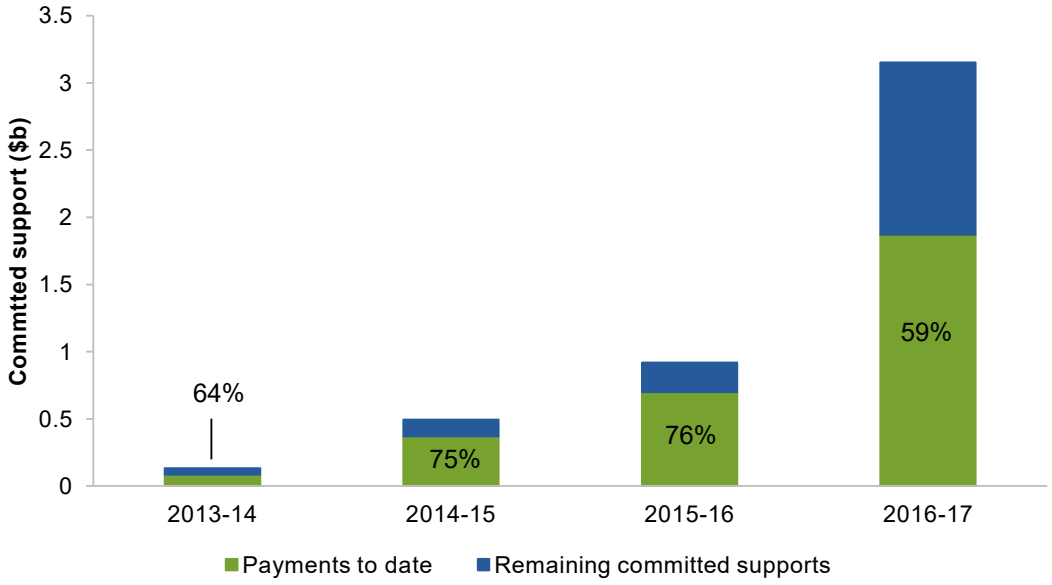
[a] For participants with multiple plans over the time period, the latest plan is used.

Source: Commission estimates based on unpublished NDIA data.

Utilisation

Participants are not using all their packages — for the final year of the trial (2015-16) just 76 per cent of committed supports were used (figure 2.10).[29] As discussed above, low utilisation is the reason why there was a surplus of about 1.5 per cent of the funding envelope at the end of the trial, despite higher than expected levels of committed support (NDIA 2016b, p. 144).

Figure 2.10 **Utilisation of committed supports**[a]



[a] Invoices for some payments for 2016-17 have not yet been received. The NDIA have indicated that the utilisation rate is likely to increase to 70 per cent once all invoices are received (NDIA 2017y, p. 37).

Source: NDIA (2017y, p. 37).

The utilisation rate for 2016-17 was substantially lower — 59 per cent of committed supports have been used to date. The lower rate is in part because not all services have been invoiced. Actuarial modelling undertaken by the NDIA indicates that the utilisation rate is likely to increase to 70 per cent once all invoices are received (NDIA 2017y, p. 37). The remaining difference can be attributed to the significant intake of participants in the first year of transition — new participants tend to have lower utilisation rates when they first enter the scheme (discussed below).

[29] This figure is based on payments that have been made to date. There can be a lag between the date a service was provided and the date that it was invoiced.

According to the NDIA (and supported by comments from other study participants), on-the-ground experience indicates that the reasons for the utilisation rates being below full utilisation vary by the individual and their circumstances. Some reasons include:

- insufficient supply of supports to meet demand, especially for specific supports (such as short-term accommodation) and in particular markets (such as remote and very remote areas) (Commonwealth Ombudsman, sub. 137; Inclusion Australia, sub. PP357; Macarthur Disability Services, sub. 57; APA, sub. 93; PDCN, sub. 29; Public Service Research Group, sub. 56; VICSERV, sub. PP284)
- participants experiencing difficulties navigating the system, which can mean they are unable to implement a plan once it has been approved (ABF, sub. 48; CSSA, sub. 166; Macarthur Disability Services, sub. 57; PDA, sub. 38; Vision Australia, sub. PP210)
- scheme participants not needing all the supports they are entitled to (planners overestimating the amount of funded support that will be needed, or including supports that do not meet the needs of participants) (Macarthur Disability Services, sub. 57; Vision Australia, sub. PP210)
- the market for plan supports (such as support coordination and plan management) being relatively immature and therefore limiting the help that participants can obtain (Anglicare Australia, sub. 157)
- some participants cannot easily access information about how much of their supports are available (Public Service Research Group, sub. 56).

Some underutilisation of supports is expected in the early stages of the scheme — as participants and providers adapt to a new system for providing disability care — but utilisation rates are expected to rise over time. In fact, utilisation rates did increase over the period 2013-14 to 2015-16, before dropping when a substantial number of new participants entered the scheme in 2016-17 (figure 2.10).

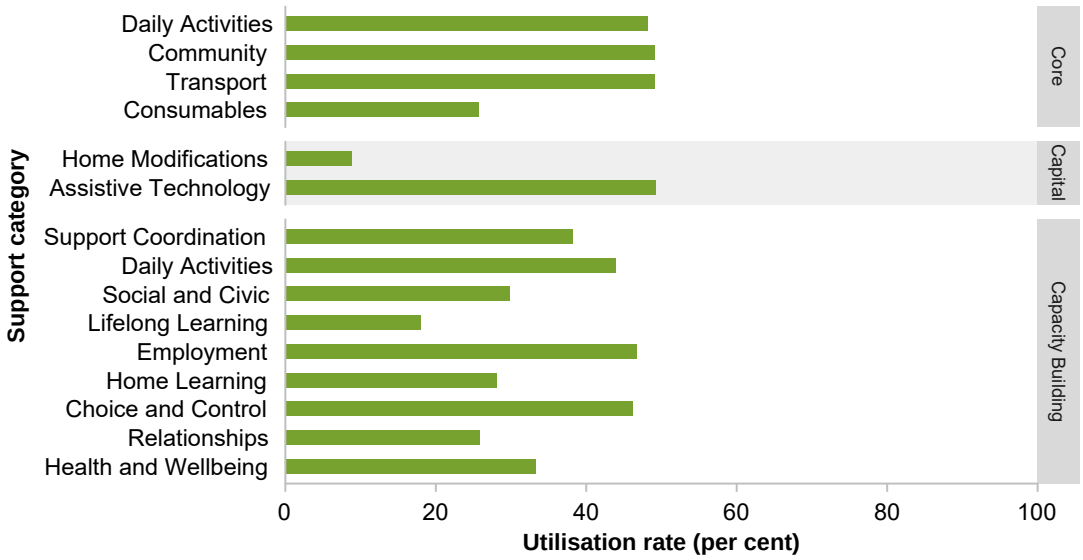
The NDIA (sub. PP327, p. 12) said that 'participant utilisation rates have increased as participants spend more time in the Scheme'. While the NDIA's estimates of scheme costs implicitly assume that all committed supports are spent when the scheme is fully implemented, the NDIA (sub. 161, p. 70) said that 'in a person-centred system the utilisation rate will never be 100%'. The NDIA also noted experience in other schemes suggests a utilisation rate of between 80 and 95 per cent could be expected.

Utilisation by support type

While there are data on utilisation rates disaggregated by support type, it needs to be interpreted with caution as it is not possible to incorporate claims data relating to in-kind supports (these data need to be sourced directly from jurisdictional reconciliations of in-kind supports). This means that disaggregated utilisation rates will be lower than the overall figure.

Keeping that caveat in mind, there are clear differences between the utilisation rates of committed supports for some support categories (figure 2.11). In 2016-17, the transport, assistive technology and social and civic support categories had the highest utilisation rates (each at 49 per cent) and the home modifications support category had the lowest (9 per cent utilisation rate).

Figure 2.11 **Utilisation rates by support type[a]**



[a] There are two reasons why the utilisation rates presented in this figure will be an underestimate: claims data relating to in-kind supports are not included, and invoices for some payments for 2016-17 have not yet been received. However, this is unlikely to have a significant impact on the relativities between support categories.

Source: Commission estimates based on unpublished NDIA data.

Utilisation in subsequent plans

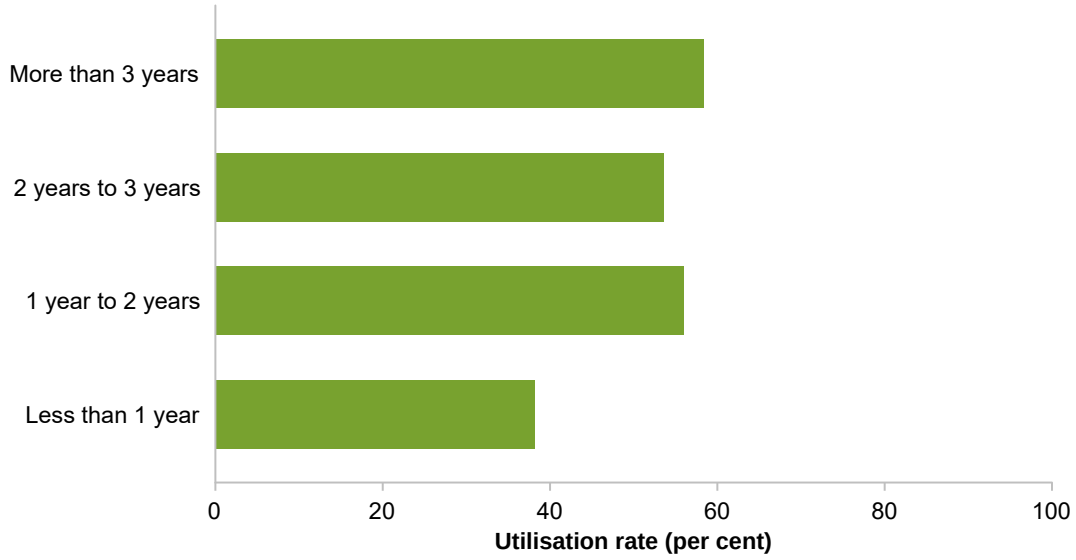
Utilisation rates are higher for participants who have been in the scheme for more than a year compared with those in their first year in the scheme (figure 2.12). But there are no significant differences in the utilisation rates for participants who have been in the scheme for more than a year (about 56 per cent). After adjusting for missing in-kind payments (about 13 per cent)[30] and the payments that have not yet been received (about 11 per cent),[31] and recognising the data integrity issues that impact the calculation of utilisation rates, the

30 The utilisation rate for 2016-17 data provided to the Commission is 46 per cent, 13 percentage points lower than the reported utilisation rate in the latest NDIA quarterly report (NDIA 2017y, p. 37).

31 The latest NDIA quarterly report notes that the utilisation rate is likely to eventually rise to 70 per cent once all invoices are received (NDIA 2017y, p. 37)

utilisation rate for participants who have been in the scheme for more than a year would be 80 per cent in 2016-17.

Figure 2.12 **Utilisation rates in 2016-17 by time in scheme[a]**



[a] There are two reasons why the utilisation rates presented in this figure will be an underestimate: claims data relating to in-kind supports are not included, and invoices for some payments for 2016-17 have not yet been received. However, this is unlikely to have a significant impact on the relativities between different lengths of time in scheme.

Source: Commission estimates based on unpublished NDIA data.

Some emerging cost pressures

Bringing the analysis of these three components of scheme costs together, the early scheme data suggest that NDIS costs are broadly in line with the NDIA's long-term modelling estimates.

While more children are entering the scheme than expected, this has been *more* than offset by lower levels of utilisation than expected. If the rollout of the scheme also remains behind the bilateral estimates, it is highly likely that scheme costs in 2019-20 will be lower than the NDIA's projections (this will be because fewer people than expected are accessing support).

However, it is critical that emerging cost pressures are managed as utilisation rates are expected to increase. The Department of Social Services (sub. 146, p. 20) echoed this sentiment, noting that 'better management of cost pressures should reduce the impact of increasing utilisation rates'. That said, if the cost pressures emerging from the trials and transition are not addressed, the financial sustainability of the scheme over the longer term will be at risk.

The NDIA is tasked with ensuring that the NDIS is financially sustainable, and this involves identifying and managing emerging cost pressures. The Scheme Actuary compares the experience of the NDIS to projections on an ongoing basis and reports to the Board quarterly. If cost pressures are detected early, management responses can be put in place before problems become entrenched.

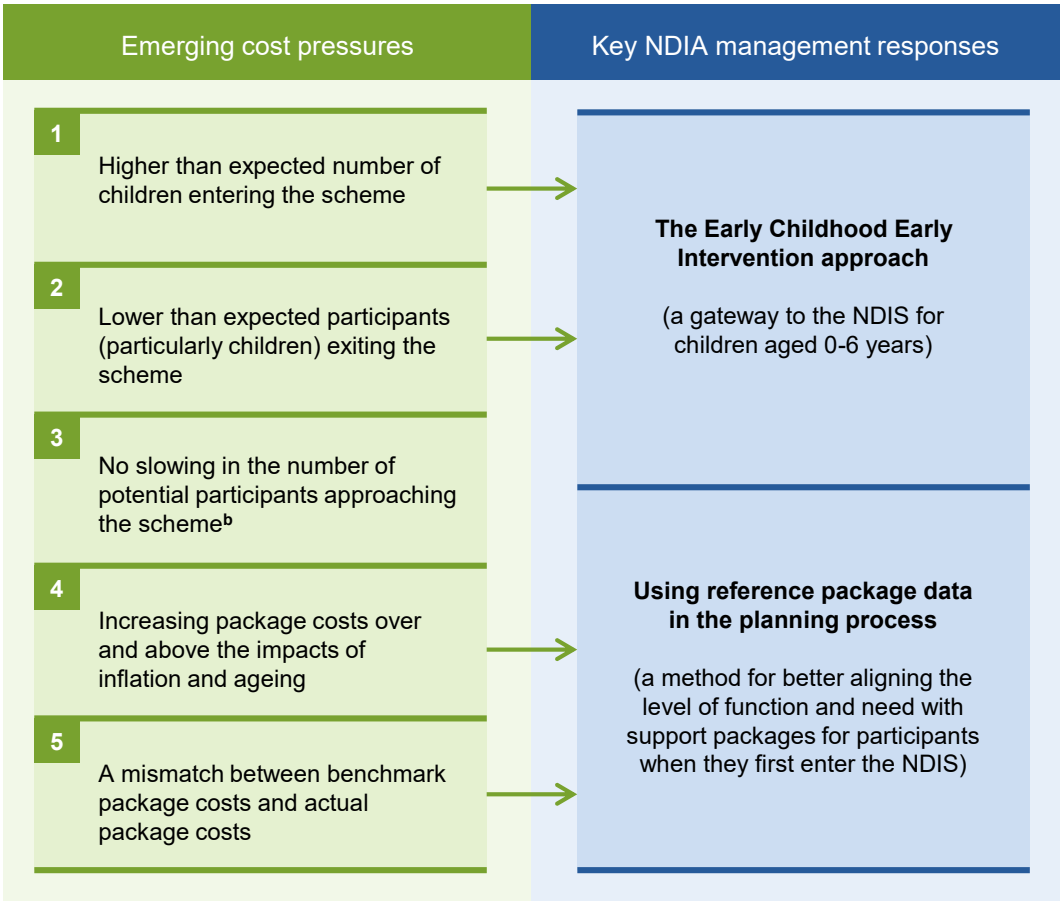
In the NDIA's most recent annual report (released in October 2016), the Scheme Actuary identified five cost pressures from the trial sites that need to be managed for full scheme, including:

- a higher than expected number of children (especially in the trial sites of South Australia, Victoria and the ACT)
- increasing package costs over and above the impacts of inflation and ageing (as plans are reviewed)
- potential participants continuing to approach the scheme (the number of people approaching the scheme in some trial sites that have been operating since 2013 is more than would be expected if only people with newly acquired disabilities were approaching the scheme)
- a lower than expected number of participants exiting the scheme (particularly children who entered the scheme under the early intervention requirements)
- a mismatch between benchmark package costs and actual package costs. There is a greater than expected level of variability in package costs for participants with similar conditions and levels of function (NDIA 2016b, pp. 16, 144).

In line with the insurance approach to identifying risks early and putting in place management responses, the NDIA has put in place initiatives to address these cost pressures (figure 2.13). The responses include the Early Childhood Early Intervention approach (chapter 4), and the use of reference package data in the planning process (chapter 5) (NDIA 2016b, pp. 16–17, 56–57).

While it is too early to conclusively assess the effectiveness of these initiatives, data for 2016-17 may indicate that the new planning process is helping to mitigate the cost pressures related to package costs (table 2.4). (Uncertainty about the effect of phasing schedules make strong conclusions difficult.)

Figure 2.13 **The NDIA's responses to emerging cost pressures**[a]



[a] This figure includes the NDIA's two main responses to emerging cost pressures. The NDIA has initiated several smaller projects to address emerging cost pressures, such as an analysis of reasonable and necessary costs across the lifespan of participants. These are detailed in the NDIA's 2015-16 Annual Report (NDIA 2016b, pp. 145–146). [b] Potential participants continuing to approach the scheme is not a cost pressure that can easily be addressed by the NDIA.

Source: NDIA (2016b, pp. 144–146).

Table 2.4 **The latest information on NDIS cost pressures**

Cost pressure	*2016-17 update*
Higher than expected numbers of children	The prevalence of 0–6 year olds did not significantly change in 2016-17, but the prevalence of 7–14 year olds and 15–18 year olds increased.
Lower than expected participants exiting the scheme	Few participants exited the scheme in 2016-17.
No slowing in the number of potential participants approaching the scheme	This trend continued in 2016-17 (though there was some reduction in New South Wales and the ACT).
Increasing package costs over and above the impacts of inflation and ageing	The rate of increase in package costs between plans increased in the first three quarters of 2016-17. In the last quarter, the rate decreased but it remains above expected levels.
A mismatch between benchmark package costs and actual committed support	This cost pressure improved in 2016-17, especially in the last quarter.

Source: NDIA (2017y, p. 39).

FINDING 2.3

The National Disability Insurance Scheme, at the end of trial, came in under budget. But of concern to the Productivity Commission is that this was in large part because not all committed supports were used (in 2015-16 the utilisation rate was 76 per cent). While lower than expected levels of utilisation means lower scheme costs, it also implies poorer outcomes for participants.

Based on trial and transition data, scheme costs are broadly on track compared to the National Disability Insurance Agency's (NDIA's) long-term modelling. At this stage, early cost pressures (such as greater than expected numbers of children in the scheme) are being more than offset by lower than expected levels of utilisation.

The NDIA has put in place initiatives to address emerging cost pressures. It is too early to assess the effectiveness of these initiatives.

3 Scheme benefits

Key points

- The costs of the National Disability Insurance Scheme (NDIS) need to be considered in the context of the benefits the scheme is expected to generate.
- The NDIS is expected to generate substantial economic benefits that will significantly exceed the additional costs of the scheme. Expected benefits include:
  - improved wellbeing for NDIS participants, their families and informal carers
  - increased economic participation for NDIS participants and their informal carers
  - broader efficiency gains and cost savings in the disability support system
  - savings to other government services.
- It is too early to assess whether the expected benefits of the NDIS are being realised — current outcomes data are based on trial site data and many benefits from the scheme are expected to be realised over the long term.
- That said, there is early evidence that the NDIS is changing lives — reported benefits include improved wellbeing, more supports, and greater choice and control for many scheme participants, their families and informal carers.
- But some people with disability report poorer outcomes under the NDIS when compared with previous disability services.
- The particular groups at risk of having a less positive experience with the NDIS include people with psychosocial disability, complex and multiple disabilities, and language and cultural barriers, as well as people with disability transitioning into the community from the criminal justice system, the homeless and the socially isolated.
- The NDIS has helped some participants and their carers enter or remain in the workforce, but there are concerns that employment supports are not being considered in many plans.
  - About one in five NDIS participants over the age of 15 years currently have employment support included in their plans (and for some age groups it is higher).
- There is a need for better data and reporting (to enable better analysis) on why many participants are not accessing employment supports.

The focus of this report is on National Disability Insurance Scheme (NDIS) costs, but costs need to be considered in the context of the benefits the scheme is expected to generate. The NDIS holds the promise of transforming the lives of people with disability, their families and carers with flow-on benefits for all Australians. It also provides insurance cover for all Australians. Realising the benefits of the NDIS is critical, not only for the wellbeing of people with disability and their families and carers, but also so the community continues to be willing to pay for the NDIS.

This chapter looks at the evidence to date (noting that it is still very early days) on the benefits of the NDIS. Section 3.1 provides a brief summary of the expected benefits and discusses some of the challenges with measuring the benefits. Section 3.2 looks at early outcomes for participants, families and carers. Section 3.3 examines employment outcomes. Section 3.4 looks at early indicators of the broader economic and social benefits of the NDIS.

3.1 Expected benefits and measurement of outcomes

The NDIS is expected to generate substantial benefits that are expected to significantly exceed the additional costs of the scheme (PC 2011, p. 56). The benefits are expected from:

- improved outcomes for NDIS participants, their families and informal carers
- increased economic participation (employment outcomes) for both NDIS participants and their informal carers
- broader efficiency gains and cost savings in the disability support system and savings to other government services.

Support for the NDIS (chapter 1) is based on the potential benefits from the scheme. Every Australian Counts, for example, spoke about the NDIS giving back to the economy.

> At its heart, the NDIS is about people. The Scheme is a once-in-a-lifetime change to the way disability support is delivered in Australia. It is going to affect millions of Australians. … Long-term, the NDIS will give back to the economy. Indeed, it would cost far more not to implement it. The NDIS will create jobs in the sector; improve long-term outcomes for people with disability, families and carers; and decrease reliance on health care and welfare. (sub. 92, p. 2)

And the Mental Health Community Coalition of the ACT said that it:

> … views the NDIS with great hope. It holds promises for a better more integrated life for people living with disability. It offers flow on benefits that will affect all Australians. But we must take care to ensure that we get it right. This requires time, investment, flexibility and persistence. (sub. 135, p. 2)

Tracking the benefits

Comparing the benefits of the scheme relative to expectations is difficult (and arguably more difficult than making the same comparison for costs). Some of the benefits are difficult to calculate because they are intangible (for example, the benefits to people with disability from greater choice and control). This was acknowledged by the Australian Federation of Disability Organisations.

> Some economic outcomes are easily captured and quantified — investment in capacity building or home modifications or equipment can reduce support costs in the long term. And if an NDIS participant is supported to move into employment, or a family carer re-enters the workforce, the economic impact of that change can be measured.
>
> But other, just as important outcomes, are not only more difficult to capture, they are more difficult to assign value. What value can we assign, for example, to increased inclusion? To increased independence? To increased dignity? (sub. PP325, p. 6)

But while it can be challenging to measure intangible outcomes, they can make a significant difference to the lives of people and need to be considered.

Many NDIS outcomes — such as the benefits of early intervention (chapter 4), efficiency gains in the disability sector, savings to government services and increased workforce participation (and the resulting fiscal savings) — will only be realised over the long term. This in part reflects the scheme's adoption of insurance principles that allow for upfront investments where these have the potential to yield future benefits. As the Victorian Government said:

> The NDIS' financial sustainability will critically depend on effective application of insurance principles to drive early investment that will save future costs by improving outcomes for people with disabilities, including their capacity to live independently and participate in social and economic life. This will also reduce the longer term reliance of people with disabilities and their carers on mainstream services and income support. (sub. 174, p. 14)

Data that can be used to assess the benefits of the NDIS are limited at this early stage of the scheme rollout. There are two main sources of data that provide some early insights.

- The NDIS Short Form Outcomes Framework (box 3.1).
- The intermediate report of the NDIS evaluation undertaken by the National Institute of Labour Studies (box 3.2).

Because of limited data, this chapter also relies on anecdotal information from stakeholders (in comments, submissions and consultations) to gain insights on benefits and areas where benefits could be at risk of not being realised. The limitation of anecdotal evidence is that it provides no information about the frequency that particular anecdotes (including issues) arise. Going forward, it is important that the right data are collected to ensure that benefits can be more comprehensively tracked as the scheme is fully rolled out and over the long term. Data issues are discussed in more detail in chapter 13.

Box 3.1 The NDIS Short Form Outcomes Framework

The National Disability Insurance Scheme (NDIS) Short Form Outcomes Framework is an approach to measure the outcomes of NDIS support. It includes eight indicators of participant experience (known as participant domains) as well as outcomes related specifically to families and informal carers (table below). It was piloted in the first three months of 2015 and is now being rolled out scheme wide.

The Framework will allow tracking of participant and scheme progress over time, and demonstrates how participants are faring relative to other Australians and to other OECD countries. It will also contribute to an understanding of what types of supports lead to good outcomes for people with disability, their families and carers.

Between November 2015 and July 2016, the NDIA collected data from existing participants to provide an early indicator of participant progress under the NDIS. More recent data mostly reflect participants' lives when joining the NDIS to form a baseline that can be used to assess the benefits of the scheme.

Participant domains
Choice and control — improved choice and control and planning and delivery of supports
Daily activities — increased ability to undertake daily activities with adequate levels of support
Relationships — increased levels of social inclusion and reduced experiences of loneliness
Home — improved satisfaction with home environment now and five years into the future
Health and wellbeing — improved health and wellbeing and increased ease of access to health services
Lifelong learning — increased opportunities to learn new things
Work — increased uptake of paid employment (and the associated social inclusion)
Social, community and civic participation — increased participation in community activities chosen by the participant, and reduced negative experiences associated with being excluded
Family and carer domains
Families have the support they need to care
Families know their rights and advocate effectively for their family member with disability
Families are able to gain access to desired services, programs, and activities in their community
Families have succession plans
Parents enjoy health and wellbeing

Sources: NDIA (2015d; sub. 161, pp. 27–36).

Box 3.2 **NDIS Evaluation**

In 2013, the Australian Government Department of Social Services commissioned a consortium led by the National Institute of Labour Studies to conduct an evaluation of the trial of the National Disability Insurance Scheme. The study monitors and evaluates the experience of participants, and their families and carers, service providers and their workforce in the trial sites of the ACT, Victoria, New South Wales, Northern Territory, South Australia and Tasmania.

An initial report, that described how the evaluation was being conducted, was delivered to the Department of Social Services in December 2015.

An intermediate report, based solely on trial site data, presented a synthesis of the quantitative and qualitative evidence collected to date and was released in December 2016.

- The qualitative evidence was sourced from in-depth interviews of people with disability, their families and carers (123 interviews), disability service providers (49), disability workforce stakeholder organisations (29) and National Disability Insurance Agency staff (87).
- The quantitative evidence is based on a survey of about 4400 people with disability and about 3400 families. Survey participants were split into two groups — those included in the NDIS trial and those outside the NDIS trial — and their experiences compared.

A final report is scheduled to be completed later in 2017. It will incorporate an additional wave of survey data.

Source: Mavromaras, Moskos and Mahuteau (2016, p. ix–x, 18).

3.2 Outcomes for participants, families and carers

Generally, people with disability and their families face social and financial challenges and, as a group, are among the most disadvantaged in Australia (PC 2011, p. 112). People with disability are more likely to experience relatively poor health, lower levels of participation in education, training and employment, social exclusion, lack of access to goods, services and facilities and ongoing discrimination (COAG 2011, p. 12).

The NDIS is designed to deliver much needed support to improve outcomes for participants, their families and carers. Personalised supports are one of the main ways the benefits of the NDIS are realised (discussed in chapter 5, box 5.1).

The NDIS is improving lives

The NDIS is improving lives. Reported NDIS benefits include improved wellbeing, access to more supports, and improved choice and control for many scheme participants, their families and carers.

Participants and carers report improvements in wellbeing

One of the prime motives behind the NDIS is to improve the wellbeing of people with disability. Wellbeing is expected to improve under the NDIS via better quality of care, increased independence, and increased engagement in the economic and social life of the community.

When outcomes for NDIS participants are improved there are flow-on benefits to their families and informal carers. For example, reasonable and necessary care for participants may result in increased opportunity for informal carers to increase their social and economic participation.

Many submissions and comments received as part of this study spoke about the NDIS improving the lives of participants, their families and carers (box 3.3).

The NDIS evaluation found that many NDIS participants, their families and informal carers have experienced improvements in quality of care, independence and overall wellbeing.

- 49 per cent of participants said the quality of care had improved with the NDIS.
- Many participants can now take part in activities independently and are able to follow interests and social activities that had previously been inaccessible.
- Carers reported an 'increased sense of positivity and wellbeing' because their NDIS participants were more involved in activities they enjoyed and were able to participate in wider interests outside of the home.
- The evaluation also reported that qualitative evidence 'makes clear that on the whole the NDIS has improved the wellbeing of scheme participants and their family members and carers' (Mavromaras, Moskos and Mahuteau 2016, pp. xv, xvi, 38).

The NDIS Short Form Outcomes Framework (based on data collected from existing participants over the period November 2015 to July 2016) also reported:

- about two-thirds of scheme participants aged 15 years and over said the NDIS had helped with daily living (64 per cent for participants aged 15–24 years and 71 per cent for participants aged 25 years and above)
- almost two-thirds of participants aged 15 years and over said the NDIS helped with health and wellbeing (62 per cent of participants aged 15–24 years and 65 per cent of participants aged 25 years and over)
- 89 per cent of carers with children aged under five years said the NDIS had improved their child's development (NDIA, sub. 161, pp. 36, 38).

Box 3.3 The NDIS — changing lives of participants, their families and carers

APC Prosthetics:

> … the participant outcomes from the scheme have been overwhelmingly positive. Many participants are enjoying improved mobility and improved quality of life outcomes that were simply not available through the existing State-based treatment pathways. (sub. PP244, p. 1)

Anne Hansen:

> … I have seen the life changes in people with disability who now have NDIS funding. They are now accessing community, having a good life and have hope for their futures. The burdens are off the family, some aged carers, and there is job creation. Broken wheelchairs are now being replaced and people who never had wheelchairs, now have and can access the community. I now see happy people. (brief sub. 2)

Kerrie Newton:

> My NDIS plan has given me funding for someone to come into the home to help. This has taken an enormous amount of pressure off my family so they can live a more normal life. I also received some transport funding and for the first time in four years I have been able to leave the house independently. I am feeling more positive about my future. (brief sub. 154)

Lorraine Rodrigues:

> The NDIS to me is knowing that my son will have a future of his own to look forward to if I am unable to care for him for whatever reason. (brief sub. 3)

The stories of Oni and Harry provided by the National Disability Insurance Agency:

> 'I've been working with a speech therapist to get my speech up and it's really helping. I can say a few more words and actually pronounce them properly and all that,' Oni remarked … 'He's only been in one year and the changes have been remarkable. I've seen his confidence improve out of sight. I've heard him be able to speak and say words that we didn't even know he knew,' Chelinay remarked.
>
> 'The NDIS has definitely improved our lives – Harry's and ours as a family,' she said. 'We've been able to get funding to purchase Harry a manual wheelchair … now he can access places he could never in his electric wheelchair, so he now has more flexibility. He was recently able to go the beach with his classmates – something he had never been able to do before!' (sub. 161, pp. 41–43)

The NDIS is providing more supports to many participants

Early indications are that most NDIS participants are accessing more supports under the NDIS than under the previous disability system, including more hours of support, a wider range of support and greater access to equipment.

- The NDIS evaluation found that 'the majority of respondents receive increased supports as a result of becoming NDIS participants' (Mavromaras, Moskos and Mahuteau 2016, p. xi).
  - The average number of different supports accessed by participants increased from about 2 to 3 under the NDIS (Mavromaras, Moskos and Mahuteau 2016, p. 32).
- The Every Australian Counts online survey reported that 78 per cent of participants and 74 per cent of carers said they had the same or more support than before the NDIS (Every Australian Counts 2017).

- The NDIS Short Form Outcomes Framework reported that 88 per cent of carers with children aged under five years said the NDIS had improved their child's access to specialist services (NDIA, sub. 161, p 36).

Many participants to this study also said that they are accessing increased supports under the NDIS. For example, Merle Searle said:

> The NDIS has made such a huge difference to us and our young man on a day to day basis as we are in the older age bracket i.e. over 70 and now because of the extra funding he has support workers that can take him into the community. (brief sub. 17)

Karen Wakely said:

> We began implementing our plan in Jan 2016. In a little over 12 months, the change it has facilitated has been extraordinary. For the first time we have been able to access meaningful therapeutic supports. (brief sub. 43)

The NDIS is giving many participants more choice and control over supports

In addition to improved wellbeing and more supports, a key marker of the success of the NDIS is whether the scheme is providing more choice and flexibility in the timing of supports and who provides them.

The NDIS evaluation found that 44 per cent of participants surveyed had a greater say over the supports they received, and 46 per cent had more choice over who provided their supports (Mavromaras, Moskos and Mahuteau 2016, p. 60). However, the NDIS Short Form Outcomes Framework data suggest that the percentage of people benefiting from more choice and control under the NDIS is significantly larger — 73 per cent of scheme participants aged 15–24 years stated that they had more choice and control over their life (NDIA, sub. 161, p 36).

A number of submissions to this study also commented on the NDIS providing greater choice and control. For example, Robert Altamore said:

> The NDIS has changed my life because it has given me the ability to set my own goals, exercise my choices and given me control of my money to spend on the adaptive technology and the training I need to change my life and participate in the general community. (brief sub. 36)

And Helen Harrop said:

> My son has been a NDIS participant since August 2016. He is 26 years old, … the benefits to my son within this short time span have been terrific. For the first time in his life he has control. Within his plan he has more opportunity to get out and experience many different options so he can enjoy life. (Every Australian Counts, sub. 92, p. 14)

FINDING 3.1

Early evidence suggests that the National Disability Insurance Scheme is improving the lives of many participants and their families and carers. Many participants report an increase in the amount of support provided, more choice and control over the supports they receive, improvements in their quality of care, greater independence and an increase in overall wellbeing.

But not all are having a positive experience

Some people with disability report poorer outcomes under the NDIS when compared with previous disability services. The NDIS evaluation found that:

- about 16 per cent of participants reported feeling that they had less choice and control of their supports under the NDIS
- about one-quarter of participants are accessing fewer distinct supports (Mavromaras, Moskos and Mahuteau 2016, pp. 60–61).

A Melbourne Social Equity Institute survey (42 NDIS participants and carers who were part of the Barwon trial) reported that:

  - participants' expectations and experiences of the NDIS were strongly influenced by their circumstances
  - resources to help people exercise choice and control over their support were not always available
  - in some cases, service users had limited choice over what was available for them to purchase with their funding package, especially in regional areas
  - participants feel like their views are often overlooked in planning processes
  - participants who do not fully understand the system tend to feel disadvantaged. (Warr et al. 2017, pp. 7–8)

The NDIA (2017y, p. 28) also found a fall in participant satisfaction with the scheme since it entered the transition phase — the percentage of participants describing satisfaction with the Agency as good or very good dropped from an average of 95 per cent in 2015-16 (quarter 4) to 84 per cent in 2016-17 (quarter 4). This may be linked to the speed of the rollout and changes to planning processes over that period (chapter 5).

In some cases, participants are not realising the benefits of the NDIS because they are finding it difficult to access disability supports (chapter 2 discusses underutilisation of supports). The NDIS evaluation attributes this to lengthy waiting lists for some providers or types of support, a lack of local providers, and lack of quality provision. Unmet demand for supports is more common for those living in rural and remote areas (15 per cent more likely than

those in urban areas), and for older participants (Mavromaras, Moskos and Mahuteau 2016, p. 31). This is discussed further in chapter 7.

Some of the most vulnerable are at risk of not realising NDIS benefits

Early evidence suggests that people experiencing poorer early outcomes under the NDIS tend to be some of the most vulnerable people with disability.

According to the NDIS evaluation, participants who are receiving less NDIS support are often those who are unable to effectively advocate for services on their own behalf, and participants who struggle to understand the sometimes complex NDIS processes (Mavromaras, Moskos and Mahuteau 2016, p. xi).

> … vulnerable families, those unable to navigate the NDIA website to find what services and providers were available, and those less able to articulate support needs, are less likely to experience greater choice over their supports. (Mavromaras, Moskos and Mahuteau 2016, p. xiii).

In particular, both the qualitative and quantitative data from the NDIS evaluation indicate that people with mental health and psychosocial disability are more likely to report less choice and control over supports since becoming NDIS participants (Mavromaras, Moskos and Mahuteau 2016, p. xiii).

Study participants also identified a number of groups who appear to be at risk of having a less positive experience with the NDIS. These include people with psychosocial disability, complex and multiple disabilities, and language and cultural barriers, as well as people with disability transitioning into the community from the criminal justice system, the homeless and the socially isolated (box 3.4).

It is important to monitor the utilisation of NDIS supports to identify gaps where vulnerable groups may be 'falling through the cracks'. This study identifies a number of areas where support for vulnerable people with disability could be improved.

- Chapter 4 recommends a specialised psychosocial gateway to improve how the scheme engages with people with psychosocial disability.
- Chapter 5 looks at planning and the use of specialised planning teams.
- Chapter 6 discusses the role of Local Area Coordinators and interface issues between the NDIS and mainstream services.
- Chapter 7 discusses provider of last resort arrangements.
- Chapter 10 considers support coordination.

Box 3.4 Concerns that for some the NDIS experience is less positive

Health Services Union:

> Increasingly, social policy theorists and researchers are positing that the NDIS has 'been constructed predominantly with people with physical and sensory disabilities in mind. For this constituency, who have less difficulty in negotiating the world, the [scheme's] emphasis on individual autonomy and agency makes the most sense. For those with complex and multiple disabilities, and for people with cognitive and intellectual impairment, in contrast, the benefits are less clear, and an individual approach can be counterproductive.' HSU members have echoed these sentiments. (sub. 132, p. 20)

Cohealth:

> It is [also] anticipated that the capacity for outreach will be significantly diminished due to the NDIS pricing structure. The most marginalised and vulnerable groups (eg homeless, CALD [culturally and linguistically diverse] communities, young people, Aboriginal and Torres Strait Islanders), and those who are particularly unwell, often need assertive and active outreach to engage. …
>
> With a framework based on individual choice and control, consumers who don't have knowledge of the NDIS, the ability to advocate for themselves or connections with support services (eg people who are homeless or socially isolated) may miss out on the benefits of the NDIS. It is critical that existing services and supports continue to be funded to ensure supports are provided to the most vulnerable groups. (sub. 50, p. 13)

Early Childhood Intervention Australia Victoria/Tasmania:

> ECIA members report lower numbers of children and families from some backgrounds accessing the NDIS system. In particular, there are fewer families from culturally and linguistically diverse (CALD) backgrounds, fewer Aboriginal and Torres Strait Islander families and fewer vulnerable children and families. Providers largely attribute this to the many hours of extra support required in pre-planning to facilitate access for these families to the scheme. (sub. 129, p. 8)

Psychiatric Disability Services of Victoria:

> … as implementation of the NDIS is rolled out across our State, we are becoming increasingly concerned that the design and functionality of the NDIS does not appropriately align with the needs and requirements of people living with a mental illness. (sub. 169, p. 2)

Butterfly Foundation:

> Concern has been expressed, by a number of key organisations in the mental health sector, consumers and carers that the NDIS may not deliver on promised benefits for Australians living with complex mental illnesses, such as eating disorders. There is a fundamental tension between the NDIS' aim to support those with permanent and incapacitating conditions, and the belief that recovery from mental illness is possible. (sub. 78, p. 3)

Prader-Willi Syndrome Association of Australia:

> Even though some people with PWS can read, and speak quite well, their other cognitive limitations means they cannot take up the level of choice and control anticipated by the NDIA. People with PWS struggle with abstract concepts like a service level agreement, and cannot plan to monitor, or comprehend under-performance by providers, never mind dismiss them. They cannot understand invoicing or budgeting on an NDIS scale, nor the criticality of completing multiple layers of administration to ensure service delivery. (sub. PP228, pp. 2–3)

Public Health Association of Australia:

> Successful navigation of, and interaction with, a complex service environment at a time of rapid change and stress, such as release from prison, is likely beyond the capacity of most individuals with cognitive disability without support. Any gaps in the support and care from the lack of integration between the criminal justice system and disability systems will likely magnify the disadvantage for this vulnerable population. (sub. 134, p. 8)

FINDING 3.2

Not all participants are benefiting from the National Disability Insurance Scheme. The groups at risk of having a less positive experience include those with psychosocial disability, complex and multiple disabilities, and language and cultural barriers, as well as people with disability transitioning into the community from the criminal justice system, the homeless and the socially isolated.

3.3 Employment outcomes

For all individuals, the benefits of working in paid employment include increased economic security and improved wellbeing. For people with disability, the benefits of employment can also include feeling valued, useful and included in everyday life (NDIA 2017u, p. 4). As Michael Boyle commented:

> Work is important to the health and wellbeing of everyone but especially to those who are ill or have a disability and suffer consequent lack of self-esteem or possess limited opportunities for socialisation. Work helps in dealing with isolation and depression which add to the problems and difficulties of those with a disability and may be reflected in demands for further NDIS assistance. (sub. 27, p. 7)

For the community, greater workforce participation of people with disability can mean savings to government budgets (reduced welfare payments and increased taxable income). Epic Employment Services said:

> Throughout EPIC's 27 year life, we have seen time and time again the importance of helping someone find a job. The economic and social benefits that accompany employment for both the individual and the community cannot be overstated. Through employment, people have a reduced reliance on income support, make greater tax contributions and become consumers of more goods and services. (sub. 70, pp. 1–2)

But there can be barriers for people with disability participating in employment. The NDIS evaluation found that workforce barriers include:

- a person's health and disability
- a lack of opportunities
- employers' opinions of people with disability
- difficulties with transport and parking
- difficulties using facilities or equipment
- lack of schooling, training or experience (Mavromaras, Moskos and Mahuteau 2016, p. 78).

People with disability have lower labour force participation rates and higher unemployment rates than those without disability. In 2015, about 53 per cent of working-age Australians

with a reported disability were in the labour force and 10 per cent were unemployed. For those with a profound or severe core activity limitation, the labour force participation rate was significantly lower at 25 per cent and the unemployment rate higher (almost 14 per cent). This compares with an unemployment rate of about 5 per cent and a labour force participation rate of about 83 per cent for people of working-age without disability (ABS 2016a).

However, with the right supports, employment barriers can be surmountable for many people with disability. The story of Ben Hunter (box 3.5) is one example of how well targeted, individualised supports can lead to rewarding work opportunities and increased social inclusion.

Box 3.5 Reaching employment goals, the story of Ben Hunter

Ben is 21 years old, has Down Syndrome and is non-verbal. He is also the front man for the baking business, Ben & Co, Bakers with Purpose.

> … with Ben's NDIS funding, and with his career front of mind, Carolyn [Ben's mum] left her job as a primary school teacher, employed support workers and started Ben & Co, Bakers with Purpose. Selling produce at regular market stalls, the family business's focus is to now provide opportunities for young people with intellectual disability — to fill the gap they identified with Ben. …
>
> Carolyn said. 'Often when young people with intellectual disability leave high school they fall through the cracks. Many struggle to find purpose and direction in their lives. Most are relegated to non-customer-service type work where they don't get as many opportunities to regularly interact with the general public. We want to help change this'.
>
> She said their aim was to provide employment and mentoring experiences through Ben & Co. to help support young people with intellectual disability to acquire and further develop their social skills, alongside their hospitality and retail skills. (The Queensland Times 2017)

While Ben & Co started as a way to increase opportunities for Ben, it has grown into an enterprise helping young people of all abilities find their social independence and participate in the local economy (NDIA 2017e, p. 18).

Caring for a person with disability also impacts on employment. In 2015, the labour force participation rate for primary carers (56 per cent) and other carers (77 per cent) was lower than that for non-carers (80 per cent). Carers were also less likely to be employed (66 per cent) compared with non-carers (76 per cent)[32] (ABS 2016a).

The NDIS is expected to increase employment by:

- providing more appropriate support that allows participants to manage their disability in the workforce

[32] Participation and employment rates for carers aged 15 to 64 years. Primary carers are the main providers of informal care to people of any age with disability. Other carers provide informal assistance (but not the main care) to people of any age with disability and to older people (aged 65 years and older) without disability.

- making it easier to obtain care through providers, thereby freeing up informal carers to enter the workforce or increase their hours worked (NDIA, sub. 161, p. 30).

Estimates of potential employment benefits under the NDIS are presented in box 3.6.

Box 3.6 Potential employment outcomes from the NDIS

Increased participation of people with disability

- The Productivity Commission (2011, pp. 960–963) estimated that if Australia were to reach the average OECD relative employment rate for people with mild to profound disabilities, employment would rise by 100 000 people by 2050. And this, in turn, would increase Australia's GDP by an estimated 0.2 percentage points, or $8 billion in 2050. (The Commission also estimated that broader Disability Support Pension reforms could increase employment by an additional 220 000 people).
- PwC (2011, p. 26) estimated that if Australia realised disability employment ratios comparable to the top eight OECD economies, the employment increase could be 50 000 higher than the Productivity Commission's estimate.
- National Disability Services worked with State and Territory Governments to model the potential employment impact of the NDIS. In New South Wales a potential employment uplift of between 7800 and 12 400 people with disability has been identified (NDIA, sub. 161, p. 30).
- The NDIA (sub. 161, p. 31) estimated that the fiscal impact would be between $2.1 billion and $4.4 billion per year if between 103 000 and 218 000 people with disabilities are able to increase their hours of work or join the workforce (noting that the upper bound is based on the impacts of broader Disability Support Pension reforms).

Increased participation of informal carers

- The Productivity Commission (2011, p. 966) estimated that there were 120 000 unemployed, co-resident primary carers of people with disabilities who would be eligible for funded supports by the NDIS. If a conservative half of these unemployed carers returned to work, Australia's GDP was estimated to increase by $750 million annually.
- PwC (2011, p. 25) estimated that about 80 000 disability carers could enter the workforce or increase their hours worked as a result of the NDIS.
- National Disability Services work (with State and Territory governments) identified that 10 700 carers (on a full-time equivalent basis) in New South Wales and 4000 carers in Western Australia could return to the workforce as a result of the NDIS (NDIA, sub. 161, p. 31).
- The NDIA (sub. 161, pp. 31–32) estimated that the fiscal impact would be between $0.9 billion and $1.7 billion per year if between 56 000 and 104 000 carers could increase their hours worked as a result of the NDIS.

The NDIS has improved employment outcomes for some

The NDIS has helped some participants and their informal carers enter or remain in the workforce (box 3.7).

Box 3.7 Some participants report improved employment outcomes

Karene Gravener:

> I have improved physically, emotionally and mentally because of the support of the NDIS. We, as a family, have been able to live life, and pursue our dreams. My husband has been able to be in full-time employment without the stress of being a carer, and we are building our own home. (brief sub. 96)

Lauren McGowan-Slee:

> My condition got worse about seven years ago, and at my worst, I couldn't get out of the house and sometimes even bed. Last week I started full time work, a feat that was once seen as impossible. It's not easy. I get fatigued and crash out most evenings and end up in bed quite early, but I don't mind because I am living a meaningful life!
>
> Because of the NDIS, I have supports that mean I can do a job that works with my disability and have the physical home tasks I can't do taken care of. I can sit and use my brain with no worries, so that is what I do for work, but I struggle to do physical tasks so I get help for that. (brief sub. 52)

Richelle Carta:

> I was struggling to sustain my lifestyle with very minimal funding but due to the NDIS I can continue to be a wife, mum, work full time and have a life with my family by having ongoing funding to provide me with morning and night personal care support seven days a week. (brief sub. 111)

Lynne Foreman:

> … I can now choose who cares for me, as I now have a choice. I have the hours I need to live my life and also because of flexibility in my plan, I am now an employee … Most of us now feel we can take part in the community, and I know some because of the NDIS have part-time jobs. We are healthy in our mind and that's a good thing in its self. (brief sub. 71)

Susanna Goodrich:

> My son Toby is sixteen. He has Down Syndrome. He's had a rough few years with an autoimmune condition … The NDIS has provided funding that has changed Toby's life. His week has opened up from a routine of school, family life and the occasional social event, to a week that looks much like his other teenage brothers: he plays sport, goes out with peers, works in a part time job and will soon be learning how to catch the bus to the local shopping and entertainment hub. (brief sub. 39)

But some concern that participation benefits will not be fully realised

Some stakeholders argued that a more concerted effort is needed to realise the expected benefits of increased economic participation under the NDIS. National Disability Services, for example, said:

> Increasing the employment participation of people with disability and carers is fundamental to the financial sustainability of the NDIS. … The Productivity Commission anticipated that the then proposed NDIS would generate profound economic benefits and that a key source of these benefits would be 'increased economic participation for people with disabilities … and their informal carers'. … To date, the proportion of NDIS plans with employment supports is disturbingly low … (sub. 51, p. 3)

In 2016-17, the NDIA reported that:

- 16 per cent and 26 per cent of NDIS participants aged 15 to 24 years and 25 years and over respectively were in paid employment

- 30 per cent of family members/carers of participants aged 25 years and over were working in a paid job (about 45 per cent for carers of participants aged 0–24 years)
  - of those that had a paid job, 76 per cent of family members/carers of participants aged 25 years and over were permanently employed (74 per cent and 73 per cent for carers of participants aged 0–14 and 15–24 years, respectively)
- 57 per cent of family members/carers of participants aged 25 years and over said they were able to work as much as they wanted (42 per cent and 47 per cent for carers of participants aged 0–14 and 15–24 years, respectively)
  - of those unable to work as much as they want, over 80 per cent cite their family member with disability as a barrier to working more and about 30 per cent cited insufficient flexibility of jobs as a barrier to working more (NDIA 2017y, pp. 26–27).

Confusion around what employment supports are provided by NDIS

Employers, employment services and the NDIS all have a role in supporting the employment of NDIS participants (box 3.8).

Submissions to this study raised concerns about a lack of awareness of what employment supports are available in the community. Legacy Australia, for example, said:

> For many people with disability, getting a job is near impossible. Another simple but very important issue is that both those responsible for providing facilities and services and those in need of assistance are often unaware of the resources that are already available in the community. For example, many employers (including Government agencies) are not aware of programs such as 'Job Access'. There is a need to put more effort into ensuring that the extensive resources that are available in the community are communicated to those who need to know. (sub. 168, p. 3)

Others said there is confusion between what employment supports are available under the NDIS as opposed to mainstream services. Deafness Forum of Australia said:

> There is likely to be disagreement or confusion between existing programs and the NDIS in relation to which program is responsible for the cost of providing support to people who qualify for assistance through several programs. For example, an NDIS participant requiring particular technology or an Auslan interpreter to support them in the workplace might reasonably expect to have those needs met in their NDIS plan. However there is also the option to access technology and Auslan interpreters through the Job Access Employment Assistance Fund. This appears to be duplication in service provision that could lead to double dipping, or more likely, lead to the person not being able to access the support they need in a timely way if the NDIS and Job Access dispute which program is responsible for funding the supports. (sub. 127, p. 15)

Box 3.8 Employers, employment services and the NDIS

Employers

Employers are responsible for:

- making reasonable adjustments to enable people with disability to access their workplace
- employment-specific aids and equipment such as computers and modified desks
- reasonable adjustments to buildings, such as installing ramps
- transportation for work activities, such as attending a meeting (NDIA 2017o).

Employment services

Employment services and programs (including both disability-targeted and open employment services) are responsible for providing advice and support to:

- people with disability to prepare for, find and maintain jobs
- employers to encourage and assist them to hire and be inclusive of people with disability in the workplace (including support, training and resources, funding assistance to help employers make reasonable adjustments, and incentives for hiring people with disability, such as wage subsidies).

Disability Employment Service (DES), and Job Services Australia (JSA) providers are the primary source of assistance to prepare for, find and maintain employment (NDIA 2017o).

The NDIS

The NDIS funds supports to assist participants with employment where these are beyond the requirements of employment services and employers. The scheme also funds supports that participants would require regardless of the activity being undertaken. The scheme does not fund the cost of education, such as course fees. These remain the responsibility of the education system and individuals. NDIS employment supports include:

- assisting participants (who are not eligible for DES or JSA assistance) to build their skills and capacity to participate in employment, as well as assistance to find and maintain employment
- personal care or assistance with transport where the participant requires these supports regardless of the activity they are undertaking
- assistive technology devices such as wheelchairs and personal communication devices
- supported employment, such as services offered by Australian Disability Enterprises (NDIA 2017o).

The NDIS also provides School Leaver Employment Support (SLES), a reasonable and necessary support for Year 12 school leavers, to assist them to transition from school and reach their employment goals. SLES was introduced because the NDIA identified a need for employment support to 'start young to set up expectations for employment' as a strategy to address a culture of low employment expectations (from participants, families, planners and the community) for people with disability. SLES is tailored to meet participants individual goals and includes work experience, job skills training, travel training and links to ongoing support such as DES (De Natris and Battersby 2016).

An effective interface between NDIS employment supports, and other mainstream employment services is essential for achieving good outcomes for NDIS participants. Spinal Cord Injuries Australia stressed the importance of a well-integrated system of employment supports.

> … emphasis should be put on assisting people into the workforce through targeted support and designed in a way that works flexibly with mainstream employment assistance — the two areas should not work in isolation but [be] integrated across service provision. (sub. 61, p. 4)

And there must be clear boundaries between the responsibilities of the NDIS and mainstream employment services for the NDIS to be financially sustainable.

Employment supports are one of a number of disability support areas where interface issues are emerging between the NDIS and mainstream services. Interface problems and the role of Information, Linkages and Capacity Building in providing linkages to other services (including employment services) are discussed in chapter 6.

Concern that participants are not accessing NDIS employment support

There is concern that many NDIS participants (that could benefit from the opportunity to work) do not have employment supports included in their plans. For example, Westhaven Association said:

> The evidence from the plans being produced to date shows NDIA has failed to ensure that NDIS participants are supported to gain productive employment. Without the employment outcomes expected from the scheme, NDIS may not achieve the return originally projected by the Productivity Commission. (sub. 81, p. 2)

Some stakeholders said that planners do not have a good understanding of what employment supports are appropriate for scheme participants (House with No Steps, sub. 104, pp. 5–6; Roundsquared, sub. 170, pp. 5–6) and as a result, scheme participants are not offered employment supports, or encouraged to think about how they might increase their economic participation.

A number of stakeholders suggested that planners and LACs should be more focused on employment outcomes. National Disability Services, for example, said:

> A broad spectrum of employment options should be open to people with disability, including Supported Employment Enterprises … More must be done to boost demand for, and access to, NDIS employment supports. NDIS planners and LACs should adopt a 'work first' approach which motivates and assists an increased proportion of NDIS participants to connect with work. (2017a, pp. 8–9)

Similarly, Milner & Clyde said:

> We understand that one of the fundamental premises upon which the sustainability of the NDIS has been built is that increased levels of labour force participation by people with disability, and also by carers, will result in lower support and income replacement costs and liabilities. Currently, there is little evidence that there is a focus on workability. … We therefore believe

> that the introduction of a focus in participant plans on work participation is urgently required and should be actively monitored. (sub. 94, p. 2)

Qualitative evidence from the NDIS evaluation found that while there was an increase in participation in employment related activities over time, only a few NDIS participants were undertaking volunteer work, work experience, supported employment and paid work. Further, the evaluation reported that:

> Increased economic participation amongst people with disability was considered a long term process, with time needed to develop job-readiness skills, create programs to support both participants and employers, and to change cultural beliefs about employability and opportunities for employment for people with disability. It was argued that more needed to be done to develop effective guidance, supports and linkages to employers in order to open up labour market opportunities for people with disability. (Mavromaras, Moskos and Mahuteau 2016, p. xvi)

Recent unpublished NDIA data[33] indicate that $108 million — 2.4 per cent of NDIS funding for committed supports — is committed to employment supports (chapter 2, figure 2.9). While some stakeholders consider this to be a relatively small amount for a support that is expected to generate significant benefits, what is more important (than comparing funding of employment supports with other supports under the NDIS) is to look at whether the funding for employment supports is meeting its objectives.

About 9000 NDIS participants (or 19 per cent of participants over the age of 15 years) currently have employment supports in their plans. And for some age groups it is higher:

- 32 per cent for NDIS participants aged between 19 and 24 years
- 22 per cent for those aged 25 to 34 years.

On average, participants received $12 000 committed funding for employment support (table 3.1), however, some plans have over $35 000 of committed employment support funding.

Employment support varies by type of disability and level of function. The disability groups most likely to have employment supports in their plans are those with intellectual disability (28 per cent) and autism (24 per cent). By level of function, 23 per cent of NDIS participants with a relatively high or medium level of function have employment support in their plans, compared with 9 per cent of participants with a relatively low level of function (table 3.1).

[33] Commission estimates based on unpublished NDIA data on participants with plans from July 2016.

Table 3.1 **NDIS employment support, participants 15 years and older**

Group	*Number with NDIS employment support*	*Percentage of group with employment support*	*Average support ($)*
Disability Group			
Intellectual Disability	5 044	28	12 783
Autism	1 728	24	12 785
Psychosocial disability	798	15	8 582
Cerebral Palsy	326	13	12 307
Acquired Brain Injury	268	12	10 704
Other Physical	219	7	8 913
Other Neurological	205	7	10 033
Visual Impairment	163	11	9 103
Hearing Impairment	128	9	7 953
Spinal Cord Injury	31	4	5 476
Multiple Sclerosis	31	2	3 469
Sensory/Speech	19	18	9 715
Stroke	22	2	5 545
Other	14	12	9 480
Age Group			
15–18 years	1 151	16	12 553
19–24 years	2 497	32	13 996
25–34 years	1 668	22	10 475
35–44 years	1 362	19	10 643
45–54 years	1 450	17	11 327
55–64 years	821	10	11 124
65+ years	47	4	12 847
Level of function[a]			
High	2 747	23	11 958
Medium	5 105	23	12 046
Low	1 139	9	11 521
Total	**8 996**	**19**	**11 953**

[a] This excludes 5 participants whose function is listed as not applicable.

Source: Commission estimates based on unpublished NDIA data, participants with plans from July 2016.

There are a number of reasons why increased economic participation flowing on from the NDIS may take some time.

- NDIS-funded initiatives to engage community and businesses to improve employment outcomes for people with disability are still being rollout out (Information, Linkages and Capacity Building funding was not part of the NDIS trial, chapter 6).

- The NDIS is most likely to be effective for people entering the system for the first time and will thus have a greater effect as time goes on.[34]

There is some early evidence that employment support is increasingly being included in plans, but the number of plans (with employment support being considered) that have been reviewed is relatively small.[35]

There is a need for better data and reporting (to enable better analysis) on why many participants (currently about 80 per cent of participants over the age of 15 years) are not accessing employment supports. In particular, work prospects vary by level of disability and some NDIS participants, such as those with a profound or severe core activity limitation, may never have the capacity to work. The NDIA should collect data on whether or not participants eligible for individualised supports through the NDIS have a disability that limits their capacity to work.

The ABS *Survey of Disability, Ageing and Carers* collects data on employment restrictions including whether a person with disability:

- is permanently unable to work
- restricted in the type of work they can or could do
- needs, or would need, at least one day a week off work on average
- is restricted in the number of hours they can, or could, work
- requires special equipment, a modified work environment or special arrangements
- needs ongoing assistance or supervision
- would find it difficult to change jobs or get a preferred job
- needs assistance from a disability job placement program or agency (ABS 2016a).

NDIA employment data should be collected in a format similar to this to enable the comparison of NDIS employment outcomes with ABS data on the outcomes of people with disability outside of the NDIS.

[34] In 2011, the Commission noted that those who have been in the system for a while often 'have missed opportunities for early intervention, had poor educational experiences, been dogged by low expectations by others, faced a community culture not strongly conducive to their employment and had long breaks from employment that erode skills and confidence' (PC 2011, p. 960).

[35] Commission estimates based on unpublished NDIA data (of participants with at least two plans and where the previous plan was at least 6 months old) indicate that of the participants with employment support in at least one plan, 25 per cent of participants gained employment support when the plan was reviewed, 57 per cent maintained employment support and 17 per cent no longer had employment support included in their plan.

The NDIA should also consider collecting and publishing information on other reasons why NDIS participants may not be accessing employment support. For example, a participant may:

- be permanently retired from the workforce
- already be employed and not in need of employment support
- be receiving all necessary support from mainstream employment services
- have low expectations of finding employment
- be unaware that employment supports are available under the NDIS.

RECOMMENDATION 3.1

The National Disability Insurance Agency should collect and publish data on whether or not participants eligible for individualised supports through the National Disability Insurance Scheme have employment restrictions. Data should be collected in a format similar to data collected on employment restrictions by the Australian Bureau of Statistics Survey of Disability, Ageing and Carers.

3.4 The broader benefits of the NDIS

As discussed throughout this chapter, the NDIS is expected to generate a number of broader economic and social benefits beyond the improved outcomes of people with disability and their families and carers.

In particular, the scheme is expected to replace funding from a range of other government programs. Examples include:

- the National Disability Agreement
- Home and Community Care
- residential and community aged care
- aids and appliance schemes
- transport taxi subsidy schemes
- psychiatric disability community supports (PC 2011, p. 779).

A review by the Australian Government Actuary in 2011 estimated these offsets to be worth about $11 billion in 2018-19 (AGA 2012, p. 26).

Beyond government program offsets, the NDIS is expected to have a range of additional indirect fiscal impacts. These include a reduced burden (and therefore cost savings) on the health and justice systems and reductions in the lifetime cost of disability as a result of early

investment and intervention. The NDIA's preliminary estimates (sub. 161, p. 29) suggest that the NDIS will reduce:

- costs for the health system by between $140-$300 million each year (by reducing hospitalisations for people with disability and limiting the need for people with disability to remain in hospital due to a lack of more appropriate arrangements)
- justice system costs by between $350-$850 million each year (by reducing incarceration rates of those with mental disabilities)
- supported accommodation costs by between $1.2-$1.6 billion each year (as a result of the increased ability for people with disabilities to live independently).

At this early stage of the rollout, it is difficult to measure whether these broader benefits are being realised. Chapter 13 discusses in more detail how benefits should be tracked over the longer term.

4 Scheme eligibility

Key points

- The eligibility requirements of the National Disability Insurance Scheme (NDIS), as set out in the *National Disability Insurance Scheme Act 2013* (Cwlth), are consistent with the principles of the scheme.
- However, eligibility is broader than the Commission recommended in 2011 in two key areas: the inclusion of people with substantially reduced functional capacity to undertake learning or social interaction; and children with developmental delay. These broader criteria have cost implications for the scheme. These groups were not included in the Commission's 2011 costings of the scheme.
- Data are not available to assess the cost implications of adding learning and social interaction to the eligibility criteria for disability requirements. The National Disability Insurance Agency (NDIA) should improve its data collection in this area.
- Trial site data show that a significant number of children are entering the NDIS with developmental delay.
  - Early intervention for children with developmental delay can yield benefits. This suggests that including these children is consistent with the insurance principles of the scheme. The NDIA should monitor research in this area and build its evidence base on what early intervention supports work for children.
  - The definition of developmental delay, as prescribed in the NDIS Act, sets a high standard for children to be eligible for individualised supports. However, during the scheme's trial, a high proportion of children in the scheme were found to not have a significant functional deficit relative to their peers. This partly reflected the transition arrangements for clients transitioning from state and territory schemes.
  - The recently introduced Early Childhood Early Intervention (ECEI) pathway is a tighter gateway in principle, and should result in better enforcement of the eligibility criteria for children aged 0-6 years (in all areas, including developmental delay). However, it is too early to assess the effectiveness of the ECEI approach in practice.
- While there is value in maintaining diagnostic lists that streamline access to the NDIS, the NDIA should make public the process for changing the conditions in these lists, including under what circumstances a change may be considered.
- There is broad support for people with psychosocial disability being included in the NDIS. That said, many concerns were raised about how some aspects of psychosocial disability align with the design and operation of the scheme.
  - The boundaries of the scheme are important, and should not be changed. However, a specialised psychosocial gateway should be introduced to improve how the scheme engages with people with psychosocial disability on an operational level.

For the National Disability Insurance Scheme (NDIS) to deliver cost effective outcomes and remain financially sustainable, it is important that the eligibility criteria are aligned with the objectives of the scheme. The legislated eligibility criteria, as they currently stand, target those people with disability who the Commission intended the scheme to cover. However, the criteria are somewhat broader than that proposed by the Commission in 2011 (PC 2011, pp. 174–175), and this has cost implications for the scheme.

There are a number of factors that affect scheme participant numbers, including the:

- size and age profile of the Australian population
- prevalence, incidence, nature and severity of disability within the population
- eligibility criteria
- effectiveness of entry pathways in upholding the eligibility criteria
- effectiveness of exit pathways when people no longer meet the eligibility criteria for individualised supports.

This chapter looks at the factors from this list that are relevant to the design of the NDIS — the eligibility criteria (section 4.1) and entry and exit pathways (section 4.2). One of the key eligibility issues raised in this study was the inclusion of psychosocial disability in the NDIS. This issue is discussed in section 4.3.

4.1 The eligibility criteria

The NDIS is for all Australians. It provides insurance against the costs of support in the event that a person acquires or is born with a significant disability. And anyone with, or affected by, disability can approach the NDIS for information, linkages and capacity building. Individualised supports under the NDIS, however, are targeted at people with permanent and significant disability or those who meet early intervention requirements. In this context, 'eligibility criteria' refers to access to these individualised supports.

The eligibility criteria are critical in an uncapped scheme

The NDIS is a new way of providing disability supports. When services were block-funded, governments had tight control of how much money was provided for disability services. However, individualised supports provided under the NDIS are uncapped — so long as an individual meets the eligibility criteria, and the supports provided are 'reasonable and necessary supports' (chapter 5), an individual will receive the support that they need and for as long as they need (often for their whole lifetime). This means that from a budgetary perspective, the NDIS is less certain than previous models of disability support.

The eligibility criteria are the main instrument available for determining how many people will receive individualised support through the NDIS. It is important that these criteria are clear, aligned with the objectives of the scheme, and rigorously upheld.

Eligibility differences when compared to PC 2011 recommendations

When the Commission designed the NDIS in 2011, it recommended that the eligibility criteria for individualised supports uphold the following principles:

- individuals should have a disability that is, or is likely to be, permanent reflecting the irreversible nature of disabilities; and
- individuals would meet one of the following conditions:
  - have significantly reduced functioning in self-care, communication, mobility or self-management, and require significant ongoing support (the recommendation to restrict access to people with significant, ongoing support needs — rather than anyone with disability — reflects the objective that the NDIS embody a risk-pooled insurance scheme, which focuses on minimising the impact of high cost, low frequency events)
  - qualify for an early intervention group (covering people for whom there is good evidence that early intervention would be safe, cost-effective and significantly improve outcomes — box 4.1) (PC 2011, pp. 13–14).

The Commission also recommended that participants meet residence and age requirements.[36]

Box 4.1 Why early intervention is important

An important recommendation in the Commission's 2011 *Disability Care and Support* inquiry was that individualised supports be available to 'an early intervention group, comprising of individuals for whom there is good evidence that the intervention is safe, significantly improves outcomes and is cost effective' (PC 2011, p. 63).

A key tenet of the NDIS is that it takes a lifetime approach to providing care and support. Early intervention is one way to embody this. Early intervention seeks to incur expenditure during the early stages of a person's disability in order to improve (or maintain) their functioning later on, or reduce the volume of supports that they need later in life.

Providing early intervention support through the NDIS can mean:

- a better quality of life for scheme participants by addressing many of their needs early, and building or maintaining their functional capacity
- a delay in the need for care (or a lower cost of providing care) in later stages of a participant's life, which contributes to a more financially sustainable scheme.

[36] In 2011, the Productivity Commission proposed that the NDIS would not cover people acquiring a disability over the age pension age (PC 2011, p. 14). At that time, the age pension age was 65 years.

The eligibility criteria for the NDIS (as set out in ss. 21–25 of the *National Disability Insurance Scheme Act 2013* (Cwlth)) are broadly in line with what the Commission recommended in 2011 (table 4.1). However, there are two key differences:

- a person can receive individualised supports under the disability requirements if they have substantially reduced functional capacity to undertake the activities of *learning or social interaction* — the activities proposed by the Commission were restricted to mobility, self-care, self-management and communication (PC 2011, p. 198)
- a child can receive individualised supports under the early intervention requirements if they have developmental delay.

Table 4.1 **A summary of the NDIS eligibility requirements**[a]

Age requirements	Residence requirements
Aged under 65	• Australian citizen • Permanent resident • Hold a protected special category visa
And meet either:	
Disability requirements	**Early intervention requirements**
Disability attributable to one or more: • intellectual • cognitive • neurological • sensory • physical impairments; or • an impairment attributable to a psychiatric condition; and	• Has one or more identified intellectual, cognitive, neurological, sensory or physical impairments that are, or likely to be, **permanent**; or • Has one or more identified psychiatric conditions that are, or likely to be, **permanent**; or • Is a child who has developmental delay; and
The impairments are, or are likely to be, **permanent**; and	The early intervention support is likely to benefit the person by **reducing the person's future needs** for supports in relation to disability; and
Impairments substantially reduce **functional capacity** or **psychosocial functioning** to undertake one or more of the following activities: • communication • social interaction • learning • mobility • self-care • self-management.	The early intervention support is likely to benefit the person by: • **mitigating or alleviating** the impact of the person's impairment on their functional capacity • **preventing the deterioration** of such functional capacity • **improving** functional capacity • strengthening the **sustainability of informal supports** available to the person, including through building the capacity of the person's carer.

[a] This figure represents an overview of what the Commission considers to be the main aspects of the eligibility criteria. The NDIS Act prescribes that more requirements are met than those outlined here.

Source: NDIS Act, ss. 21–25.

Both these differences allow more people to qualify for individualised supports under the NDIS than the Commission included when costing the scheme. The extent to which the less restrictive eligibility criteria are contributing to scheme participation, and consequently, scheme costs, is a key question for this study.

Based on the eligibility criteria proposed in its 2011 report, the Commission estimated that approximately 410 000 people would be eligible for individualised supports under the NDIS (PC 2011, p. 160). Using the Commission's estimates as a basis, the NDIA has increased the estimated number of scheme participants to 460 000 (or 475 000 including those aged over 65 years, as discussed in chapter 2). This change in expected numbers was mostly attributable to population increases and participants aged over 65 years.

Adding learning and social interaction to the disability requirements — what is the effect?

Data are not available to make an assessment about the impact on scheme costs of adding learning and social interaction to the eligibility criteria for the disability requirements. However, Speech Pathology Australia said advice from their members who are NDIS providers is that:

> … they have not been providing services to children whose only disability relates to learning and literacy — thus, it is our conclusion that the increased numbers of people entering the Scheme is not due to the eligibility of people whose *only* functional disability relates to learning and/or social interaction. (sub. 136, p. 15)

It seems reasonable to assume that relationships across domains exist. However, the NDIA does not collect data specifically on which, or how many, of the six activity domains specified in the Act that scheme participants enter through. This means that assessing the extent to which one particular domain is driving entry into the scheme, or how common it is for scheme participants to have reduced functional capacity across multiple domains, is not possible.

Collecting data at entry on which domains apply to each participant would not only inform what parts of the eligibility criteria are having a large impact on participant numbers (and therefore scheme costs), but also allow for more granular analysis of who is in the scheme and what their needs are likely to be. Such information may also be useful to the NDIA in its monitoring and forecasting roles.

RECOMMENDATION 4.1

When determining that an individual is eligible for individualised supports through the National Disability Insurance Scheme under the disability requirements, the National Disability Insurance Agency should collect data on which of the activity domains outlined in section 24 of the *National Disability Insurance Scheme Act 2013* (Cwlth) are relevant for individuals when they enter the scheme.

There was broad support for the collection of these data, including from Legal Aid NSW (sub. PP245, p. 4), Flourish Australia (sub. PP246, p. 2), Multiple Sclerosis Australia (sub. PP283, p. 5), Bruce Bonyhady (sub. PP333, p. 9) and the Queensland Government (sub. PP345, p. 5).

The NDIA — in response to the Commission's position paper — agreed that collecting data at entry about which domains apply to each participant would provide useful information on the drivers of scheme costs (sub. PP327, p. 16). The NDIA also said that collecting specific data on the activity domains will require data definitions and response formats to be developed, and suggested that the information begin to be published from the commencement of the full scheme (1 July 2019) (sub. PP327, p .17). This timeframe is reasonable.

Including developmental delay in the early intervention requirements — what is the effect?

A child has developmental delay if it takes longer for them to reach age-specific milestones than other children. The term developmental delay is used in the absence of a diagnosed condition — that is, there is usually a more specific condition causing the developmental delay, including disability, but this condition is not yet able to be formally identified. This can be because it is difficult to reach an accurate diagnosis given the age and capabilities of the child.

The 'developmental trajectory' of children with developmental delay varies. In some cases, children may 'catch up' to their peers either with or without support. Others may need more substantial support for a longer period, which is often the case if the underlying condition causing the developmental delay is a significant disability.

The effect of including developmental delay as a condition eligible for individualised support was explored in detail by Dyson, Cutter and Moore (2015). The review, which was commissioned by the Department of Social Services (DSS), found that:

- about 11 600 children with developmental delay or global developmental delay would be eligible for support under the scheme (p. 15) (box 4.2), with an estimated annual cost of $155 million
- the vast majority of children in the scheme with developmental delay or global developmental delay could be expected to progress to full scheme participation — in part because of the high access requirements for developmental delay, and in part because developmental delay and global developmental delay is 'often predictive of the future diagnosis of intellectual disability' (p. 87)
- ' … the costs associated with including children correctly identified as having [developmental delay or global developmental delay] is of immaterial consequence to the sustainability of the NDIS' (p. 9)

- given the likelihood that a child with developmental delay would progress to the full scheme, early intervention could reduce costs to the scheme in the longer term by reducing future need (p. 17).

Box 4.2 Developmental delay and global developmental delay – what is the difference?

Definitions for developmental delay and global developmental delay vary. The Commission looked at many definitions to draw out the key features that define the conditions.

A child has *developmental delay* when they take longer than other children to meet age specific milestones in a specific area (or domain). Because children develop at different rates, and some will inevitably reach a milestone before others, most definitions require that a child be substantially or significantly behind their peers before they are identified as having developmental delay.

In contrast, a child is considered to have *global developmental delay* if they take longer to meet specific milestones across multiple domains. Some definitions require only more than one domain to be affected, while others require all domains to be affected. The definition of global developmental delay published by COAG in 2012, required a delay across a majority (out of five) domains.

Different definitions also outline different domains to be considered. However, they often include:

- motor skills (both gross and fine)
- speech and language skills
- social and/or emotional skills
- cognitive ability.

The definition of developmental delay for the purposes of the NDIS is set out in section 9 of the Act, and is spelled out in full in box 4.4.

Sources: COAG (2012a, p. 4); Disability Services Commission (2011, p. 12); QDCCSDS (2014, pp. 4–5).

Including developmental delay is consistent with the objectives of the scheme

The evidence base on the effectiveness of early intervention in improving the trajectories for children with developmental delay, or reducing the future costs of their care, is still being developed. Nevertheless, there is general acceptance that for children with developmental delay, access to early intervention leads to improved outcomes (box 4.3).

Such evidence suggests that there is a firm rationale for children with developmental delay to be eligible for individualised supports under the early intervention requirements of the NDIS. In 2011, the Commission recommended that the NDIA build an evidence base on early intervention, in part to inform what forms of intervention are beneficial and therefore warrant potential funding through the scheme (PC 2011, p. 632). As discussed later in the chapter, the NDIA is working on developing the evidence base on early interventions for children.

The evidence on early intervention for children with developmental delay should be a particular focus, given the developing evidence base, and given the higher than expected number of children entering (and the lower than expected number of children leaving) the scheme.

Box 4.3 Evidence supports early intervention for developmental delay

Evidence points to children with developmental delay benefiting from early intervention supports. For example, when summarising the evidence, KPMG said:

> For children already exhibiting developmental delay, effective early intervention strategies can both alter the course of their developmental trajectories and prevent the onset of secondary complications … The earlier a child is identified as having a developmental delay or disability, the more likely they are to benefit from strategies targeted towards their needs. The success of early intervention strategies not only assists families through the provision of extra support for their child, but also decreases costs to schools and communities in the later years as children transition to school. (2014, p. 3)

Dr Michael Guralnick — now the Director of the Center on Human Development and Disability in the University of Washington — presented a similar conclusion:

> Early intervention for children at risk and for those with established intellectual disabilities is now firmly embedded in the context of general early childhood development. An overarching developmental framework has been advanced and has achieved a high level of consensus; one that is relevant to typically developing young children and to those vulnerable to a range of developmental problems, particularly intellectual disability. (2005, p. 318)

Guralnick also noted the:

> … long-established intervention science indicating that comprehensive early intervention programmes can, at a minimum, help prevent the substantial decline in intellectual development that generally occurs across the early childhood period for children with developmental delays. (2017, p. 211)

Early intervention for children with developmental disability was also described to be 'of clear benefit' by the Royal Australasian College of Physicians (2013, p. 2), while the World Health Organisation notes that early intervention for children with disability can enhance developmental competencies, minimise secondary complications and build the effectiveness of support networks (WHO 2012, p. 27).

The Victorian Government submitted that:

> Access to high quality early childhood intervention services has been demonstrated to improve outcomes for children with disabilities and their families. For families, the earlier the interventions begin, the easier it will be for them to adapt to the challenges they face when their children are identified with a disability or developmental delay. (sub. 174, p. 9)

Numbers in the scheme to date

Trial site data (to June 2016) show that just under 4000 individuals (or roughly one-third of the 11 600 estimate by Dyson, Cutter and Moore (2015)) entered the scheme with a primary health condition recorded as being either developmental delay or global developmental delay (NDIA 2016p, p. 58, table 2.1.11(c)). If the prevalence rate experienced in trial sites was observed nationally, there would be more children with developmental delay in the scheme than Dyson, Cutter and Moore's estimate.

However, trial site prevalence rates may not be reflective of prevalence rates expected on a national level. Further, the NDIA has recently redesigned the entry pathway for children aged 0–6 years with the introduction of the Early Childhood Early Intervention (ECEI) approach (discussed below). This changes how the eligibility of children is assessed, and is designed to better ensure that the eligibility requirements for individualised supports are upheld.

Two possible explanations for higher numbers of children

There are two possible reasons why there may be more children with developmental delay in the scheme to date than expected:

- more children meet the eligibility criteria than expected or
- assessment processes allow children who do not meet the eligibility criteria to enter the scheme.

This section looks at the eligibility criteria for developmental delay. The extent to which assessment processes could be contributing to higher than expected numbers is discussed in the next section.

The definition of developmental delay for the purposes of the NDIS is outlined in box 4.4. A child with developmental delay must meet this definition to be eligible for individualised supports under the early intervention requirements (as well as meeting residency requirements).

Box 4.4 How does the NDIS define developmental delay?

The definition of developmental delay is set out in section 9 of the NDIS Act. It states that developmental delay means a delay in the development of a child under 6 years of age that:

(a) is attributable to a mental or physical impairment or a combination of mental or physical impairments; and

(b) results in substantial reduction in functional capacity in one or more of the following areas of major life activity:

  (i) self-care

  (ii) receptive and expressive language

  (iii) cognitive development

  (iv) motor development; and

(c) results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated.

Source: NDIS Act.

Some study participants raised concerns about the adequacy of the developmental delay definition in the NDIS Act. However, most of the evidence presented to the Commission on developmental delay suggests that the current definition requires a significant threshold to be met. For example, Dyson, Cutter and Moore (2015, p. 11) found that the definition of developmental delay prescribed in the Act sets 'a high access hurdle', particularly the requirements for there to be a substantial reduction in functional capacity, and the exclusion of children who only require uni-disciplinary intervention.

The ACT Government also said that a delay across one domain was in itself generally insufficient to qualify for individualised supports through the NDIS:

> … the NDIA has recently changed the operational guidelines relating to eligibility to the scheme for developmental delay. Specifically, the 'need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated' is being interpreted to mean children with only one area of delayed development are not eligible. As a result, the NDIA access team deems children with one area of delay not eligible for the scheme because they do not require interdisciplinary care and these children are no longer receiving (or renewing) packages or early intervention supports. (sub. 156, p. 9)

In making this point, the ACT Government expressed concern that this pushes the cost of providing support to people with a delay in only one area back onto State and Territory Governments. The fact that the NDIS sets a high access hurdle — which the Commission considers to be important — means that some children will require support outside the scheme. Consequently, all governments need to work together to ensure that there are supports outside the NDIS for children who do not meet the eligibility requirements.

Because the criteria that children must meet to qualify for individualised supports under the scheme is high, this suggests that it is the process by which children are entering the scheme (not the eligibility criteria) that is resulting in higher than expected numbers. This is consistent with evidence provided by the NDIA that a significant proportion of children who entered the scheme during the trial stage appeared to have little or no reduction in their functional capacity compared to their peers (discussed in the next section).

The number and cost of children with developmental delay in the scheme should continue to be monitored by the NDIA. Should changes to assessment processes be made, but children who do not meet the definition of developmental delay (as outlined in the Act) continue to enter the scheme, there is a strong case for changing the definition of developmental delay in the Act so that it is clearer under what circumstances a child would qualify for individualised supports.

4.2 Are entry and exit pathways effective?

Effective entry pathways are imperative to the successful functioning of the NDIS. They uphold the eligibility criteria of the scheme and only allow people who meet these criteria to qualify for NDIS supports. Excessively porous pathways may allow people who do not meet eligibility requirements to access the NDIS, placing cost pressures on the scheme.

There are two main pathways for people to enter the NDIS:

- the Early Childhood Early Intervention (ECEI) pathway for all children aged 0–6, including those with developmental delay (NDIA 2016g)
- a general pathway for people aged 7–65 years (NDIA 2016m).

Entry into the NDIS can be self-initiated, or facilitated by the NDIA (this includes the NDIA contacting people receiving disability services that are being phased into the NDIS when the scheme becomes available in their area).

The NDIA also has a list of defined programs (run by governments prior to the introduction of the NDIS). People receiving supports through these programs do not need to show that they meet the disability requirements, as the requirements for the programs and the NDIS are considered 'equivalent' (NDIA 2016m).

The NDIA said that these defined programs could be a contributing factor to the higher than expected number of children entering the scheme:

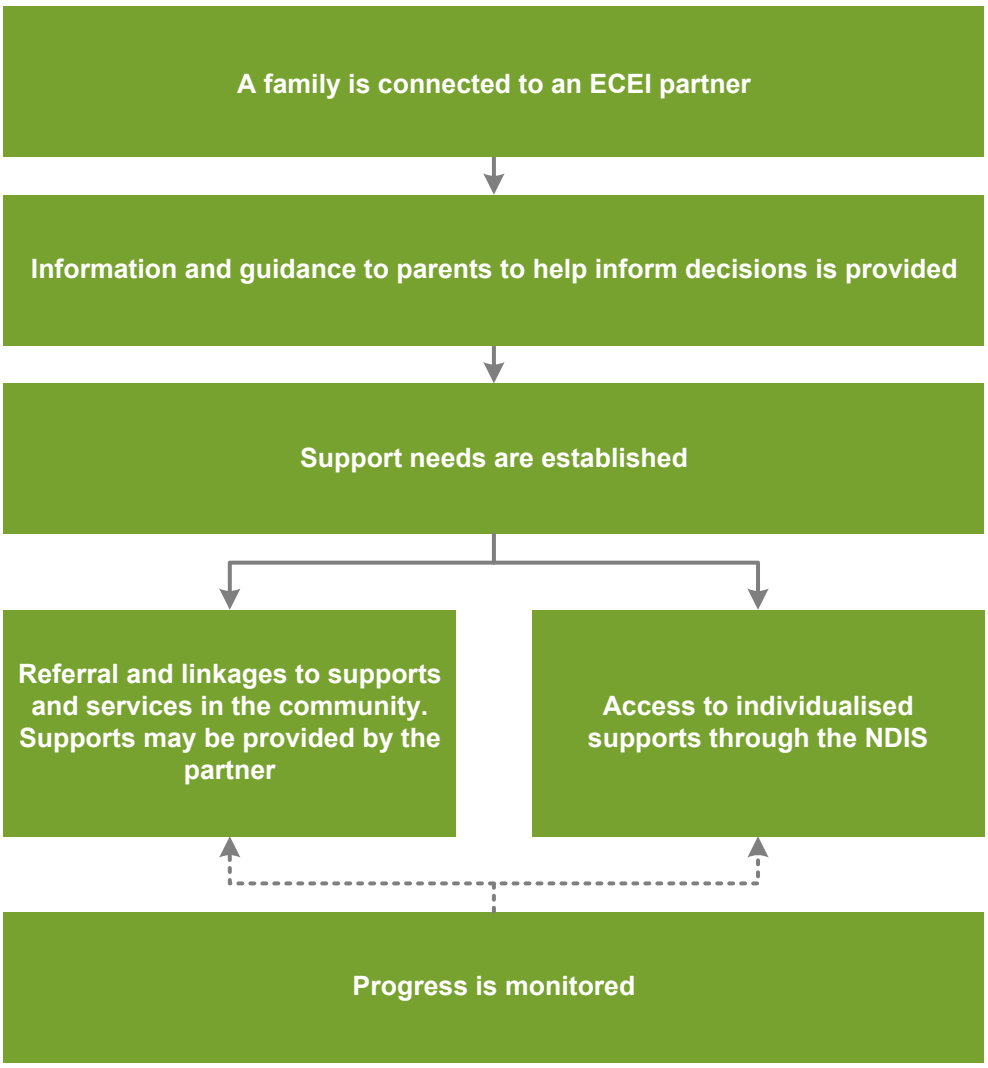
> The NDIA has observed that the change to the access criteria around developmental delay in conjunction with the diagnostic entry criteria for Commonwealth, State and Territory programs to support children with autism has led to increased numbers. (sub. 161, p. 75)

However, as an entry pathway, these lists are relevant during the transition phase of the NDIS, but will become largely redundant at full scheme.

The Early Childhood Early Intervention pathway

In response to the higher than expected number of children entering the scheme in the trials, the NDIA introduced the ECEI pathway for children to enter into the scheme (NDIA 2016b, p. 16). Prior to the ECEI pathway — which commenced in 2016 and is being rolled out in line with the full scheme — children entered the scheme via the general pathway — through the lodgment of an access request and subsequently an assessment of eligibility and need. Figure 4.1 summarises how the ECEI pathway works.

Figure 4.1 **The ECEI process**



Source: Adapted from NDIA (2017f).

Under the ECEI approach, a family with a child with disability or developmental delay seeking support is connected to an ECEI 'partner' in their local community. To be a partner, an organisation must be approved by the NDIA and have experience in early childhood intervention.

Partners assess the support needs of a child with disability and their family and, based on the assessment, determine the supports and services the child needs. Early childhood partners can provide:

- information and linkages to mainstream supports and services
- 'timely short to medium early childhood early intervention supports' — examples of these supports include: information, family based education, parenting support services and therapy (DSS 2016b, p. 11)
- access to a NDIS plan. If it is considered that a child is best supported by a NDIS plan, it remains a NDIA delegate who determines whether a child is eligible and approves a plan, although the ECEI partner is responsible for providing information that will inform a decision on access and assisting with plan development (DSS 2016b, pp. 11–18).

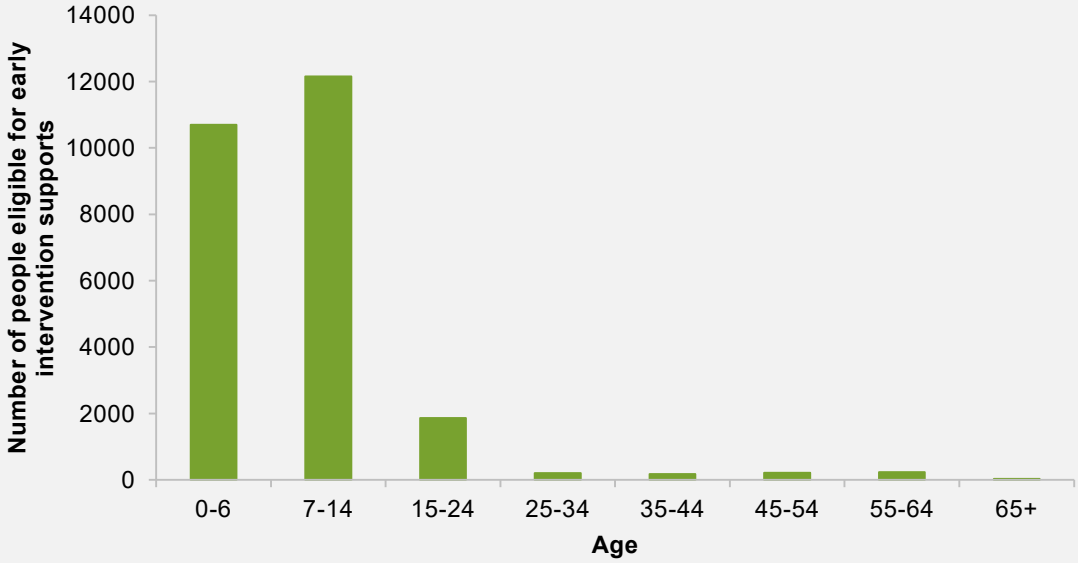
On paper, the ECEI approach does not appear to be very different to how people enter the NDIS under the 'general' pathway. However, the specialised nature of ECEI partners, and the fact that they can provide short- and medium-term support, and refer children to mainstream services, means that the ECEI approach places significant emphasis on upholding eligibility while supporting less severe cases outside of the scheme. The ECEI approach seeks to reduce the number of children with milder levels of disability from entering the scheme, thereby reducing cost pressures.

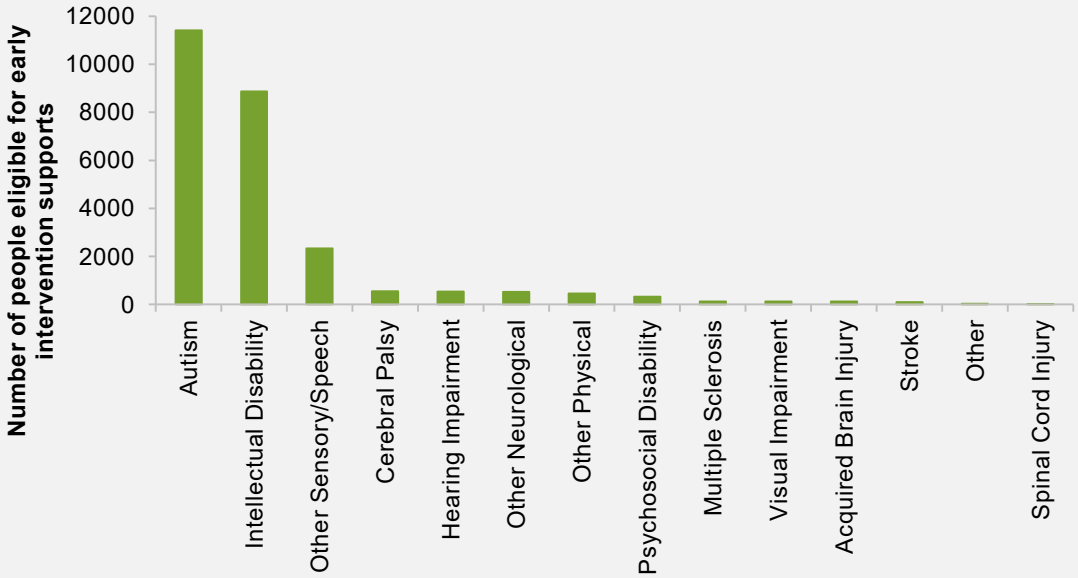
NDIA data on 'who' qualifies for early intervention through the legislated early intervention criteria show that almost 90 per cent are children, and are participants with autism or intellectual disability (box 4.5).

Box 4.5 Who is eligible for NDIS early intervention?

NDIA data provide insights on the main groups who qualify for early intervention in the scheme. Most (about 90 per cent) of those who entered the scheme under the early intervention criteria outlined in the NDIS legislation are children (aged under 15 years of age) and most have either autism or intellectual disability (based on access decisions between 1 July 2013 and 30 June 2017).

People who entered the NDIS by the early intervention criteria, by age and disability





For plans effective from July 2016, the average annual committed support for people who entered under the early intervention requirements was just over $18 100. For people receiving early intervention supports for autism and intellectual disability, the average annualised committed packages were about $17 700 and $17 100 respectively.

Source: NDIA, unpublished data.

What study participants had to say about the ECEI approach

In general, study participants were positive about the likely effectiveness of the ECEI approach (box 4.6). The New South Wales Government, for example, said 'the ECEI process represents best practice for children under 7 years' (sub. 60, p. 17).

Box 4.6 General support for the ECEI approach, but some concerns

Lifestart Co-operative Limited:

> Over time, if implemented correctly with experienced and well credentialed Early Childhood Partners, outcomes for children, their families and the scheme will be positive. [The ECEI approach] should ensure that children get the right support, in a timely manner and in the right amount. It should see the number of children requiring individualised plans decrease. This trend has emerged with the introduction of ECEI Partners in the Nepean Blue Mountains where Lifestart has provided children with supports and assistance where these children and families were able to be well supported without a plan. (sub. 97, p. 4)

National Disability Services:

> NDS … supports the concept of the ECEI approach. The broad gateway of ECEI enables some children with lesser needs to receive short-term assistance … It also allows time to see how a child responds to short-term early intervention before making a decision on eligibility, while still giving immediate access to an NDIS package to those with obvious significant and long-term disability. (sub. 51, p. 4)

The Department of Social Services:

> The early indications are that the inclusion of developmental delay in the NDIS and the Early Childhood Early Intervention (ECEI) gateway approach is effective in supporting children. It is expected a number of these children will meet their development goals and will not require long-term NDIS supports. (sub. 146, p. 3)

Allied Health Professions Australia:

> AHPA and its members support the role of early intervention but note that the early childhood early intervention (ECEI) approach may risk excluding children with a need for support, increasing the burden on other systems and schemes. If the scheme doesn't meet the child's needs there is the risk that this may result in higher levels of support in the future negating the purpose of early intervention programs. (sub. 37, p. 10)

However, some study participants expressed concerns about how the ECEI approach is working for particular disability types, including children with hearing impairments (Deafness Forum of Australia, sub. 127, p. 13, The Shepherd Centre, sub. 107, p. 4). For example, the Royal Institute for Deaf and Blind Children said:

> Models such as the ECEI have resulted in a cost shift from the Agency to providers, with little specificity around specific abilities. The ECEI process has imposed significant and redundant elements for children with hearing impairment, and if strictly implemented would actually delay access to services. (sub. 95, p. 7)

While children with hearing and other sensory disabilities are likely to make up a small proportion of the children who access the ECEI approach, this underscores the need for the ECEI approach to be versatile enough to accommodate all disability types, particularly as it is intended to represent the primary entry pathway into the scheme for children aged 0–6.

Before the ECEI approach was introduced, the number of children receiving individualised supports through the NDIS without having a substantial functional deficit relative to their peers was significant. The NDIA pointed to their analysis of PEDI-CAT scores for a sample of children who entered the scheme during trial which found that:

> … the aggregated scores indicated that, overall, around 40% of participants had scores of 30 or more ('average') across each of the four domains. That is, these participants did not seem to have any identified deficits, compared to the normal range for their age. (sub. 161, p. 78)

To provide additional context around this statement, in its submission in response to the position paper, the NDIA noted that children who entered the scheme through the trial were assessed on the basis of a medical diagnosis. The 40 per cent figure was found by back testing a sample of children who entered during trial with the PEDI-CAT assessment tool (sub. PP327, pp. 19-20).

A small number of study participants questioned the appropriateness of the PEDI-CAT tool and how it was applied to certain types of disability (chapter 5). The Commission is not in a position to comment on the validity or accuracy of the PEDI-CAT tool. However, it is a common tool used by the NDIA to assess the severity of disability in children (a factor in determining eligibility for the scheme), and to have such a significant proportion of children in the scheme with mild or no identifiable deficits relative to their peers points to the importance of having a tight and rigorous entry gateway.

Children with mild or no deficits in the NDIS clearly runs counter to the objectives of the scheme, and depending on the volume of supports that these children receive, could have significant cost and equity implications. As such, a tighter gateway that better assesses eligibility is necessary.

The ECEI approach can be this tighter gateway. Using specialised organisations with experience in identifying and treating developmental delay and childhood disability should result in more accurate assessments of whether children meet the criteria for individualised supports under the NDIS. The emphasis on providing timely short- and medium-term supports as well as support through mainstream services to children with needs, but not severe enough to warrant entry into the NDIS, is also positive.

A version of the ECEI approach (for children and young people under 18 years) was part of the early NDIS transition in the Nepean Blue Mountains. According to the New South Wales Government, 'anecdotal evidence from this process suggests the effectiveness of the model in diverting children from specialist disability supports funded by the NDIS to mainstream and community based support options' (sub. 60, p. 18).

However, it is too early to tell if the ECEI approach has been successful in upholding the eligibility criteria of the NDIS, and contributing to beneficial outcomes for children who are ineligible for individualised support. And as the DSS observed, the 'gateway's actual success will be dependent on services outside the NDIS being available, and the management of family expectation about how children's needs are better met' (sub. 146, p. 13).

The NDIA has developed an evaluation and monitoring framework for the ECEI approach. In time, this framework should assist with monitoring children's pathways (including entry and exit from the NDIS via the gateway) and evaluating the effectiveness of the ECEI approach.

The Brotherhood of St Laurence commented on the importance of ECEI being evidenced-based:

> As the initial roll-out of the NDIS nears completion, children with developmental delays will be the largest group of people with disability entering the NDIS. Understanding what works for children who gain access to the NDIS is vital to manage costs. To ensure the NDIS provides value for money and can reduce the life-long impact of developmental delays on children, ECEI needs to be underpinned by a strong evidence-based practice, policy and research agenda. Most importantly, ECEI staff need access to the latest research and evidence to inform service design and practice. This is especially important given the emerging findings that some interventions and/or programs can be harmful and/or have limited evidence regarding their efficacy. (sub. 189, p. 12)

Mental Health of Young People with Development Disabilities also pointed to the potential harm that can result from interventions that are not evidence-based:

> Non-evidence based intervention, even if delivered by well-meaning therapists and service providers, have significant potential to do more harm than good, advance behavioural and emotional problems and limit a child's ability to develop. … It is imperative the NDIA has a mechanism to ensure that all stakeholders of the NDIS — participants and their families and carers, professional staff developing plans with participants, and practitioners and organisations delivering services — receive clear and empowering information regarding the high value of evidence-based interventions, supports and programs. (sub. PP269, p. 3)

The NDIA is also developing an early intervention approach for the 7–14 years cohort (sub. 161, p. 26).

Concerns about the ECEI approach KPIs

One of the 'Performance Indicator Targets' that applies to ECEI partners is that '<50% of children who connect with the Partner are referred for access to the NDIS' (DSS 2016a, p. C-6). Amaze (sub. PP281, p. 10) submitted that this target is inappropriate in an entitlement-based scheme and could be affecting the practices of ECEI partners.

The Commission is also concerned. One of the key features of the NDIS, compared with previous models of disability support, is that it is not rationed — anybody who meets the eligibility criteria can and should receive support. Whether a child meets the eligibility criteria should be the driver of access.

As such, the Commission considers that a target that seeks to ensure that less than 50 per cent of children who approach ECEI partners are referred for NDIS access is not appropriate. It is an unacceptable outcome if ECEI partners were to not recommend NDIS access for an

eligible child because they were required to meet a target. And there could be instances when more than half of the children who approach an ECEI partner will meet the eligibility criteria to qualify for access to the NDIS.

The target should be removed.

RECOMMENDATION 4.2

The National Disability Insurance Agency should remove the Performance Indicator Target placed on Early Childhood Early Intervention partners that seeks to ensure that less than 50 per cent of children who connect with the partner are referred for access to the National Disability Insurance Scheme.

The 'general' pathway

For people aged 7–65 years, entry to the NDIS begins with the lodgment of an access request. This can be lodged through a form, but is increasingly being completed by telephone. In lodging an access request, a potential scheme participant provides information on their age and residency status (the first two components of the eligibility criteria), as well as information about their disability.

To demonstrate their disability, an applicant is typically required to provide evidence of the condition from their treating doctor or specialist. The NDIA may also require evidence from an applicant's health professional on the impact of the disability on the applicant's ability to undertake tasks related to mobility, communication, social interaction, learning, self-care and self-management. For some conditions (contained in a list maintained by the NDIA), the impact of the disability on a person's functional capacity is assumed and further evidence is not required (NDIA nda).

The NDIA has 21 days to either decide whether the prospective participant meets the eligibility criteria, or to request additional information (NDIS Act s. 20). The additional information may require the potential participant being assessed or examined, and the NDIA has the authority to nominate where this occurs (s. 26(1)).

The Commission was presented with little evidence to suggest that the entry pathway for people under disability requirements is having an undue influence on scheme costs.

The role of diagnostic lists

The NDIA maintains lists — List A and List D — that allow streamlined access to the NDIS for people with certain conditions. Broadly speaking, these lists mean that, if someone has a condition on the list, they automatically meet certain parts of the eligibility criteria (box 4.7).

Box 4.7 **List A and List D**

List A

If an individual has a condition outlined in List A, the National Disability Insurance Agency (NDIA) 'will be satisfied that the person meets the disability requirements without further assessment', meaning in effect, the permanence of an individual's condition, and its impact on their functional capacity, is assumed (residence and age requirements still must be met). List A contains about 30 conditions. For some listed conditions, a specified level of severity must be met in order for the streamlined entry arrangements to apply.

List D

Under the NDIS Act, when assessing whether a potential participant is eligible for individualised supports under the early intervention requirements, the NDIA must be satisfied that the supports will benefit the person by reducing future need (s. 25(1)(b)) and benefit the person in one of the ways prescribed in s. 25(1)(c) (table 4.1).

However, if a child (aged under seven years) has a condition that is on List D, the NDIA 'is satisfied that the child meets the early intervention requirements without further assessment'. List D contains about 130 conditions, including global developmental delay.

Developmental delay (as defined in the Act) is not contained in the list, however it is given streamlined entry arrangements under the *National Disability Insurance Scheme (Becoming a Participant) Rules 2016* (Cwlth) (r. 6.10) that states that the CEO is taken to be satisfied that a child satisfies s. 25(1)(b) and s. 25(1)(c) if 'one or more of the child's impairments is a mental or physical impairment which, by itself or in combination with other mental or physical impairments, results in developmental delay' (p. 14).

Sources: NDIA (2016m, nda).

These lists represent a tradeoff. The appeal of the lists is that they:

- place less of an onus on a potential participant to demonstrate eligibility
- provide a degree of certainty for people with these conditions and their families that they will be supported through the NDIS
- reduce the administrative burden on the NDIA.

However, the lists can affect incentives. They can also be an overly generous entry pathway if set too expansively.

In the case of List D, which applies only to early intervention entry for children under 7 years, the presence of a diagnostic list can run counter to the insurance principles if it leads to the entry of children who are unlikely to benefit from individualised support. The list could also conceivably inhibit exits from the scheme — if diagnosis, rather than expected benefits form the basis of early intervention, a child may remain eligible so long as their condition is present, even if the participant has received early intervention and the expected benefits have been realised (or are unlikely to be realised).

While many post position paper submissions commenting on the lists acknowledged the tradeoff of maintaining these lists, the vast majority considered the benefits to outweigh potential risks.[37] The NDIA also supported maintaining the lists, noting that with List D:

> The NDIA is of the opinion that List D does not result in supports being provided to children who are unlikely to benefit from them. (sub. PP327, p. 18)

In arguing for maintaining List A, the NDIA said there was 'little evidence to suggest that entry pathways for people under the disability requirements is putting pressure on scheme costs' (sub. PP327, p. 19). However, the Agency did identify that:

> Autism Spectrum Disorders may represent a difficulty for List A, and there is evidence to suggest that use of the diagnosis process for autism may differ from the process's intent (resulting in access to the Scheme where eligibility requirements would not otherwise be met). (sub. PP327, p. 19)

Given the broad support for the lists, and little evidence that the lists are leading to people entering the scheme who would not meet the wider eligibility criteria, there seems to be value in maintaining the lists. However, because the lists are a key entry pathway, they should be monitored to ensure they work as intended.

There also needs to be an expedient process to change the lists if new information becomes available (for example, there may be new evidence that people with a particular condition respond differently to early intervention than previously thought) or if there is evidence that the lists are providing an entry pathway for people who would not meet the wider eligibility requirements (as the NDIA suggests might be emerging with respect to Autism Spectrum Disorders).

Given that the lists sit in the NDIA's operational guidelines, rather than the more formal NDIS Rules, there should be fewer barriers to the NDIA modifying lists as required. There is, however, limited transparency about the process by which the lists may be changed — something that was noted by some study participants (Children and Young People with Disability Australia, sub. PP358, p. 4 and National Disability Services, sub. PP295, p. 2). National Disability Services, for example, said in relation to List D:

> It is not clear why some conditions with widely varying degrees of severity are listed and others (such as autism) are omitted. The reasons for inclusion on the list or exclusion should be transparent. (sub. PP295, p. 2)

[37] Study participants who supported maintaining List A and/or List D included: Legal Aid NSW (sub. PP245, pp.4-5); Youngcare (sub. PP253, p. 3); ACT Disability, Aged and Carer Advocacy Service (sub. PP260, p. 3); Victorian Council of Social Service (sub. PP264, p. 3); EACH (sub. PP276, p. 5); Speech Pathology Australia (sub. PP303, p. 5); Amaze (sub. PP281, p. 8); National Disability Services (sub. PP295, p. 2); Early Childhood Intervention Australia Vic/Tas (sub. PP301, p. 2); and the Benevolent Society (sub. PP334, p. 6).

The Commission considers that there are benefits from increased transparency about the process by which the content of List A and List D may be changed. Greater transparency would:

- help the public to understand the purpose of the lists and why some conditions are included on the lists and others not
- impose a level of discipline on the NDIA to ensure that the lists do not remain static, but rather are adjusted to reflect new evidence, or to address concerns that people with listed conditions who are entering the scheme may not meet the wider eligibility criteria.

RECOMMENDATION 4.3

The National Disability Insurance Agency should make public a process for changing the conditions listed in List A and List D of the operational guidelines on access to the National Disability Insurance Scheme, including identifying under what circumstances a change in the lists may be considered.

There is limited information on exits

As discussed in chapter 2, a cost pressure identified by the NDIA is the lower than expected rate at which people are exiting the scheme. At the end of June 2017, just over 1000 participants had exited the scheme, with most of these exits being people who had permanent disability plans, rather than early intervention plans (NDIA 2017y, p. 16).

In its most recent Annual Financial Sustainability Report (2015-16), the NDIA stated that its baseline actuarial model assumes an exit rate of 2.1 per cent of participants each year. However, observed exit rates (as of 30 June 2016) were lower (1.2 per cent per annum). Exit rates of children are particularly low — 0.7 per cent per annum for children aged 0–6 years and 0.3 per cent for children aged 7–14 years (NDIA 2016a, pp. 36–37).

The exit rates included in the NDIS model are long term assumptions. It may take some years before participants — particularly children — receiving capacity building supports through the early intervention requirements are in a position to leave the scheme. The NDIA is monitoring exit rates and should continue to consider actions that will arrest trends in exit rates that do not appear to be consistent with the aims of the scheme.

4.3 Psychosocial disability and the NDIS

Support for including psychosocial disability in the NDIS …

In 2011, the Commission recommended that people with permanent psychosocial disability with significant long-term support needs be supported through the NDIS (PC 2011). The recommendation was made on the basis that:

- the day-to-day support needs for people with significant and enduring psychiatric disability are effectively the same as people who have an intellectual disability or an acquired brain injury
- some important parts of the care that is needed to be provided to people with psychosocial disability — namely community-based supports such as outreach or day programs — are best met through the NDIS
- providing supports to people with psychosocial disability through the NDIS provides them with the wider benefits of the scheme, including personalisation of supports to meet the needs of the individual and more choice over what supports are provided, when and by whom (PC 2011, pp. 186–189).

These points remain salient, and lend support to people with psychosocial disability being supported through the NDIS. And, while the Commission heard a range of views about whether the NDIS represents the 'right' vehicle to provide support to people with psychosocial disability, most submissions to this study were optimistic and/or supportive about the role the NDIS is playing in meeting needs of people with psychosocial disability (box 4.8).

That said, as discussed in chapter 3, there is evidence that some people with psychosocial disability are experiencing less positive outcomes than others in the scheme. For example, people with psychosocial disability are more likely to report less choice and control over supports since becoming a NDIS participant compared with other groups of participants in the scheme (Mavromaras, Moskos and Mahuteau 2016, pp. xi–xiii) and are more at risk of experiencing poor outcomes.

Box 4.8 Strong support for the NDIS from the mental health sector

Flourish Australia:

> Flourish Australia strongly supports the NDIS and the opportunity it provides for greater certainty, choice and control, and economic and social participation for people with disability who require life-long support. We are also strongly supportive of the inclusion of psychosocial disability within the Scheme's remit, and have seen firsthand the benefits of the Scheme for the people we support and their families. (sub. 74, p. 1)

Mental Health Community Coalition of the ACT:

> MHCC ACT views the NDIS with great hope. It holds promises for a better more integrated life for people living with disability. (sub. 135, p. 2)

The National Mental Health Commission:

> The NMHC considers the NDIS to be an important initiative with its promise of individualised care and choice for eligible people with psychosocial disability. It is a potentially very important element in addressing the long standing unmet needs of people with mental illness for effective community and disability supports. (sub. 153, p. 1)

Mental Health Australia:

> The National Disability Insurance Scheme (NDIS) is an historic opportunity to improve the lives of people who have for far too long missed out on the support they need to live contributing lives in the community. Mental Health Australia strongly supports the policy intent underpinning the Scheme, and hopes to work with government over the long term to maximise choice and control for people living with mental illness and psychosocial disability. (sub. 155, p. 3)

The Department of Health:

> There is broad stakeholder support for the inclusion of psychosocial disability in the NDIS, with feedback suggesting that participants are receiving better and more effective support and assistance under the NDIS than what was available to them before accessing the scheme. (sub. 175, p. 2)

… but there are some concerns about how well it fits in the scheme

While there is broad support for psychosocial disability to be included in the NDIS, several study participants identified parts of the scheme's design that are challenging for people with psychosocial disability. For example, the requirement that an impairment be 'permanent', was identified as being incompatible with recovery models used to support people with psychosocial disability. It was also suggested that the requirement could preclude people with significant needs from seeking or receiving support from the scheme. The Royal Australian and New Zealand College of Psychiatrists said that it was concerned about:

> … the centrality of disability 'permanence' in the eligibility criteria for the NDIS as the language of 'permanence' does not fit with the recovery-oriented approach of the mental health sector … Eligibility criteria that relies on permanence may therefore contribute to many individuals not seeking, or opting out of, treatment if that treatment is predicated upon their acceptance of the lifelong nature of their illness. (sub. 158, p. 2)

Mental Illness Fellowship of Australia Inc also said that it:

> … maintains that the criteria for permanency in the context of psychosocial disability is inappropriate, as it is not based in prognostic evidence, is incongruent with recovery-orientated practice, and is unnecessary for ensuring the NDIS supports those most in need. (sub. PP338, p. 2)

And the New South Wales Government:

> The recovery focus in contemporary mental health practice does not align neatly with the NDIS requirement that psychosocial disability is considered a permanent disability. (sub. 60, p. 14)

Similar arguments were presented by the Butterfly Foundation (sub. 78, p. 3), Top End Association for Mental Health Inc (sub. 102, p. 9), Anglicare Tasmania (sub. 145, p. 24), Mental Health Australia (sub. 155, p. 8) and VICSERV (sub. 169, p. 7), amongst others. Some stakeholders suggested that, for psychosocial disability, the permanent requirement should be amended. However, others, such as the National Mental Health Commission, argued that that the concepts of permanence and recovery are not necessarily mutually exclusive:

> The NDIS requirement for Tier 3 participants to establish a 'permanent impairment' can appear to be somewhat at odds with the more strengths-based concept of 'recovery' used in mental health. 'Recovery' is not synonymous with the absence of illness. Rather, it means people who are living with, or have experienced, mental illness can nevertheless lead contributing and meaningful lives, in which they feel safe and secure, have connections with community and family, are engaged in social and economic participation (whether paid or not), and are physically and mentally thriving (not just surviving).
>
> From this perspective, recovery is not inconsistent with the philosophical underpinnings of the NDIS that aim to support people with lifelong disability to live an ordinary life so they can engage in education, employment and community activities. (sub. 153, pp. 1–2)

The DSS made a similar point:

> The investment approach of the NDIS and the recovery model of mental health are both about building capacity, and are well aligned. In the NDIS context, recovery is about achieving an optimal state of personal, social and emotional wellbeing, as defined by each individual, whilst living with or recovering from mental health issues. Recovery approaches acknowledge that the effects of illness and subsequent psychosocial disability may or may not diminish over time. This means that while some people may recover to the point they do not require any mental health or disability supports, others will always require supports to assist and maintain their recovery, ongoing community participation and social inclusion. Similarly, the idea of permanence is about the irreversible nature of a disability, regardless of whether it is chronic or episodic. Therefore the eligibility criteria should not be changed in relation to people with psychosocial disability. (sub. PP318, p. 12)

Concerns about how permanency relates to psychosocial disability are not new. The issue was examined in detail by EY as part of its *Independent Review of the NDIS Act*. The review found ' … there is currently not a case to amend the NDIS Act to address concerns about the

concept of permanency in the context of mental illness' (p. 36), citing a number of reasons (box. 4.9).

Box 4.9 The independent review of the NDIS Act and the concept of permanency in the context of psychosocial disability

In July 2015, the Australian Government commissioned EY to conduct an independent review of the NDIS Act. The review recommended that the need for an impairment to be permanent in the context of mental illness should not be changed. The review provided four reasons to substantiate this.

- The concept of permanency is 'neither minor nor tangential, but central to the design of the NDIS' (p. 36). The review noted that amendments to permanency provisions could (even unintentionally) widen the scope of the scheme, with potential cost implications.
- The legislative framework already accommodates some of the concerns that stakeholders expressed to that review, such as allowing impairments to fluctuate or vary in intensity, or by allowing for the prospect that a person's functional capacity, including their psychosocial functioning, may improve.
- The available evidence at the time did not suggest that permanency provisions were dampening participation in the scheme for people with mental illness.
- The NDIS had 'invested considerable effort in attempting to enhance the responsiveness of the NDIS to people with mental illness' (p. 38).

Source: EY (2015, pp. 34–38).

The Commission supports including people with psychosocial disability in the NDIS. The evidence suggests that a significant number of people with psychosocial disability are eligible and are successfully engaging with the scheme.

- At the end of June 2017, there were about 6000 active participants with psychosocial disability with approved plans, accounting for seven per cent of scheme participants (NDIA 2017y, p. 19).
- Data (to December 2016) also indicate that 81 per cent of people with psychosocial disability who lodged an access request to the NDIS are eligible for the scheme, although this is a lower acceptance rate compared with most other conditions[38] (NDIA 2016r, p. 56).

Scheme boundaries are important, and as the scheme matures and people become more familiar with the scheme, these should become clearer. The Commission cautions against changing the eligibility criteria to relax or loosen the definition of permanency and how it relates to psychosocial disability. Requiring that a condition be permanent is a key tenet of

[38] Across all disability types, about 93 per cent of access determinations found the applicant eligible. The conditions with the highest proportion of successful access requests were autism and cerebral palsy (99 per cent) and the conditions with the lowest were 'other' (67 per cent) and 'other physical' (73 per cent) (NDIA 2016r, p. 56).

the NDIS. Removing or relaxing this requirement would represent a significant risk to the financial sustainability of the scheme.

And while demonstrating permanence may be more difficult for people with psychosocial disability (than for people with other types of disability), permanence is about the irreversible nature of disability which may be of a chronic, episodic nature. The NDIS Rules and operational guidelines accept that a permanent condition may be episodic requiring different amounts of support at different times.

That said, the Commission accepts that some aspects of psychosocial disability do not sit that well in the NDIS, given the design of the scheme and how it operates. In the position paper, the Commission explored the idea of a specialised entry gateway for people with psychosocial disability. Study participants were generally supportive of the idea (box 4.10).

Box 4.10 Participant support for a specialised gateway

Mental Health Australia:

> The development of a psychosocial gateway should commence in tandem with the NDIA's reforms to the wider planning process. Early work on the key design features of a psychosocial gateway should be done with consumers and carers, providers and peak advocacy organisations. (sub. PP321, p. 20)

Victorian Government:

> Current access processes for these people are not operating satisfactorily, evidenced by the high (and growing) number of plan cancellations in Victoria particularly affecting persons with psychosocial needs. Victoria supports the PC's suggestion for a dedicated psychosocial gateway and would welcome the opportunity to be involved in determining its optimal design. (sub. PP298, p. 2)

VICSERV:

> We also note that the Commission raised the concept of a specialised 'gateway' as a unique entry pathway for people with psychosocial disability. Such a pathway would help forge a connection with organisations that already have considerable expertise in psychosocial disability, and would provide linkages to supports and services for individuals with severe and persistent mental illness, but who are ineligible for an NDIS package. (sub. PP284, p. 5)

The Victorian Council of Social Service (VCOSS):

> VCOSS believe the option of a specialist psychosocial gateway has potential to improve people's access to the scheme. (sub. PP264, p. 3)

Why a specialised gateway is needed

There are particular challenges with effectively engaging people with psychosocial disability who may — for example — be hard to reach, or may be distrustful of attempts to provide them with support. As Flourish Australia said:

> … people with a lived in experience of a mental health issue that results in psychosocial disability can also be distrustful of, or find it difficult to navigate government bureaucracies and programs. Some may require time, additional support and/or the chance to hear first-hand from peers about their experience, before they are prepared to give something a go. (sub. 74, p. 6)

A similar point was made by the Mental Health Community Coalition of the ACT:

> Many potential NDIS participants with PSD [psychosocial disability] have a long history of interaction with government services. Over the course of this journey they have been let down many times; made to feel like 'the other'; and spent many hours of time pursuing things that produce little benefit. They have felt judged and demeaned in the process. They are, understandably, suspicious of government as a result. They are not necessarily keen then, to engage with yet another long and involved government initiative that invades their privacy; and another degrading experience of having someone they have no relationship with making such important judgements about them. These are the hurdles faced by service providers in getting many people with PSD to engage in the NDIS. (sub. 135, p. 15)

These characteristics of psychosocial disability present significant challenges for the scheme, particularly in engaging, assessing and planning for people with psychosocial disability. A number of stakeholders suggested that these processes are not functioning well (chapter 5). For example, the Mental Illness Fellowship of Australia pointed out that current assessment and planning practices may be anxiety inducing or traumatic for people with psychosocial disability:

> Having to re-contact a range of people to gather evidence on the history of illness, as well as the experience of being 'interviewed' and assessed, can be experienced as extremely invasive and in some cases, triggering. Symptoms related to psychosocial disability itself can present barriers to access, such that those with anxiety and trauma may require significant support to prepare and attend assessment appointments in which they are exposed to strangers and may feel threatened, judged or vulnerable. Practices by the NDIA or its agents such as calling transitioning participants without fore-warning, conducting telephone interviews, and/or failing to communicate regularly with applicants has exacerbated participants' anxiety and caused considerable distress. (sub. 122, p. 9)

The Joint Standing Committee on the National Disability Insurance Scheme also noted problems with the planning process for people with psychosocial disability:

> Overall, the committee believes the planning process has not been operating well for people with psychosocial disability and has resulted in many cases with less than satisfactory experiences and outcomes for participants … Given the episodic nature of mental health conditions, an agile planning and review process is crucial to ensuring that participants have continuity of appropriate support. (JSCNDIS 2017c, p. 34)

And Neami National pointed to reasons why the planning process may need to be different for people with psychosocial disability:

> Within the NDIS, planning is comprehended as a relatively simple process of information gathering and interpretation, with needs converted into actions through a plan that will last 12 months. This works for some but not all people with a psychosocial disability. For some people planning is a process, dependent on an interactive relationship developed over time, with needs revealed through this relationship, and required actions negotiated between the consumer and planner over time. … The current NDIS process does not accommodate this more interactive approach to planning that has been a strength of community provided mental health services, in particular in meeting the needs of people who are disengaged or marginalised. (sub. 63, p. 6)

One Door Mental Health also said:

> Of critical importance when engaging consumers and carers is that engagement must occur on the participant's terms in a manner appropriate to their individual circumstances. There should be no underlying assumption of readiness for any phase of access to the NDIS. Cold-calling potential participants asking if they need support, with no insight into the support the person needs, is both distressing and ineffective. (sub. PP266, p. 8)

Specialisation is one way to overcome the unique challenges around successfully engaging people with psychosocial disability in the NDIS. One of the key concerns raised by study participants was the knowledge, skills and experience of planners in relation to psychosocial disability. Neami National, for example, said:

> A significant proportion of people with mental illness and related psychosocial disability experience conditions that can present as complex due to factors including: the fluctuating and episodic nature of their condition; difficulties engaging in assessment or service provisions; cognitive deficits that are not necessarily apparent. To ensure effective planning occurs, planners require specific knowledge, skills and experience in engaging and working with people with mental illness and related psychosocial disability. (sub. PP347, p. 5)

One Door Mental Health argued that this is one area where leveraging industry expertise and establishing relationships with potential participants has been underutilised. One suggestion put forward was for the NDIA to discuss the situation of potential scheme participants with current program managers to better understand the individual (sub. PP266, p. 8).

Using more specialised staff — through experience and/or training — should improve the way the scheme connects to and communicates with people with psychosocial disability. Given the current lack of a specific assessment tool and reference package for psychosocial disability, having staff who have a degree of specialisation to assess psychosocial disability is particularly critical.

The value of specialised staff was recognised by the Joint Standing Committee on the National Disability Insurance Scheme:

> Given that participants with psychosocial disability as their primary disability are expected to account for about 13.9 per cent of all NDIS participants by 2019-20, the NDIA should consider having a specialised team of NDIS planners for people with psychosocial disability. This would ensure better plan outcomes for participants, less need for reviews and ultimately contribute to the sustainability of the Scheme. (JSCNDIS 2017c, p. 34)

The NDIA has previously considered the case for a 'new' gateway for people with psychosocial disability, but identified a 'preferred' option of improving the current pathway (National Mental Health Sector Reference Group 2017, p. 2). However, given that people with psychosocial disability are one of the groups at risk of experiencing poorer outcomes in the scheme (chapter 3), the Commission's view is that a psychosocial gateway is a reform worth pursuing.

What features should a psychosocial gateway have?

While the NDIA is best placed to design a psychosocial gateway (in consultation with key stakeholders such as participants, peak bodies, providers and experts in mental health), there are number of key features that the Commission considers the gateway should have.

The first is specialised staff.

Ensuring assessment and planning is undertaken by specialised staff should facilitate better outcomes for scheme participants (because they understand the nature of psychosocial disability and are familiar with appropriate supports). It also ensures that staff are well placed to make appropriate referrals for alternative supports for people who are not eligible for support through the NDIS.

One option for the specialist gateway is to use partner organisations, similar to the ECEI approach. However, other approaches may also be effective — for example, the NDIA could foster specialisation by nominating and training planners to be used exclusively for the gateway.

The second important feature — given widespread concerns about the effectiveness of phone planning for people with psychosocial disability (chapter 5) — is face to face engagement where possible.

Neami National suggested a more iterative planning process for people for whom single-event planning is challenging. This could involve short term plans for high level support coordination, with the goal of developing a longer term plan that is aligned with the person's complex needs (sub. 63, p. 7). Planning and assessment processes should utilise existing information where possible.

Third, the gateway should consider models of outreach to improve engagement for people with psychosocial disability who are unlikely to approach the scheme. Several submissions — including Mental Health Australia (sub. PP321, p. 25), the Victorian Government (sub. PP298, p. 11) and Orygen (sub. PP254, p. 3) — emphasised the value of outreach in improving engagement for people with psychosocial disability.

The cost effectiveness of different outreach approaches need to be considered, with models selected that are expected to yield high benefits relative to the cost of establishing and maintaining them.

Fourth, the gateway should provide a 'soft entry' point for people with psychosocial disability. While the gateway would undertake an assessment of, and assist with plan development for, scheme participants, it also should have a linkage and referral function to other services and supports (like the ECEI approach) for those found to be ineligible for the scheme.

The ability of the gateway to act as an effective linkage and referral service will depend on the adequacy of services and supports provided outside of the scheme. The NDIS is not meant to support everyone with psychosocial disability, and even for those who do qualify for individualised supports, other systems will be critical to their support and care needs (for example, the health system meeting clinical needs). Many people will not meet the eligibility criteria for individualised supports and therefore will need to be supported outside of the scheme.

At present, what supports will be available for people with psychosocial disability who are not eligible for the scheme is unclear, and needs to be addressed (this issue is discussed further in chapter 6).

Finally, the gateway should have a data collection function. At a minimum, data should be collected on:

- the number of people approaching the gateway, and the number of people assessed for scheme eligibility
- basic demographic information about people who approach the gateway (such as gender, age and postcode of residence)
- information on a person's psychosocial disability, including diagnosed mental health conditions and any assessments of severity or impact on functionality that have been undertaken
- the actions taken by the gateway (for example, applying for scheme entry, or linkage to non-scheme services).

The data should be collected, used and disseminated in accordance with the principles outlined in chapter 13 of this report.

RECOMMENDATION 4.4

The National Disability Insurance Agency should implement a psychosocial gateway. The gateway should be the primary pathway that people with psychosocial disability enter the National Disability Insurance Scheme.

The gateway should:

- use specialised staff
- operate on a face to face basis to the greatest extent possible
- consider models of outreach to engage people with psychosocial disability who are unlikely to approach the scheme
- provide linkages to both clinical and non-clinical services and supports outside the scheme
- collect data on both entrants into the scheme and people linked to services and supports outside the scheme.

5 Scheme supports

Key points

- The National Disability Insurance Scheme (NDIS) is designed to cover individualised disability supports that are reasonable and necessary. This includes supports that help people with disability to pursue their goals, live independently and participate in the community and in employment. The NDIS is meant to complement other mainstream or specialist services available to the wider population, not replace them.
- The extent of support coverage matters — under-coverage could mean that the benefits of the NDIS are not fully realised, but over-coverage of supports could create cost pressures and pose a risk to the financial sustainability of the scheme.
- The overall costs and benefits of the NDIS are affected by the volume of supports funded under the scheme, as well as how supports are allocated — that is, the planning process.
  - The touchstone of what is reasonable and necessary directly impacts the quantity and types of supports funded. The concept of 'reasonable and necessary' is malleable, and allows scheme participants the flexibility to exercise choice and control.
  - The quality of planning processes is a key determinant of the success and long-term sustainability of the NDIS — it influences what costs are incurred; the predictability of costs; outcomes for participants; and the integrity of, and community support for, the scheme as a whole.
- The planning process is about matching scheme participants with supports. It involves conversations between the participant and the National Disability Insurance Agency to determine, for each participant: their goals and aspirations, their level of function and appropriate supports.
- The challenge for the planning process is finding the right balance between individualisation and good outcomes for scheme participants on the one hand, and ensuring equity among participants and the financial sustainability of the scheme on the other.
- Planning processes are currently not operating well. The speed of transition and performance indicators that focus on participant numbers have placed pressure on the National Disability Insurance Agency to finalise plans quickly, and the quality of plans has been compromised.
  - Planning conversations with scheme participants are said to be rushed and superficial. Most plans are prepared by phone, which limits engagement with participants and can mean that planners do not get the 'full picture'.
  - The planning process is not clear, transparent and accessible. Nor are processes inclusive or sufficiently flexible to accommodate differing needs, particularly for participants with complex needs or from culturally and linguistically diverse backgrounds.
  - There is variability in planner skills, experience and training. Planners often lack knowledge about different types of disability, which can hinder their ability to formulate a good plan. Planner performance could be improved by using specialised planning teams for some disabilities and better leveraging industry expertise.

The quantity and types of supports funded by the National Disability Insurance Scheme (NDIS) are key drivers of scheme costs. Supports are also important for realising many of the benefits of the NDIS (box 5.1) because they help scheme participants:

- pursue their goals, objectives and aspirations and increase their independence
- increase their social and economic participation (and increase the social and economic participation of carers)
- reduce their need for other supports and services
- develop their capacity to actively take part in the community.

For this reason, striking the right balance is crucial: over-coverage of supports could create cost pressures and pose a risk to the sustainability of the scheme, but under-coverage could mean that the benefits of the NDIS are not fully realised.

The overall costs and benefits of the NDIS are also affected by *how* supports are allocated to scheme participants. Good planning processes are important for matching scheme participants with the supports that will result in improved outcomes and help maintain the integrity of, and community support for, the scheme as a whole. Poor planning processes can increase the likelihood of cost blowouts and undermine the accuracy of cost projections, compromising the ability of governments to plan for the future of the scheme.

The *National Disability Insurance Scheme Act 2013* (Cwlth) (NDIS Act) provides for two types of supports for people with disability.

- Specialist disability supports funded by the NDIS are called *reasonable and necessary supports*. The types of supports that may be funded include: assistance with daily personal activities and household tasks; therapeutic supports (such as occupational therapy, speech therapy and behavioural support); mobility equipment; home and vehicle modifications; and services that enable employment and participation in community, social economic and daily life activities (NDIA ndf).
- The National Disability Insurance Agency (NDIA) may also provide *general supports* to people with disability, even if they are not eligible for the NDIS. General supports include: coordination, strategic and referral services and activities, to help people with disability access mainstream services, such as health, education and transport services (Commonwealth of Australia 2013b, p. 8).

This chapter is about the specialist supports that are funded under the NDIS — that is, reasonable and necessary supports. The rules governing the scope of supports covered by the NDIS are covered in section 5.1. Section 5.2 gives an overview of the process for allocating supports to individual scheme participants — the planning process. Section 5.3 discusses the key concerns raised by study participants about the planning process and considers what implications these have for scheme sustainability. The interface between the NDIS and other services is discussed in chapter 6.

Box 5.1 Many of the benefits of the NDIS are realised through supports

Brenda Gillett:

> My adult son James (39 years old) who has an intellectual disability, lived at home until almost two years ago, when we then decided it was time for him to try to live as independently as possible without our total support … James just loves his own 'unit' and his new (and much loved) support person who is enabling James to become more independent each day; and is helping him to become more inclusive in his community … James also has used funding specifically set aside for a speech pathology assessment and is looking forward to catching up with the 21st century and the rest of his generation by buying an iPad with which to look at his photos and use a communication app to help him express his needs and wants. (brief sub. 15)

Sally Shackcloth:

> My adult daughter's life has improved in many ways since she was a member of the trial group in Tasmania. An occupational therapist found that her bed was unsafe both for her and for the support workers dressing her. The physio review recommended a hip x-ray because of increasing mobility problems. The result is she is now having preventative treatment so her condition doesn't deteriorate … Very importantly, she is now participating in an ongoing speech pathology program with an expert speech pathologist as she needs a communication system tailored to her needs. Up to now she has no reliable way to communicate. (brief sub. 19)

Karen Wakely:

> For the first time we have been able to access meaningful therapeutic supports. Previously therapy was only once a month, and was inadequate for gaining any momentum. Now we access either psyc or occ therapy every week, and it has been far more effective in developing the social and practical skills needed for independent living. For the first time, my child is beginning to successfully participate in mainstream community activities. (brief sub. 43)

Lauren McGowan-Slee:

> Because of the NDIS I have supports that mean I can do a job that works with my disability and have the physical home tasks I can't do taken care of … I am excited to be a taxpayer again, it fills me with so much pride to be giving back again. With the NDIS I can afford to get to work, the transport contributions mean I don't have to reduce my work days to afford taxis. I have adaptive technology which means I can do things by myself and be safe. I am also blind and I can finally read again and I used funding to get me to a functional level so I could work. … I can afford to buy healthier food and get help preparing it instead of having to buy pre prepared meals so I have had less digestive problems, and I don't see the doctor as often. I have a person who can be with me when I do exercise so I can exercise effectively without being afraid of falling over or getting injured when I lose muscle control. (brief sub. 52)

Graham Lawrence:

> Under her NDIS approved plan, Michelle has the ability to purchase a 5 day/week community access program with a group of her peers, with arranged leisure, craft and life education activities … [this] makes it possible for the Government to save an estimated $300,000 – $400,000 p/a. This is the typical net cost of providing care (equivalent to their own home), for people with the severe levels of disability which Michelle has. (brief sub. 78)

Sonya & Stephanie Nicolaides:

> My Daughter Stephi has been on the NDIS for three months now and it has made a dramatic change to her life. She now has the same life opportunities other Australians take for granted. She is able to have regular physio and hydro therapy now, which helps with all her tight muscles. Stephi seems to be a lot happier within herself and able to move a lot easier without much pain. We were able to get ramps to the front and rear of the house, making it very easy to get Stephi in and out of the house in her wheelchair now. (brief sub. 132)

5.1 What supports are funded under the NDIS?

The NDIS is designed to cover individualised disability supports that are 'reasonable and necessary' (Gillard 2012; PC 2011, pp. 257–261).

This includes supports that help people with disability to:

- pursue their goals and maximise their independence
- live independently and be included in the community as fully participating citizens
- participate in the community and in employment (NDIS Act s. 4(11)).

However, the NDIS is not meant to replace mainstream or other specialist services available to the broader population, and does not fund supports that are covered by other areas of government (including hospital and doctor visits, and school teacher aides).

In addition, the NDIS Act s. 34(1) specifies criteria for determining whether supports (general or individualised) may be provided to scheme participants. This includes whether the support:

- will assist the participant in achieving their stated goals and aspirations
- will facilitate the participant's social and economic participation
- represents good value for money
- will (or is likely to) be effective and beneficial for the participant
- should (within reasonable expectations) be provided by families, carers, informal networks or the community
- is most appropriately funded or provided through the NDIS.

The National Disability Insurance Scheme (Supports for Participants) Rules 2013 (Cwlth) and operational guidelines maintained by the NDIA provide additional rules and guidance for deciding what supports may be approved.

What is reasonable and necessary?

Individualised support funding under the NDIS is bounded by the touchstone of what is reasonable and necessary. However, the concept of 'reasonable and necessary' is not specifically defined in the legislative framework. Notably, the NDIS Act 'does not prescribe the types of supports that would be considered 'reasonable and necessary' across all participants' (EY 2015, p. 9), nor does it provide direct guidance on how to determine whether a support is reasonable and necessary.

As the court in *McGarrigle v National Disability Insurance Agency* observed:

> Although the phrase 'reasonable and necessary supports' is used throughout the legislative scheme, including in the objects and principles provisions, it is not defined. Its meaning can be

> derived from the context in which it is used, especially in my opinion s 4(11), which sets out what reasonable and necessary supports should enable and empower people with a disability to do, read with s 14 which sets out the purposes for which funding for reasonable and necessary supports is provided. ([2017] FCA 308 at [41])

As such, the bounds of what is reasonable and necessary will ultimately be shaped by court and tribunal decisions over time, having regard to the text of the legislation, rules and operational guidelines. These decisions will affect what will be funded under the NDIS, and therefore overall scheme costs. On this basis, the NDIA identified 'decisions by the Administrative Appeals Tribunal (AAT) or court system in interpreting the boundaries of … reasonable and necessary supports' (sub. 161, p. 45) as a policy lever affecting the financial sustainability of the NDIS that is outside of its control (box 5.2).

Box 5.2 McGarrigle v National Disability Insurance Agency

Mr Liam McGarrigle is a scheme participant with autism spectrum disorder and intellectual disability. Each week, he attends a group program for three days and is employed for two days. Transport to and from these activities is by taxi or provided by a support worker. As part of his third plan, Mr McGarrigle was allocated $11 850 for 'transport to access daily activities'. This represented about 75 per cent of his total transport costs ($15 850).

In the Administrative Appeals Tribunal

Mr McGarrigle sought a review of this decision in the Administrative Appeals Tribunal, seeking to have his transport costs fully funded. The Tribunal found that, while transport is a reasonable and necessary support for Mr McGarrigle, it was open to the National Disability Insurance Agency (NDIA) to decide to fund less than the full cost of the support. The Tribunal said, 'I am satisfied that the decision to fund 75 per cent of his weekday transport costs strikes an appropriate balance between what is reasonable and necessary for him and the overall financial sustainability of the NDIS' [64].

In the Federal Court

On appeal, the Federal Court of Australia overturned the Tribunal's decision. It reasoned that the imperative language of the NDIS Act (specifically, the words 'will be funded' in s. 33(2)(b)) pointed to the fact the scheme intends that supports will be fully funded. The Court also noted that the Act does not refer to contributions from the participant towards the cost of supports.

The NDIA lodged an appeal of this decision to the Full Federal Court. It argued that the CEO of the NDIA could refuse to fund a support on the grounds of 'financial sustainability'. The Full Court did not consider this argument because it was a new argument and therefore not a permissible grounds of appeal. The Full Court dismissed the appeal on 21 August 2017.

Sources: *McGarrigle v National Disability Insurance Agency* [2016] AATA 498; *McGarrigle v National Disability Insurance Agency* [2017] FCA 308; *National Disability Insurance Agency v McGarrigle* [2017] FCAFC 132, Victoria Legal Aid (sub. PP367).

Is additional clarity required?

In the position paper, the Commission asked whether there is sufficient clarity around how and whether the 'reasonable and necessary' criterion should be applied and whether better legislative direction about what is reasonable and necessary is required. The feedback was mixed.

Clarity for scheme participants and planners

The majority of responses addressed the question of whether 'reasonable and necessary' is sufficiently clear from the perspective of planners and scheme participants. Study participants identified issues with operationalising the concept of 'reasonable and necessary'. A particular concern is that there are different perceptions about what supports are reasonable and necessary (Flourish Australia, sub. 74, p. 5; PDA, sub. 38, p. 9; MIFA, sub. PP338, p. 9; NDS, sub. PP295, p. 3). Alzheimer's Australia, for example, said:

> In our experience, there are large variances in what is considered 'reasonable and necessary' in relation to assessment planning. For example, one person with younger onset dementia was assessed and given horse riding lessons, while another person was not allowed bathroom aids. There also needs to be an oversight and improvement process that monitors how an assessor or planner determines what is considered 'reasonable and necessary'. (sub. 10, p. 13)

Some study participants also said that planners' lack of knowledge about different types of disability impacts their ability to identify what supports are reasonable and necessary for different scheme participants (AASS sub. PP330. pp. 4–5; ABF, sub. PP263, p. 4; MND Australia, sub. PP255, p. 4; MS Australia, sub. PP283, p. 5; RIDBC, sub. PP259, p. 6). The issue of planner knowledge is discussed further in section 5.3.

The NDIA (sub. 161, p. 92) also acknowledged that 'there is still confusion within the sector and the community, and to some extent within the NDIA, around the scope of reasonable and necessary supports'.

Views were split on whether this problem should be addressed through further legislative direction. Some study participants thought that legislative reform could help clear up confusion around how to operationalise the concept of reasonable and necessary supports (CMHA, sub. PP270, p. 3; Disability Services Australia, sub. PP256, p. 2; One Door Mental Health, sub. PP266, p. 6; VICSERV, sub. PP284, p. 3).

But others disagreed (AASS sub. PP330. pp. 4–5; Anglicare Australia, sub. PP339, p. 3; Mental Health Coalition of South Australia, sub. PP308, p. 3; Women with Disabilities Victoria, sub. PP282, p. 5). A key concern was that greater legislative clarity would impose greater restrictions, reducing flexibility and choice for scheme participants (NSW Government, sub. PP230, p. 3; OPA, sub. PP241, p. 1; VALID, sub. PP332, p. 3; YDAS, sub. PP262, p. 3).

The Commission agrees that amending the legislation is not appropriate for clarifying, for scheme participants and planners, what specific supports will or should be funded by the NDIS. Rather, additional guidance, where required, should be contained in rules, operational guidelines or other policy documents. As the Queensland Government said:

> [It is] appropriate for high level principles on 'reasonable and necessary' to be contained in the Act, with more detailed guidance and examples in subordinate legislation and/or … operational guidelines to facilitate consistency of decision making and expectation management. (sub. PP345, p. 7)

The NDIA has operational guidelines, practice guides, work practices and task cards to help planners exercise their judgment about what is a reasonable and necessary support. This allows for greater flexibility and individualisation, and gives scheme participants choice and control over their supports. As the NDIA explained:

> Decisions around reasonable and necessary supports require balancing the need to empower participants to explore different ways of achieving increased participation with the need to spend taxpayers' money consistent with legislation and in a way that minimizes risk of misuse or fraud. (sub. 161, p. 92)

However, as argued by a number of study participants, greater transparency and better communication is required to help scheme participants understand what supports are covered by the NDIS (Amaze, sub. PP281, p. 12; DAA, sub. PP292, p. 3; EarlyEd, sub. PP290, p. 2; Vision Australia, sub. PP252, p. 5; Women with Disabilities Victoria, sub. PP282, p. 5; YPINH, sub. PP326, pp. 2–3). Publishing examples or benchmarks of what is a reasonable and necessary support could help (AASS sub. PP330. pp. 4–5; MIFA, sub. PP338, p. 9; RIDBC, sub. PP259, p. 6; PDA, sub. 38, p. 8).

Clarity for courts and tribunals

What legislation says about reasonable and necessary supports is important because it provides courts and tribunals with a framework for evaluating whether decisions about those supports have been properly made.

In 2011, the Commission made recommendations about various criteria for determining whether a support is reasonable and necessary (PC 2011, pp. 258–259). These criteria were adapted from the Lifetime Care and Support Scheme in New South Wales and are echoed in the NDIS Act s. 34(1) (discussed above). However, the NDIS's legislative regime is different to that of the Lifetime Care and Support Scheme — and the scheme contemplated in PC (2011) — in two subtle ways.

No explicit requirement to assess whether supports are reasonable and necessary

First, while the NDIS Act repeatedly refers to 'reasonable and necessary supports', it does not explicitly state that individualised supports funded under the NDIS must be, or are assessed to be, 'reasonable and necessary'. By contrast, the New South Wales Lifetime Care

and Support Scheme explicitly requires a direct assessment of what treatment and care needs are reasonable and necessary in the circumstances (*Motor Accidents (Lifetime Care and Support) Act 2006* (NSW) ss. 11A, 23).

That said, a requirement for such an assessment may be implied by the text of the legislation. The Second Reading Speech for the NDIS Act also exhibits an intention to require an assessment of what is reasonable and necessary:

> The scheme will give people the care and support that is objectively assessed as being reasonable and necessary over the course of their lifetime. (Gillard 2012)

It also appears that the NDIA (sub. PP327, p. 23) considers itself obligated to assess whether a support is reasonable and necessary.

However, these considerations are not determinative of how a court would interpret the NDIA's obligations, and there is a risk that the legislation could be interpreted in a manner contrary to lawmakers' intentions. One way of minimising this risk would be to redraft the NDIS Act s. 34 to explicitly state that individualised supports funded under the NDIS must be, or are assessed to be, reasonable and necessary in the circumstances (Legal Aid NSW, sub. PP245, p. 7).

No explicit criteria for assessing whether supports are reasonable and necessary

Second, the NDIS Act does not explicitly provide a schema for determining whether a support is reasonable and necessary. The considerations outlined in the NDIS Act s. 34(1) are not framed as criteria exclusively for deciding whether a support is reasonable or necessary. Instead, they are considerations for deciding whether any type of support (that is, general or individualised) may be provided to scheme participants. As the court in *McGarrigle v National Disability Insurance Agency* observed:

> Although s 34 is headed 'reasonable and necessary supports', it in fact expressly deals with both general supports … and reasonable and necessary supports … ([2017] FCA 308 at [39])

Despite this, the court went on to suggest that what is a reasonable and necessary support is related to or coincides with the criteria in s. 34(1), as well as other (as yet unidentified) factors.

> Whether a support is 'reasonable' requires a different assessment to whether a support is 'necessary' … the concept of necessity would appear to tie one aspect of the CEO's assessment to an evaluation of the kinds of factors set out in [some parts of s. 34(1)]. The word 'reasonable' would appear to be directed at factors such as those set out in [other parts of s. 34(1)]). That is not to say the meaning of each word is exhausted by the factors set out in s 34(1): rather, it is to illustrate the different work that each concept does as an adjective in the phrase 'reasonable and necessary supports'. ([2017] FCA 308 at [91])

Victoria Legal Aid (sub. PP314, p. 4) considered the legislation, together with the judicial commentary in *McGarrigle v National Disability Insurance Agency*, to provide sufficient direction about what is reasonable and necessary. Other study participants also expressed a

preference that additional clarity, where required, to come from court and tribunal decisions, rather than legislative change (AFDO, sub. PP325, p. 13; Maurice Blackburn, sub. PP309, p. 6).

On the other hand, some study participants saw merit in clarifying the nature of the connection between the concept of 'reasonable and necessary' and the criteria in s. 34(1). This could be achieved by:

- framing the criteria in s. 34(1) as considerations for determining whether a support is reasonable and necessary (Legal Aid NSW, sub. PP245, p. 7)
- defining 'reasonable and necessary supports' as supports that satisfy the criteria in s. 34(1) (Dr Kylie Burns, sub. PP315, p. 3).

Ongoing evaluation and review

In 2015, an independent review of the NDIS Act found that stakeholders were generally 'supportive of how the legislative framework defines the concept of reasonable and necessary supports' (EY 2015, p. 49). The NDIA (sub. PP327, p. 23) also advised that it is not currently seeking change to s. 34(1). That said, in the 2015 review, some stakeholders raised concerns about specific elements of s. 34(1) (EY 2015, pp. 49–54). Some participants to this study also raised similar types of concerns (Dr Kylie Burns, sub. PP315, pp. 3–4; Legal Aid NSW, sub. PP245, p. 7; YPINH, sub. PP326, p. 3).

It is still early in the operation of the NDIS Act. At this stage, it is unclear what 'gaps' will emerge in the legislative framework over time and how case law will develop to fill those gaps. However, based on feedback to this study, it appears that calls for better legislative direction are stronger now than at the time of the independent review of the Act in 2015.

On this basis, there is a case for ongoing monitoring and evaluation of whether the body of law (including legislation and case law) around reasonable and necessary supports is operating in a manner that is consistent with community expectations and what is intended for the scheme. This will be particularly important in the early years of full scheme.

In 2016, COAG agreed to conduct a further review of the NDIS Act (COAG 2016, p. 7), and on 16 June 2017, the COAG Disability Reform Council agreed that the review should occur in 2021 (DSS, sub. PP318, p. 8). The Commission agrees that a further review of the legislation under full scheme should proceed. That review should consider, amongst other things, the issues relating to the drafting of the NDIS Act raised in this study, as well as the impact of court decisions on the content of the law.

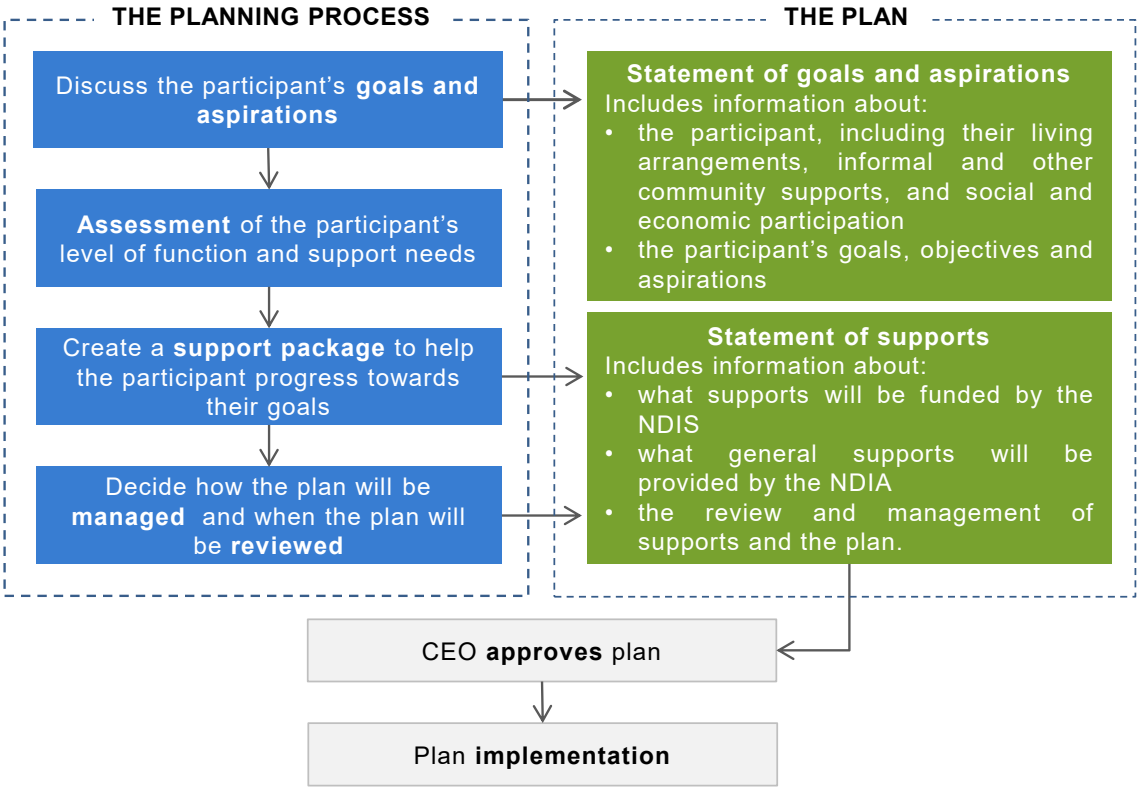
5.2 About plans and the planning process

Supports are allocated to scheme participants through a plan, which is prepared through conversations between a planner and the participant. As the NDIS Act (s. 31) states, where

practicable, the development of a plan should be individualised, be directed by the participant and maximise participant choice and control.

The planning process involves several steps (figure 5.1), designed to elicit information about the scheme participant, which is used to inform the content of the plan.

Figure 5.1 **Making a plan**



1. The participant and planner discuss the participant's goals and aspirations. This conversation is used to help put together a statement of goals and aspirations, which includes information about the participant, including: their living arrangements, informal and other community supports, and social and economic participation, as well as their goals, objectives and aspirations.
2. The NDIA conducts or considers assessments of how the participant is performing in different areas of their life ('level of function' or 'functional capacity'), including their 'activity limitations, participation restrictions and support needs arising from [the] participant's disability' (*National Disability Insurance (Supports for Participants) Rules 2013* (Cwlth) r. 4.1), and identifies areas where the participant requires support.
3. A support package is put together to help the participant progress towards their goals. The support package may include general supports, as well as reasonable and necessary supports, and is set out in a statement of supports.

4. The planner and the participant decide when or under what circumstances the plan will be reviewed. They also decide how the plan will be managed (such as self-management, management by the NDIA, or using a plan management provider), including whether support coordination is required. (Plan management and support coordination are discussed in chapter 10.) This information is also included in the statement of supports.
5. Before the plan is finalised, it must be approved by the CEO of the NDIA (or a delegate).

For most people, their first plan is completed over the phone (NDIA 2016e, p. 1), although some planning conversations do take place face to face. In its submission following the position paper, the NDIA (sub. PP327, p. 25) said it intends moving towards using face-to-face planning as a default approach.

Assessment and tools

The assessment process is about evaluating the scheme participant's level of function and identifying the supports that will allow them to progress towards their personal goals and aspirations. Choosing the right tools for the job is challenging, as there is no universally agreed assessment tool for evaluating the care and support needs of people with disability. There are, however, several features that an assessment tool should have (box 5.3).

Box 5.3 Desirable features of assessment tools

To ensure the sustainability of scheme costs, it is important that assessment tools are:

- *valid* — the tools should test what they purport to and provide a basis for accurately identifying the nature, frequency and intensity of a person's support needs. Assessment tools that are not appropriate could threaten scheme sustainability.
- *reliable* — the tools should yield consistent measures across time, individuals and situations; results should not be influenced by when or where the assessment is undertaken, who is undertaking the assessment, or the identity of the individual per se.
- *accurate* — the tools should reduce the risk that assessors and individuals overstate or understate their support needs.
- *efficient* — an efficient tool is one that collects sufficient information to assess support needs in the least costly manner.

Assessment tools also need to be continually monitored and refined to ensure that they remain in line with scheme objectives, and keep pace with evolving best practice and community expectations.

Source: PC (2011, pp. 315–320).

Since the NDIS commenced, the NDIA has used several different assessment tools as part of the planning process (box 5.4).

Box 5.4 The evolution of NDIS assessment tools

The National Disability Insurance Agency (NDIA) has undertaken significant work to identify appropriate assessment tools for identifying the support needs of scheme participants.

- *Mid-2013*: the NDIA commenced delivering the National Disability Insurance Scheme without an assessment tool, as none was available.
- *Late 2013*: adoption of the Support Needs Assessment Tool (SNAT). The SNAT attempted to identify functional support needs through a planning discussion, and provided the participant with a detailed, personalised support plan. After the first year of trial, it became apparent that the SNAT was not fit for purpose.
- *Late 2014*: further work on identifying appropriate assessment tools. This entailed a survey of functional assessment tools used around the world, and evaluating these tools for relevance, usability and reliability. The cost of acquiring and using these tools was also a crucial consideration. The process included extensive consultation and engagement with key stakeholders and experts across the key disability types, including clinical experts and researchers, and disability associations.
- *Mid-2015*: identification and testing of a new suite of assessment tools. This included different tools for 11 key disability types, and the World Health Organization Disability Assessment Schedule version II (WHODAS II) where no specific tool was identified.
- *Mid-2016*: adoption of the new suite of assessment tools. The NDIA has the capability to administer some of these assessments tools in house, but they can also rely on assessments performed by specialists.

Considerable work around assessment tools remains to be done. For example, the NDIA still has no tool for evaluating the support needs of people with psychosocial disability. Engagement with representatives in the mental health sector on this point is ongoing.

Source: NDIA (sub. 161, pp. 9–11).

Feedback about the NDIA's use of assessment tools was mixed.

- Some study participants were critical of the NDIA's assessment tools, but it was sometimes unclear which specific tools they were referring to (ABF, sub. 48, p. 10; Alzheimer's Australia, sub. 10, p. 10; Belinda Jane, sub. 80, pp. 5–6; Macarthur Disability Services, sub. 57, p. 6; QAI, sub. 115, p. 11).
- Other study participants were critical of how certain tools were used, particularly in relation to early childhood and early intervention (chapter 4). For example, the AEIOU Foundation (sub. 32, p. 8) said that PEDI-CAT is not appropriate for children with intellectual disability. The Shepherd Centre (sub. 107, p. 12) made a similar observation about young children with hearing loss. Others questioned whether NDIA staff were adequately trained to apply the PEDI-CAT tool (ECIA Victoria/Tasmania, sub. 129, p. 10; Noah's Ark, sub. 108, pp. 10–11).

Many study participants said that they were unable to obtain information about what assessment tools the NDIA uses (including tools for assessing level of function). Physical

Disability Australia said this made it difficult to comment on the appropriateness of assessment tools.

> Information about assessment tools is scarce on the NDIS website … Furthermore, there is no mention of them on the pages dealing with planning processes and planning conversations. It is therefore difficult for [Physical Disability Australia] (or anyone) to comment on them as it is not clear which assessment tools are being used and by whom. (sub. 38, p. 7)

The Centre for Disability Studies also said:

> A major barrier to the on-going improvement and implementation of the NDIS is the lack of access to, or public domain information on the assessment tool(s) in use by the National Disability Insurance Agency … we do not see why the assessment tool itself is not public domain, unless for commercial copyright reasons. Many support needs assessments in use across jurisdictions are in the public domain, or are available upon purchase or enquiry. (sub. 49, p. 2)

The NDIA is required to specify what assessment tools it uses in its operational guidelines (National Disability Insurance (Supports for Participants) Rules 2013 (Cwlth) r. 4.4), which must be published on a website and kept accurate, up-to-date and complete (*Freedom of Information Act 1982* (Cwlth), ss. 8-8B, 8D). But, in practice, study participants' knowledge about what assessment tools the NDIA uses appears to be sourced indirectly, through word of mouth or via experiences with the planning process. The Commission was also unable to determine what assessment tools are used by the NDIA, based on information in the public domain. Information about the role of assessment tools in the planning process could help participants understand how or to what extent assessment tool results influence the supports that they receive.

Using reference packages in planning

As discussed in chapter 2, the NDIA has identified increasing package costs (over and above the impacts of inflation and ageing) as a source of cost pressures. The NDIA developed reference packages to assist with monitoring scheme experience and assessing cost pressures (box 5.5). Reference packages are based on age, disability type and level of function. Reference packages can also help improve equity in the scheme by giving clearer guidance on 'typical' arrangements.

Based on the learnings from trial, the NDIA adopted a new approach to determining support packages on 1 July 2016 — this was called the 'first plan process'. This approach uses reference package data to assign scheme participants a 'typical support package' based on their age, disability type and level of function. This is adjusted to account for the individual support needs of participants to create the participant's plan (box 5.6).

Box 5.5 Reference packages

Reference packages are an 'indicative' support package, developed as a way to identify typical support needs and funding for different cohorts of scheme participants.

The National Disability Insurance Agency currently uses a suite of assessment tools for evaluating scheme participants' level of function, covering 11 key disability types. The reference package cohorts are based on these 11 disability types, age and level of function.

Reference package data were tested and validated using:

- back-captured data — that is, data about previous support packages
- expert groups in each of the 11 disability categories — these groups included academics, consumers and providers.

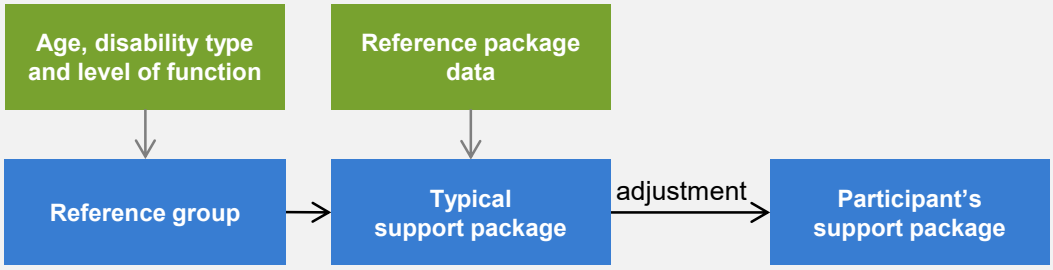
Back-captured data and the work of expert groups were also used to identify how different variables impact the value of support packages. This information allowed the Scheme Actuary to validate the assessment tools, and develop a basis for determining 'reasonable and necessary' funding at an aggregated level.

Work to refine reference packages is ongoing. For example, no reference package is currently available for people with psychosocial disability. Reference packages also have limited utility where a person has more than one disability and the secondary disability is an important contributor to support needs. As more data are collected, reference packages will become more sophisticated and better informed by actual experience.

Source: NDIA (sub. 161, pp. 10–11).

Box 5.6 Using reference package data in planning

Scheme participants are allocated a 'typical support package', based on their reference group (which is determined by their age, disability type and level of function). The typical support package may include funding across eight core domains: daily activities; social participation; consumables; transport; home modifications; assistive technology; capacity building; and support coordination.



For each participant, the level of funding is adjusted according to their circumstances. This is done using a questionnaire, which asks about each of the domains, including what supports the participant already has in place and whether these are sufficient and sustainable. For example, where it is reasonable that sustainable informal, community or mainstream supports continue to assist the participant, or where other informal, community or mainstream supports may provide a better outcome, funding is adjusted in the participant's support package.

Source: NDIA (sub. 161, pp. 10–11).

Balancing different considerations

A number of study participants argued that the use of reference package data is at odds with person-centred planning and that it limits choice and control during the planning process (AASW, sub. 124, p. 4; Flourish Australia, sub. 74, p. 13; Lifestart Co-operative, sub. 97, p. 9). ACT Disability, Aged and Carer Advocacy Service (sub. 87, p. 14), for example, said that the approach 'carries inherent risks that planners (and assessment tools) will overly rely on reference plans as opposed to taking a person-centred approach'.

A person-centred or individualised approach to planning is central to the NDIS. The scheme is about matching participants with the supports that are right for them; however, this needs to be done in the context of the sustainability of the scheme and achieving a consistent approach to funding packages.

During the first year of trial, a highly detailed and person-centred approach was taken to planning, but according to the NDIA it was found not to be fit for purpose.

> [The] Support Needs Assessment Tool (SNAT) was a construct that attempted to identify functional support need and through a planning discussion using the tool to provide the participant with a detailed personalised support plan. The SNAT was used throughout the first year of trial. However, at the end of this period, it had become apparent that the SNAT was not fit for purpose. While the SNAT delivered an individualised outcome, there was no correlation of the SNAT to the reference packages upon which the funding of the Scheme was based. (sub. 161, pp. 9–10)

While some expressed greater satisfaction with processes during trial (for example, Down Syndrome Australia, sub. 121, p. 13), according to the NDIA (sub. 161, p. 10), it led to 'highly prescriptive plans that provided detail at the daily and sometimes the hourly level minimising the flexibility for participants to exercise choice and control'.

The first plan process, introduced in 2016, sought to improve the approach taken at trial by enabling people greater flexibility in how they used their funds against goals and outcomes that they identified. It also sought to address the issues of consistency between support packages by providing guidance to planners about what support packages for different groups should look like.

The challenge for the future of the planning process is to find the right balance between individualisation and good outcomes for scheme participants on the one hand, and ensuring equity among participants and the financial sustainability of the scheme on the other. It is likely to be some time before the right balance is struck.

A dynamic process

As with all insurance-based schemes, the tools and processes for handling and assessing claims are a matter of ongoing refinement. This is necessary to ensure that the insurance scheme remains 'on track' and is viable in the long term. Dynamic processes are also

important to allow the scheme to adapt to changing circumstances or incorporate information that becomes newly available over time.

Part of this process is ongoing monitoring and evaluation (chapter 11). The NDIA undertakes internal monitoring of its processes.

> The first plan process is a dynamic process which will include ongoing refinement as more data and information becomes available. The process allows continuous monitoring of committed support and utilised support, with benchmark costs. As the NDIS moves through transition, the NDIA is continually monitoring and seeking opportunities to enhance the planning process from a participant, provider and staff perspective. The NDIA is currently reviewing the plan review process to streamline the process and ensure it continues to meet the needs of both the participants and Scheme sustainability. (sub. 161, p. 89)

In December 2016, the COAG Disability Reform Council agreed to review the first plan process at the end of June 2017 (DRC 2016). This review should consider whether the first plan process strikes the right balance between individualisation and ensuring equity across participants, and whether the process helps ensure that the scheme is sustainable in the long term.

Information about how the planning process works is important

Many study participants were unsure or unaware of how the first plan process operated. Scope Australia (sub. 72, p. 15) suggested that this was because 'communication from the Agency and its contractors has been inconsistent and at times poor'.

A number of study participants were unsure or mistaken about:

- what the first plan process was
- the rationale for adopting the first plan process
- whether or to what extent support packages were adjusted for individual circumstances
- whether or how supports received under legacy programs were taken into account.

With evolving processes, it is important that scheme participants and their families and carers can access accurate and up-to-date information about the planning process. Dr. Kylie Burns explained the importance of transparency for scheme participants:

> The use of reference packages which are not transparent and available to applicants may also create confusion and resentment in participants who legitimately understand the planning process to be highly individualised based on the provisions of legislation and the NDIS rules (which do not make reference to reference packages). (sub. PP315, p. 5)

ACT Disability, Aged and Carer Advocacy Service (sub. 87, p. 14) said, 'we would encourage a transparent and rigorous approach to consideration of benchmarking and reference plan topics'. Clear messaging about how and why things are changing is also important for maintaining the credibility of evolving planning practices.

Plan reviews

Usually, plan reviews occur as part of the planning cycle — that is, at the expiry of a scheme participant's previous plan (usually after 12 months). However, unexpected plan reviews can be triggered if the scheme participant changes their statement of goals and aspirations or requests a plan review (NDIS Act, ss. 47–48). Often plan reviews are initiated by the scheme participant because their supports do not, or cease to, meet their needs or expectations. Changes to a plan may also be required if information in the plan is incorrect or missing.

Currently, any changes to a plan require a full plan review. Several study participants advocated to allow plans to be amended or varied without triggering a full review (BCA, sub. 130, p. 5; MND Australia, sub. 45, p. 2; Woden Community Service, sub. 159, p. 10).

Full plan reviews can be time-consuming and costly, and scheme participants may also be unable to access the supports they need while they wait for their plan to be reviewed (AOPA, sub. PP294, pp. 3–4). A process for amending or adjusting plans would improve the cost effectiveness of review processes, especially when the proposed changes to the plan are minor (Jacqueline Pierce and Associations, sub. 147, p. 5).

Some also suggested that amendment processes could be used to manage supports for participants when needs change quickly — such as in the case of episodic or degenerative disorders (ABF, sub. 48, p. 3; MND Australia, sub. 45, p. 2). However, where a participant's circumstances change significantly, it will be more appropriate to undertake a full plan review (provided it is undertaken with sufficient expediency).

A process for allowing minor amendments or adjustments to plans without triggering a full plan review was supported by many participants (box 5.7). The NDIA (sub. PP327, p. 25) indicated that it is currently undertaking work to streamline the process for making small plan changes.

However, the NDIS Act s. 37 does not permit variations to a plan once it has come into effect, meaning that the implementation of an amendment process could require legislative change. As Legal Aid NSW explained:

> In our view, this change would require legislative amendment, not just a new NDIA process. Section 37(2) of the NDIA Act states that a participant's plan 'cannot be varied after it comes into effect, but can be replaced under Division 4'. Under Division 4, a participant may request a review of his or her plan at any time and may revise the participant's statement of goals and aspirations at any time, which results in the replacement of the plan. (sub. PP245, p. 8)

If this is the case, the Australian Government should amend the NDIS Act to allow the NDIA to implement a process for making minor amendments or adjustments to plans without triggering a full plan review.

Box 5.7 Many support minor amendments to plans without a full review

Early Childhood Intervention Australia:

> ECIA agrees that the NDIA should implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review. Currently, where there have been minor errors such as plan management choice, a full review is required. … . Due to growth spurts, children can outgrow a piece of equipment such as a wheelchair or orthotics that should be replaced as needed without the full review process. (sub. PP249, p. 4)

Parkinson's Australia:

> Due to progressive nature of Parkinson's there is often the need to frequently adjust plans as the illness progresses, this is particularly important for some of the atypical Parkinson's conditions, such as Multiple System Atrophy, Progressive Supra Nuclear Palsy and Cortico Basal Degeneration, which can progress rapidly. Parkinson's Australia considers that facilitating minor amendments or adjustments to plans to reflect changes in a participant circumstances or changes in the service provision environment would remove unnecessary bureaucracy and assist in the smooth operation of the scheme. (sub. PP232, p. 8)

Australian Orthotic Prosthetic Association:

> Given the issues inherent with the current planning process, plans for orthotic/prosthetic consumers are commonly inadequate and require amendment. … if a plan does not include the necessary supports that would enable a participant with limb-loss to receive a prosthetic limb, an entire review is implemented. This often requires a significant time delay, during which a participant is unable to access the necessary supports and services. For consumers of orthotic and prosthetic services, this may mean a significant period of time without the ability to access the community, mobilise and remain independent. … the current plan review process may take up to three months. (sub. PP294, pp. 3–4)

Prader-Willi Syndrome Association of Australia:

> Plan reviews must be more responsive, to avoid a costly crisis. (sub. PP228, p. 4)

MJD Foundation:

> Because of the inconsistent quality between planners, it would be sensible to have a process whereby plans can be revised without the need for a formal request for a review. (sub. PP233, p. 7)

Young People in Nursing Homes:

> The planning system must be changed to enable adjustments without the need for a full review and replacement plan to be developed. This 'dynamic plan' model should be the default position and criteria need to be developed to guide decisions about when a new plan is needed. (sub. PP326, p. 4)

Early Childhood Intervention Australia Victoria/Tasmania:

> Simplifying the review process for minor amendments will reduce costs and minimise delays for participants accessing services and supports. (sub. PP301, p. 3)

RECOMMENDATION 5.1

The National Disability Insurance Agency (NDIA) should implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review.

If required, the Australian Government should amend the *National Disability Insurance Scheme Act 2013 (Cwlth)* to enable the NDIA to implement such a process.

The role of Local Area Coordinators in the planning process

In some areas, planning discussions are conducted and plans are prepared by Local Area Coordinators (LACs). However, under current legislative arrangements, LACs do not have the power to approve plans — that is, plans prepared by LACs must still be approved by the NDIA.

In its initial submission, the NDIA (sub. 161, p. 13) said that there may be some benefits to allowing approval functions to be delegated to LACs, including increased efficiencies due to reduced double-handling of plans by LACs and the NDIA. The NDIA also said that delegating approval functions could lead to greater certainty for scheme participants.

> More importantly, it would improve the experience of participants by allowing the LAC, while in discussion about support needs and within defined parameters and agreed reporting and monitoring arrangements, to be able to confirm the level of reasonable and necessary funding and move straight to a discussion on plan implementation. (sub. 161, p. 13)

A small number of study participants supported changes to the NDIS Act to allow the NDIA to delegate plan approval functions to LACs (Disability Services Australia, sub. PP256, p. 2; South Australian Government, sub. PP354, p. 4; VICSERV, sub. PP284, p. 3). Some also said that delegation would be appropriate if it could be shown that LACs had sufficient capacity and training (CMHA, sub. PP270, p. 6; MS Australia, sub. PP283, p. 6, Speech Pathology Australia, sub. PP303, p. 9; Parkinson's Australia, sub. PP232, p. 8). The Queensland Government (sub. PP345, p. 8) also said there might be a case for 'rapid or limited approvals for participants supported by LACs engaged by the NDIA who cover very remote areas, for example, the Torres Strait Islands'.

However, the majority of study participants were opposed to allowing delegation, [39] driven mainly by concerns about:

- the risk to plan quality as a result of the NDIA having reduced control and oversight over plans and the planning process
- the capacity of LACs to perform additional functions, due to time and resource constraints
- conflicts of interest (real or perceived) between different roles — for example, giving LACs plan approval functions could compromise their ability to provide impartial pre-planning support
- reduced accountability, clarity and transparency around roles and responsibilities.

[39] Study participants who opposed the delegation of approval functions to LACs included: ADACAS (sub. PP260); AEIOU Foundation (sub. P277); AFDO (sub. PP325); Anglicare Australia (sub. PP339); ABF (sub. PP263); APS (sub. PP229); Bruce Bonyhady (sub. PP333); CPSU (sub. PP310); Flourish Australia (sub. PP246); HSU (sub. PP316); Legal Aid NSW (sub. PP245); MIFA (sub. PP338); NSW Government (sub. PP230); One Door Mental Health (sub. PP266); PWSAA (sub. PP228); RIDBC (sub. PP259); and Vision Australia (sub. PP252).

On balance, it does not appear that legislative change to enable the delegation of plan approval functions to LACs is warranted at this stage. In response to the position paper, the NDIA (sub. PP327, p. 24) also advised that it 'is not currently seeking legislative change to allow the delegation of plan approval to LAC partners'.

5.3 How is the planning process tracking?

Good planning processes are essential for the success of the scheme and long-term sustainability, as the quality of the planning process has a bearing on what costs are incurred in the scheme, the predictability of scheme costs and the integrity of the scheme (box 5.8). The Northern Territory Government said it considers the planning process to be one of the most important elements of the scheme.

> The quantity of supports received by participants is a key driver of costs, and therefore a consideration for the ongoing financial sustainability of the Scheme. However, without a high quality planning process which supports participants to identify and work towards their goals and aspirations, choice and control for participants will not be achieved. (sub. 205, p. 3)

The planning process is not operating well. The Commonwealth Ombudsman reported that the planning process is one of the main sources of complaints to the office (sub. 137, p. 7).

Participants to this study also expressed dissatisfaction with planning processes. In particular, participants expressed concern about:

- the lack of consultation and engagement with scheme participants
- the accessibility and transparency of processes and planners
- the quality of planners (including LACs undertaking planning functions).

A real concern is that poor planning processes are compromising the quality of plans. The Commission heard that plans often do not meet scheme participants' needs or expectations, and sometimes they include supports that are not wanted or needed (Macarthur Disability Services, sub. 57, p. 4). Several study participants also reported considerable variability in plans for scheme participants with similar needs (Neami National, sub. 63, p. 8; PDA, sub. 38, p. 8; PDCN, sub. 29, p. 3). For example, Brain Injury SA said:

> Brain Injury SA is aware of one household with multiple children with similar needs. Each child had a different planner and each plan provided funding for different services. In another instance, involving twins with developmental delays and similar levels of need, the plan for one child included support coordination while the plan for the other child did not. (sub. 116, p. 5)

Box 5.8 Why are good planning processes important?

Outcomes, benefits and equity

As discussed in chapter 1, financial sustainability is not just about costs. It is also about whether outcomes are being realised, and whether those who are paying for the scheme remain willing to do so (NDIA 2016h).

Poor planning processes can mean that scheme participants are allocated supports that are not right for them. This in turn can mean that many of the benefits of the scheme (such as increased quality of life, greater social and economic participation, and reduced need for other or future supports) are not fully realised. Poor planning processes can also result in greater variability in plans and outcomes for scheme participants with similar needs, compromising equity within the scheme. Together, these factors can undermine the credibility of, and community support for, the scheme as a whole — and hence its long-term sustainability.

Costs associated with reviews

Poor planning processes can result in plans that do not reflect the needs or expectations of scheme participants. Increased requests for plan reviews can add to the workload of planners. Review processes can also place greater stress on scheme participants and providers. As Occupational Therapy Australia said:

> … reviews can take months to complete, resulting in added frustration for families and potentially affecting the relationship between participant and provider. (sub. 15, p. 5)

Greater use of review processes can increase the administrative costs of the National Disability Insurance Agency, as well as costs in other areas. For example, appeals to the Administrative Appeals Tribunal or the Federal Court of Australia place a greater burden on the justice system (chapter 11).

Certainty about costs

Poor planning can introduce additional uncertainty about scheme costs (New South Wales Government, sub. 60, p. 15; PDA, sub. 38, p. 9).

- Poor planning processes can be unreliable — that is, they do not yield consistent results across time, individuals and situations. This increases the variance in the value of support packages, increasing the unpredictability of scheme costs overall.
- Poor planning increases the likelihood that participants' plans do not match their needs and expectations. This can contribute to underutilisation of plans, driving a wedge between committed and actual support funding.

Greater uncertainty around scheme costs can undermine the accuracy of cost projections, which can make it difficult for governments to plan for the future of the scheme. High variability of scheme costs also increase the risk of cost blowouts.

Market development

The supply of disability supports needs to grow significantly to meet the needs of NDIS participants. Plans specify what supports will be funded by the NDIS, which directly impacts the demand for different types of supports. This, in turn, encourages certain types of supports to be supplied in the market. Good planning processes are necessary to ensure that the signals sent to the market are those that lead to the supply of the supports that best meet the needs of people with disability.

The NDIS is a major reform and the NDIA has been given a monumental task under highly ambitious timeframes (chapter 2). Many of the NDIA's decisions about how to operationalise the planning process are influenced by bilateral estimates and community expectations around reaching new participants quickly. In addition, planning processes have had little time to mature.

However, there is real concern that some of the practices adopted to address the pressures of rollout will become entrenched in practice and in the culture of the NDIS, with implications for the long-term costs and benefits of the scheme.

The following sections discuss the key concerns raised by study participants, and policy options for ensuring that poor practices do not become structural issues that continue to affect the operation of the NDIS in the medium and long term.

Engagement with scheme participants

Engaging with scheme participants during the planning process is important not only for ensuring that they receive the supports that are right for them, but also for the long-term success of the NDIS. Physical Disability Australia suggested that engaging with scheme participants is particularly important in the early stages of planning.

> Given that many planners are new to this type of work and may have limited lived experience of disability, the validity, reliability and accessibility of the processes they use to determine what constitutes an appropriate support package depends on deep engagement with participants, their families and supporters. (sub. 38, p. 7)

The planning process needs to be sufficiently 'deep' so that planners can obtain sufficient information about a participant for them to make a decision about reasonable and necessary supports that minimise lifetime costs, while also making the process person-centred and convenient for scheme participants and their carers. Involving families, carers, support workers and advocates in the planning process can also improve understanding of the functional impact of the participant's disability, their needs and the supports that they require (VCOSS, sub. 176, p. 16).

Concerns about rushed planning

The speed of transition, as set out in Bilateral Agreements, has placed a lot of pressure on the NDIA to finalise plans quickly. This has detrimentally affected the quality of the planning process. SCIA Australia said:

> The rush to get new participants into the scheme against bilateral agreements is proving to be a major headache for the Agency and is severely affecting the quality of first plans. (sub. 61, p. 3)

Similarly, United Voice said:

> Workloads and inadequate time to do the job is one of the most often cited concerns of our members. United Voice members are concerned that [planners] do not have time to do their job properly, that they rush from client to client preventing them from providing quality support. (sub. 118, p. 8)

Study participants also reported feeling that planning meetings are rushed (Flourish Australia, sub. 74, p. 3; Hannah Potapczyk, sub. 26, p. 1; Jennifer Smith-Merry, sub. 55, p. 2; Leadership Plus, sub. 128, p. 2; Maurice Blackburn Lawyers, sub. 58, p. 13; New South Wales Government, sub. 60, p. 15). Engagement with scheme participants during the planning process appears to be fairly superficial, and the NDIA (sub. 161, p. 11) accepted that the focus on throughput during the first two quarters of transition has contributed to poorer plans.

Phone planning

Most planning conversations are now taking place over the phone, although face-to-face meetings are accommodated if required. The NDIA (sub. 161, p. 12) explained that this was a deliberate decision to allow people to enter the scheme as quickly as possible, with provision for scheme participants to consider how they will use their supports and amend their goals over the first year.

This decision was based on trial experience that recognised that people want to join the scheme as soon as they can, but also want time to think about their goals, supports and how they will use them. While it is recognised that this approach is not perfect, it was designed as a short-term measure to meet both of these objectives (NDIA, sub. 161, p. 12).

Study participants overwhelmingly expressed dissatisfaction with this approach to planning,[40] and many provided examples of poor experiences (box 5.9).

Carers Australia Victoria also identified issues with:

> … limited access to supporting documentation whilst on the phone; limited time to properly consider goals and aspirations; confusion about who they are being contacted by and for what; whether the plan will be as comprehensive as it could have been if the participant had the opportunity for a face-to-face meeting; the ability for the planner to recognise opportunities for capacity building. (sub. 131, p. 8)

[40] Study participants who were critical of phone planning included: Activ (sub. PP302); ADACAS (sub. 87); AFDO (sub. PP325); AHPA (sub. 37); ALA (sub. PP257); Alzheimer's Australia (sub. 10; sub. PP313); Australian Red Cross (sub. PP258); The Benevolent Society (sub. PP334); Brain Injury SA (sub. 116); Carers Australia Victoria (sub. 131); CMHA (sub. 9); ECCV (sub. 31); ECIA (sub. PP301); Flourish Australia (sub. 74); Inclusion Melbourne (sub. PP207); Legal Aid NSW (sub. PP245); Macarthur Disability Services (sub. 57); Maurice Blackburn (sub. PP309); Mental Health Community Coalition of the ACT (sub. 135); OPA (sub. PP241); OTA (sub. 15; sub. PP285); PDCN (sub. 29); PDA (sub. 38); SAL Consulting (sub. PP304); The Shepherd Centre (sub. 107); Social Support & Precarious Workforce Research Discussion Group (sub. 71); SUFY (sub. PP242); VALID (sub. PP332); VCOSS (sub. 176); Vision Australia (sub. 252); VMIAC (sub. 167); YDAS (sub. PP262); and YPINH (sub. PP326).

Box 5.9 Experiences with phone planning

Alzheimer's Australia:

> Annie called the Parkinson's 1800 support line as she worried about an over the phone NDIS planning session that had taken place earlier that day. Annie's volume and quality of speech has been impaired due to Parkinson's and she also requires longer to respond to questions. She felt rushed and because her response is delayed she felt that the assessor didn't get a clear indication of her needs. Annie and a Parkinson's Nurse Specialist were able to take the time [to] put information together in order to apply for a review for Annie's plan. (sub. 10, p. 8)

Ethnic Communities' Council of Victoria:

> … anecdotal evidence from advocates and providers in the North Eastern Melbourne Region indicates that some participants are not being adequately informed about the purpose of phone contact by the NDIA or their LAC. These participants are having plans being completed without realising that they are engaging in the process or providing informed consent. (sub. 31, p. 1)

Carers Australia Victoria:

> I received a telephone call from an NDIA representative and requested a face-to- face meeting … The planner requested information regarding my son and said there were notes from his case manager which would be used to help create his plan. I inquired about the case manager, as I was not aware my son had one. The name given was of a man I had spoken to about 20 years ago. The planner said they have all his needs documented. I reiterated the need for a face-to-face meeting to discuss our changing circumstances and the support that my son needs to live independently and future support needs. I was offered a meeting three days later, 90km from my home, which was not possible for me to attend. When I received a follow up call, I thought it was to schedule another time for a meeting, instead it was to tell me that a plan had been created for my son and that I should login to the Portal to see it. A week later I received a copy of the plan in the mail. The plan contained information about my son from over 20 years ago. (sub. 131, p. 9)

Some felt that phone planning limits engagement with the scheme participant and does not allow the planner to see the full picture. For example:

> [Phone planning] is a transactional and blunt approach at a critical stage of a participant's navigation and interaction with the scheme … We feel utilization of phone-planning also creates assumptions of living situation by planners, who are unable to adequately capture the requirements and considerations of participants and respect the role of family, carers and other persons who are significant in the life of the participant. (Social Support & Precarious Workforce Research Discussion Group, sub. 71, pp. 2–3)

And:

> … an assessment completed by phone does not take the person's disability into account and fails to provide the added awareness and accommodation that are possible in a face-to-face meeting. Planners ask questions over the phone, which sometimes assume ability that does not exist. However, this is not evident to the planner because they are not with the person being assessed. They also lack the ability to make observations about the situation of the participant at the time of the phone call, which may involve distractions. (Brain Injury SA, sub. 116, p. 9)

Blind Citizens Australia (sub. 130, p. 3) also said that conducting meetings over the phone 'severely compromises the ability of people who are blind or vision impaired to demonstrate

the difficulties they may face with completing tasks like reading, navigating the environment or household chores'.

Others expressed concern that phone planning takes scheme participants by surprise or does not allow participants to be supported by family, carers or advocates (Flourish Australia, sub. 74, p. 12). Physical Disability Council of New South Wales said:

> Phone plans … do not allow for participants to be supported simultaneously by carers or other important parties; physical sharing of important resources such as weekly planners or aspirational plans; equal access for peoples with specific communication needs; or allow planners to observe physical cues and surroundings for possible supports or equipment needs. (sub. 29, p. 3)

Phone planning is especially problematic for scheme participants with particular accessibility requirements (discussed below), such as mental illness (CMHA, sub. 11, p. 6; Flourish Australia, sub. 74, p. 3), cognitive impairment and neurodegenerative diseases (Alzheimer's Australia, sub. 10, p. 5) or people of culturally and linguistically diverse backgrounds (ECCV, sub. 31, p. 1; VCOSS, sub. 176, p. 9).

The Commonwealth Ombudsman reported that the bulk of complaints he had received about the planning process were from people who participated in phone planning. The Ombudsman suggested that it would be useful to compare the outcomes, satisfaction and review rates of face-to-face and phone planning discussions, noting that:

> While phone meetings likely provide the most cost effective method for planning when only simple administrative overheads are considered, there may be merit in considering whether — if participants who have phone meetings are more likely to subsequently complain or seek review — the time spent on those subsequent interactions detracts from the cost effectiveness of planning by phone. (sub. 137, p. 8)

The Northern Territory Government also said that better outcomes were achieved when face-to-face planning was used.

> In the NT, the planning processes negotiated through the Bilateral Agreement between the Commonwealth and NT to transition the NDIS allow for a more … intimate planning process, with NDIA planning meetings occurring face-to-face and with a representative from the participant's service provider. This also ensures a comprehensive handover and in remote parts of the NT, particularly in remote Aboriginal communities, this approach has been working well. (sub. PP359, p. 6)

Some study participants argued that phone planning should only be used at the request of the scheme participant (Amaze, sub. PP281, p. 6; CMHA, sub. PP270, p. 5; Cohealth, sub. PP261, p. 2; Parkinson's Australia, sub. PP232, p. 3; YDAS, sub. PP262, p. 3). In its submission, the NDIA (sub. PP327, p. 25) stated that it is moving towards using face-to-face planning as a default approach, in response to feedback from scheme participants.

Consulting with participants about plan content

Consulting with scheme participants and their family, carers and advocates is essential to the success of the planning process. However, the Commission heard that, in many instances, scheme participants were not consulted about the content of their plan.

In particular, scheme participants were not permitted to view plans before they were finalised. Community Mental Health Australia said:

> Clients are generally not permitted to see a plan before it is finalised, which anecdotally providers state is hindering clients understanding of their plan … There are incidents where people don't know what they are going to get until the plan is submitted — and there is currently no opportunity to take time to consider the plan before it is finalised. (sub. 11, pp. 3, 11)

Several study participants said that scheme participants should be able to view and comment on their draft plans before they were finalised (CSSA, sub. PP278, p. 3; Family Advocacy, sub. PP346, p. 7; Inclusion Melbourne, sub. PP207, p. 12, Vision Australia, sub. 252, p. 3). National Disability Services explained:

> During the trial phase of the NDIS, participants were invited to comment on their draft plan before it was finalised. That practice has largely ceased. The consequence is that participants can end up with a plan that doesn't reflect their needs and goals. Some participants receive plans they don't recognise. Consistent with the NDIS's focus on choice and control, participants should always have the opportunity to comment on their plan before it is finalised. (2017a, p. 7)

It may be the case that calls for scheme participants to see draft plans are symptomatic of broader concerns about a lack of consultation during the planning process. Poor consultation and communication appear to have resulted in scheme participants being surprised by, or confused about, the content of their final plan. Sufficiently deep consultation practices need to be built into the NDIA's planning process, so that plans adequately meet participants' support needs.

A formal process for allowing scheme participants to view and comment on draft plans could mitigate some of the issues arising from inadequate consultation, but would not address the problem directly. A more direct approach could be to improve consultation and communication with participants during the planning process. This should be accompanied by a process for making minor amendments or adjustments to draft plans (recommendation 5.1), so that errors can be easily corrected.

There also appears to be limited consultation about the length of plans. At present, plans typically run for 12 months, with only a small number of plans made for more than a year. For many scheme participants, shorter plans represent an opportunity to frequently assess whether their allocated supports are in line with their needs. But longer plans may be appropriate for participants whose needs are relatively stable and predictable. Some study participants expressed a preference for longer plans (Autism Association of Western Australia, sub. PP219, p. 11; Name withheld, sub. PP215, p. 4). Greater consultation and flexibility around the length of plans would promote individualisation and choice and control

in the planning process. Decisions about when a plan should be reviewed should take into account the participant's preferences and circumstances, including the stability and predictability of their needs.

The lack of participant involvement is not confined to first plans. Several study participants said that consultation around subsequent plans was also inadequate. Some reported that first plans were simply being 'rolled over' (CPSU, sub. 76, p. 9; HSU, sub. 132, p. 12). For example, the Summer Foundation recounted a mother's experience with her child's third plan.

> No actual review took place and her daughter received a 'form' letter advising that her plan would continue 'as was' for the next 12 months and if she required any changes to apply for an internal plan review within 3 months of receiving this letter! This letter was not even signed! (sub. 113, p. 21)

Others, however, said that requests to have a plan 'rolled over' were ignored.

> In February I was contacted by an NDIA employee to have my plan review early. I tried to ask for it to be rolled over as I had not been able to fully activate the plan. I explained about the portal being down for months which was experience[d] by a large number of service providers. This person would not consider this and proceeded to state I was to be reviewed by phone. (Tricia Curley, sub. 140, p. 4)

Under the current timetable, the NDIA is required to complete a large number of plans in a relatively short period of time, and this has influenced how planning processes are undertaken. However, it is essential that the NDIA undertakes its planning function adequately and in a way that does not undermine the objectives of the scheme. An increased focus on the quality of the planning process will no doubt make it more difficult for the NDIA to keep to the timetable set out in the Bilateral Agreements. But if the quality of plans is compromised because of a focus on participant numbers, this will undermine the effectiveness of the scheme and have implications for long-term costs.

For this reason, it is important that the NDIA's performance is measured based on whether and how effectively it is realising outcomes under the NDIS, rather than just participant numbers (chapter 11). A greater emphasis on reporting on the quality of planning processes will help shift the focus towards better quality plans and give the NDIA the incentive and latitude to focus on participant experience and outcomes.

Accessibility of the planning process

A lack of clear and transparent information

Study participants expressed frustration about the lack of clarity and transparency around the planning process.[41] Noah's Ark, for example, said:

> … there is no information about the planning process and how it is supported in the public domain. There has been a significant change in how plans have been written. These changes have not been documented or an explanation provided. (sub. 108, p. 9)

Mamre Association also said there is a lack of consistency with clear, concise and factual information.

> It is often left up to the general disability sector to try to navigate their way through 'forensic' investigation as to what the information means. There simply is very little capacity within the sector itself to invest in something so time consuming. (sub. 47, p. 1)

And Family Advocacy (sub. PP346, p. 10) said scheme participants experienced difficulties understanding their plans because they were filled with jargon and not available in plain English. Vision Australia argued for better online information:

> The NDIS planning process, even with the new resources rolled out in the past few months, is opaque. Providers who already engage with the system and have a good understanding still struggle to explain it to participants. The NDIA website is confusing: something as simple as a '*the Six Steps to NDIS Success'* would be hugely beneficial, as the lack of a clear process or flowchart hampers participant understanding. (sub. PP252, p. 1)

Scheme participants and their carers need access to relevant, current and accurate information about the planning process that they can easily understand. But there appears to be limited information available to help scheme participants and their families, carers and advocates navigate the system. This is particularly problematic for scheme participants who do not have the time or capacity to navigate a complex and confusing system.

Scheme participants are also often not aware or informed about their rights and options. For example:

- some participants did not know that they could request a face to face planning meeting instead of phone planning (ADACAS, sub. 87, p. 15; Social Support & Precarious Workforce Research Discussion Group, sub. 71, p. 3)
- others were unaware of their entitlement to have an advocate present at their planning meeting — not having an advocate present can negatively affect outcomes for

[41] Participants who expressed concern about the lack of clarity and transparency around the planning process included: Autism Aspergers Advocacy Australia (sub. 178); DPO Australia (sub. 165); Flourish Australia (sub. 74); Inclusion Melbourne (sub. PP207); Mamre Association (sub. 47); Mental Health Community Coalition of the ACT (sub. 135); Name withheld (sub. PP215); Noah's Ark (sub. 108); SWAN Australia (sub. 86); and Tandem (sub. PP212).

participants with limited ability to self-advocate (ABF, sub. 48, p. 9; New South Wales Government, sub. 60, p. 15; Vision Australia, sub. PP252, p. 3).

A lack of information about review processes was also identified as an issue (Legal Aid NSW, sub. PP245, p. 9). For example, Brain Injury SA said:

> … information provided to participants about review is unclear and inadequate. There is minimal information about the process and no information about how or where participants can get help with a review … Further, Brain Injury SA has received anecdotal evidence from parents and guardians that NDIA has not been informing participants of their right to an internal review or external merits review through the [Administrative Appeals Tribunal]. (sub. 116, pp. 9–10)

The NDIA (sub. PP327, p. 26) acknowledged that 'participants have expressed the desire for greater transparency in the planning process and what is required of them'.

Planners are not easily reached

The Commission heard that planners were not identifiable and accessible to scheme participants (AHPA, sub. 37, p. 14; Family Advocacy, sub. PP346, p. 9; OTA, sub. 15, pp. 4–5). The Disability Services Commissioner said:

> Planners are not clearly identifiable and accountable. A participant told us that the planner got his plan wrong and he couldn't call the planner directly to talk about the issue. He raised further concerns that no one at the NDIA records his calls, so he feels he cannot escalate his complaint, as there is no record of his previous contact. (sub. 35, p. 5)

Brain Injury SA also said:

> The 1800 phone number is the only number provided to participants and service providers. Anyone wanting to speak to a planner, even in response to a message that has been left by the planner, must use this number … there is usually a 45 minute wait for calls to be answered. When the call is answered, there is no certainty that the call will be transferred to the relevant office or planner. (sub. 116, p. 10)

Planning processes are not inclusive for all

It is important that planning processes are accessible, inclusive, and sufficiently flexible to accommodate the needs of different scheme participants. This is especially true for participants with complex needs or from culturally and linguistically diverse backgrounds.

As the New South Wales Government said:

> Many NDIS participants that are participants of other state services (justice, mental health) do not have the capacity or capability to interact with the NDIS without intensive support. They may have no natural supports, like family or friends in their lives; they may have family that do not support their best interests; or they may have limited experience as consumers generally and may not be able to exert their rights as participants in the NDIS. Some people with complex needs

> may not be able to define their needs or understand what reasonable and necessary supports they would need to support them. (sub. 60, p. 17)

Planning processes need to be sensitive to the intersection between disability and other social issues, such as homelessness, family violence, and alcohol and other drug use. Study participants also highlighted the importance of providing gender-responsive services (ACT Government, sub. 156, pp. 28–9; DPO Australia, sub. 165, p. 14; Leadership Plus, sub. 128, p. 2; Richard Kennedy, sub. 2, p 2; VCOSS, sub. 176, p. 10; Women with Disabilities Victoria, sub. 111, p. 2).

Needs arising from disability

Many study participants said that planning processes are not inclusive and overlook the needs of people with disability. Sharing Places said:

> People with intellectual disabilities and very high and complex support needs are not understood by NDIA. People with high and complex needs would greatly benefit from a more in depth assessment and planning process. (sub. 53, p. 2)

Communication accessible processes are also important for people with vision or hearing impairment (ABF, sub. 48, p. 9; Deafness Forum of Australia, sub. 127, pp. 16–7; Speech Pathology Australia, sub. 136, pp. 28–9). But Australian Blindness Forum said:

> … participants in the NDIS cannot access any NDIS information in alternative formats. This means that people who are blind or vision impaired cannot independently register themselves with the NDIS or read their own plans. (sub. 48, p. 9)

Vision Australia (sub. PP210, p. 7) called for plans, information and forms to be made available in a wider range of formats, including braille, to ensure that information is accessible for scheme participants.

Planning can also be challenging for people whose needs can change quickly — such as episodic or progressive disorders. Study participants identified psychosocial disability (box 5.10) and degenerative disorders (box 5.11) as particular problem areas.

Language and cultural barriers

Study participants observed that planning processes do not adequately cater for people of different cultural and linguistic backgrounds (Companion House, sub. 84, p. 2; Jesuit Social Services, sub. 117, p. 3; Neami National, sub. 63, p. 6; Northern Territory Government, sub. 205, p. 7; Social Support & Precarious Workforce Research Discussion Group, sub. 71, p. 6; VCOSS, sub. 176, p. 9; VMIAC, sub. 167, pp. 6–7).

Box 5.10 Mental illness and psychosocial disability

The National Disability Insurance Scheme is designed to cover disabilities that are permanent, including those of a chronic episodic nature, such as mental illness and psychosocial disability.

> 'Permanent' refers to the irreversible nature of the disability, even though it may be of a chronic episodic nature. For example, this would include people with significant and enduring psychiatric disabilities, who periodically rely exclusively on support from the clinical services of the mental health system, but at other times are able to live in the community provided they have appropriate supports. (PC 2011, p. 14)

However, the episodic nature of mental illness can mean that some scheme participants' needs are unpredictable. To some extent, this runs contrary to the planning process, which, in broad terms, requires a forecast of the participant's support needs over the life of the plan.

This problem is exacerbated by 'inflexibility in changing arrangements in response to fluctuations in support need because of escalating illness' (Mind Australia, sub. 144, p. 8). This can create incentives for participants to overstate their support needs, so that they can be sure that they have access to adequate support during times of high need.

Due to the nature of their disability, people with psychosocial disability may at times find it difficult to articulate or disclose their support needs during the planning conversation (Anglicare Tasmania, sub. 145, p. 32; VMIAC, sub. 167, p. 7; VICSERV, sub. 169, p. 4). For this reason, such participants 'may need more than one meeting to develop plans due to [the] fluctuating nature of conditions' (Social Support & Precarious Workforce Research Discussion Group, sub. 71, p. 6).

Box 5.11 Progressive and degenerative disorders

Study participants said that certain progressive or degenerative disorders sat poorly with the 'investment approach' of the scheme. For example, Neurological Alliance Australia said:

> … the progressing and complex needs of people with neurodegenerative diseases have been overlooked due to lack of understanding of these diseases or for the sake of expediency … People with a progressive neurological disease run counter to the 'traditional' trajectory of someone on the NDIS: that is, an ability to enhance independence and re-ablement through a more effective engagement of services. For someone with a neurodegenerative disease, however, care needs inevitably increase over time. (sub. 30, pp. 1–2)

In addition, current planning processes do not account for the changing needs of people with progressive or degenerative disorders. Calvary Health Care Bethlehem said:

> For people with progressive disorders, the person's needs can change more rapidly than expected, so there needs to be sufficient flexibility in the plan being reviewed and amended to accommodate unforeseen needs arising. This needs to happen in a timely manner. (sub. 64, p. 2)

Similarly, MND Australia said:

> Plans are based on the 'now' and do not take account of the rapid and increasing needs caused by the progressive degenerative nature of [motor neurone disease], requiring review planning earlier than is necessary. (sub. 45, p. 9)

MND Australia (sub. 45, p. 7) also reported that between June 2016 and January 2017, all plans for people with Motor Neurone Disease in New South Wales and the ACT required review, primarily due to a poor understanding by planners of degenerative diseases.

For many, language barriers can prevent meaningful engagement with planning processes. Neami National (sub. 63, p. 6) said that 'consumers without English as their first language describe difficulties in participating in planning and in getting plans that they can fully implement on account of their language needs'. This is an issue which disproportionately affects Aboriginal and Torres Strait Islander communities:

> English is a second language for many Indigenous people in remote communities. The majority of participants in Barkly identify as being Aboriginal or Torres Strait Islander and for 67% English is not their first language. Many have limited capacity to understand or read it. This has a significant impact on their ability to have genuine input into the formulation of their plans and also impacts on decision making and choice. (Brain Injury SA, sub. 116, p. 3)

And those of refugee background:

> People with disability from a refugee background are often not well equipped to navigate the NDIS in planning meetings and to negotiate a package of supports from providers. Many have little or no understanding of the context of the broader social support system in Australia. (Companion House, sub. 84, p. 2)

Cultural barriers can also make accessing and interacting with the planning process difficult. In particular, there may be confusion about the purpose of planning conversations and there is a risk that scheme participants do not communicate their needs due to different cultural or social norms. (Social Support & Precarious Workforce Research Discussion Group, sub. 71, p. 6). There may also be greater mistrust of government services or an aversion to sharing personal information (VCOSS, sub. 176, p. 9).

Access can be especially difficult for some Aboriginal and Torres Strait Islander communities. Brain Injury SA said:

> Many Aboriginal people can be transient in nature and to uphold their cultural requirements. Therefore, participants are not in regular receipt of mail or telephone communication. In the Barkly region there is no mail delivery to homes and most people do not regularly check their PO Box. If they do not receive a hard copy of their plan they are advised to go onto the portal and get it online. However, many do not have access to computers, nor the awareness of how to use them. Consequently, many participants do not know they have a plan or, if they do, what is in it. (sub. 116, p. 3)

The Australian Medical Association emphasised the need to have culturally appropriate processes and cited evidence of poor planning practices.

> … we were told that in one Aboriginal community, NDIA assessors did not leave their vehicle, instead they yelled questions of Aboriginal people regarding their disabilities … there was no verification of the person's identity other than to ask their name and conduct a conversation from a driveway. Another reported case was that Aboriginal people with disability were asked to leave their homes and find their way to a waiting vehicle for an assessment; this included an Aboriginal person in a wheelchair. (sub. 120, p. 5)

The role of pre-planning support

Pre-planning support can help participants navigate a confusing and complex system. Pre-planning support is directed at helping the participant prepare for the planning conversation, including:

- thinking about their goals and aspirations
- preparing documentation to support the assessment process
- thinking about what supports are available and can help them.

Demand for pre-planning support services is influenced by how accessible and complex planning processes are, as well as the scheme participant's capacity (including their ability, willingness, skills and resources) to navigate those processes (chapter 10). Pre-planning support is provided by a range of different organisations, including advocacy groups and service providers.

Several study participants noted that pre-planning assistance is costly to provide (House with No Steps, sub. 104, p. 5; Mamre Association, sub. 47, p. 2; VICSERV, sub. 169, p. 4). Some argued that the NDIA should do more in the area of pre-planning support (ADACAS, sub. 87, p. 16; CMHA, sub. 11, p. 10; Cohealth, sub. 50, p. 10). Others called for governments to provide additional funds to facilitate pre-planning support (Amaze, sub. 160, p. 5, sub. PP281, p. 7; Cohealth, sub. 50, p. 10; NSW Disability Network Forum, sub. 18, p. 3; Social Support & Precarious Workforce Research Discussion Group, sub. 71, p. 9).

Pre-planning services are one of the core functions of LACs. During transition, LACs were meant to be 'on the ground' in each area six months before the NDIS was rolled out in that area, in part to provide pre-planning support. However, the speed of the rollout has meant that this was not possible and LACs have not undertaken the pre-planning functions as envisaged (NDIA, sub. 161, p. 56). The NDIA needs to have LACs in place so they can provide pre-planning support.

There is also scope for the NDIA to improve transparency and clarity around planning processes. This includes providing clear and up-to-date information about what to expect during the planning conversation, when it will occur, and how the information gathered during that conversation will be used. The planning process could also be made more accessible, especially for people with complex needs and those with different cultural and linguistic backgrounds.

These changes could reduce the need for extensive pre-planning support, and relieve some of the pressure on advocacy groups and service providers to provide such services.

The NDIA is currently undertaking a review of the participant pathway to identify what changes or improvements should be made to planning processes (while achieving the number of completed plans as specified in Bilateral Agreements) to achieve plans that:

- maximise choice and control for scheme participants and contribute to improved participant outcomes
- are of a high quality in terms of a positive participant experience, compliance with all statutory requirements and consistency
- are financially sustainable so that the aggregate value of all plans remains within the funding envelope (sub. 161, p. 4; sub. PP327, p. 22).

However, the NDIA is operating under demanding time and resource constraints, and there are trade-offs between the quality of planning processes and how quickly the scheme can reach new participants. As noted earlier, better planning processes could involve compromises in terms of participant throughput.

RECOMMENDATION 5.2

The National Disability Insurance Agency should:

- review its protocols relating to how phone planning is used
- provide clear, comprehensive and up-to-date information about how the planning process operates, what to expect during the planning process, and participants' rights and options
- ensure that Local Area Coordinators are on the ground six months before the scheme is rolled out in an area and are engaging in pre-planning with participants.

Planners

Planners are an essential part of the planning process and exert considerable influence on scheme participants' experiences within the NDIS. Sufficiently skilled and impartial planners can improve the quality of the planning process and outcomes for scheme participants. As ACT Disability, Aged and Carer Advocacy Service said:

> It is crucial that the NDIA continue to recruit planners with the right combination of skills, experience and passion, that they offer good training and that workload pressures for NDIA staff are managed. Planners need the skills to be able to tailor the planning approach, and their communication style to participants with different needs … (sub. 87, p. 13)

Conversely, planners with less experience, skill or training can have a detrimental effect on the quality of plans and participant outcomes. This is because they may have less knowledge about what supports are appropriate, meaning that plans may include inappropriate supports or fail to include appropriate ones (Brain Injury SA, sub. 116, p. 5).

Impartial planners are also important for scheme participants' experience of the planning process and the quality of plans. As one study participant said:

> The planners can have a great impact both positive and negative on the resulting plans. The planners biases also have an impact on both the discussion and resulting plan of a participant. For two years, the planner I had, put me in a box and thought she knew what and how I wanted supports. She would not listen until I had a panic attack in the meeting. It was only then she started listening. (Hanna Potapczyk, sub. 26, p. 1)

Skills, training and knowledge of specific conditions

A number of study participants were critical of the skills, experience and training of planners as a whole (Carers Australia Victoria, sub. 131, p. 12; DAA, sub. 119, p. 3; Legal Aid NSW, sub. PP245, p. 9; Matt Burrows, sub. 7, p. 3; Mental Health and NDIS Facebook Support Group, sub. 8, p. 3). The Public Service Research Group reported feedback that:

> There's not adequate induction support and supervision training provided to the people who are doing the planning … If we can't get the planning right we're not going to get the scheme right. (sub. 56, p. 6)

Speech Pathology Australia (sub. 136, p. 28) also noted that information about the level of qualifications and training required of planners is not publicly available. And many participants expressed concern about planners' limited disability knowledge.[42] For example, the Australia Physiotherapy Association said:

> Our members report that service planning is being undertaken by staff who have little competence in the specific field of disability relevant to the participant's needs and thus that service plans are at odds with the needs which the NDIS is designed to meet. (sub. 93, p. 13)

In particular, the Commission heard concerns that planners had limited knowledge about specific conditions (box 5.12), such as motor neurone disease, multiple sclerosis and dementia, Prader-Willi Syndrome, autism and Parkinson's Disease.

The Commonwealth Ombudsman reported that:

> Some stakeholders have told us about planners who asked parents when their child was likely to 'recover' from a life-long disability, and others who told people with psychosocial disabilities they should 'try to be more positive'. (sub. 137, p. 8)

[42] Study participants who commented on planners' limited disability knowledge included: AASS (sub. PP330); ABF (sub. 48); ACIA (sub. 141); AHPA (sub. 37); Alzheimer's Australia (sub. 10, sub. PP313); Amaze (sub. PP281); Anglicare Tasmania (sub. 145); APA (sub. 93); APodC (sub. 52); Belinda Jane (sub. 80); Cheryl McDonnell (sub. 79); CMHA (sub. 11); Cohealth (sub. 50); Commonwealth Ombudsman (sub. 137); DPO Australia (sub. 165); Macarthur Disability Services (sub. 57); Macular Disease Foundation Australia (sub. 75); Mental Health Australia (sub. 155); Mental Health Community Coalition of the ACT (sub. 135); Mind Australia (sub. 144); MJD Foundation (sub. PP233); MND Australia (sub. 45); Neami National (sub. 63); OPA (sub. 46); OTA (sub. 15); Parkinson's Australia (sub. PP232); PWSAA (sub. 112); VICSERV (sub. PP284); Vision Australia (sub. PP210); and VMIAC (sub. 167).

Box 5.12 Concerns about planners' limited knowledge of specific disabilities

MND Australia:

> LAC's do not have the expertise to support people with MND [motor neurone disease] … They have no understanding of MND and the disability it creates. They attempt to plan via a telephone conversation, when speech and communication can be one of the early losses created by MND … Several people in Victoria had plans developed by the LAC planner that did not include assistive devices — even though the participant was sitting in a wheelchair at the time! … Face to Face meeting with NDIS planner with experience in complex neurological conditions is imperative. (sub. 45, pp. 8–9)

Alzheimer's Australia:

> NDIS planners, while eager to assist, have very limited knowledge of younger onset of dementia and Alzheimer's disease, and minimal information on what services a client with progressive functional decline may need. They also lack the capacity to estimate the number of hours of support and appropriate resourcing that would be required. (sub. 10, p. 16)

Amaze:

> Concern has been expressed to Amaze about planners and LACs lack of understanding of how a participant's autism may impact on their engagement in the planning process, for example by limiting their capacity to comprehend long verbal advice in planning meetings, to understand the specific intent/meaning of questions asked and provide appropriate and complete answers. (sub. PP281, p. 11)

Prader-Willi Syndrome Association of Australia:

> Anyone acting as a Planner for a person with PWS should be properly informed about the complexity of the condition, *plus the types of risks likely to arise within the planning process*. (PWSAA, sub. 112, p. 4)

Autism Advisory and Support Service:

> Most planners come from an administrative background and have no educational experience or lived experience of what disabilities are (we are often asked what is Autism by planners) nor understand relevant questions to ask in order to extract meaningful data from participants or their families. (sub. PP330, p. 4)

Mental illness and psychosocial disability were also areas of concern among study participants (CMHA, sub. 11, pp. 9–10; Cohealth, sub. 50, p. 10; Macarthur Disability Services, sub. 57, p. 4; Mental Health Carers Australia, sub. 181, p. 10; Neami National, sub. 63, p. 6) and the Joint Standing Committee on the NDIS found that planners had insufficient knowledge about psychosocial disability (JSCNDIS 2017c, p. 26).

Planners, according to a number of study participants, also have limited knowledge of appropriate supports for certain conditions, such as the role of occupational therapists (OTA, sub. 15, p. 4), prosthetics (AOPA, sub. PP294, p. 2), specialist disability accommodation (Quality Living Options Bendigo, sub. PP220, p. 1) and podiatry (APodC, sub. 52, p. 2). VCOSS gave the example of:

> … a deaf participant with cochlear implants [being] allocated two hearing aids in their package, despite hearing aids being ineffective for people with cochlear implants. (sub. 176, p. 12)

The Commission also heard that planners are ill-equipped to connect scheme participants with employment supports (House with No Steps, sub. 104, pp. 5–6; Round Squared, sub. 170, p. 3).

Study participants overwhelmingly agreed that planners performed better when they understood what needs arise from a person's disability. As Community Mental Health Australia said:

> If a planner understands the depths of a person's disability and what is needed to support the individual, the package developed will suit them over a longer term. This reduces the need for a plan to be amended in the future, thereby reducing administrative burden on the NDIA and building confidence in the process for the consumer. (sub. 11, p. 4)

Australian Lawyers Alliance (sub. PP257, p. 8) suggested that planners being familiar with disabilities can speed up the planning process while also better meeting participants' needs.

Improving planners' performance

Planners should, at a minimum, have a general understanding about different types of disability. Several study participants called for planners to receive more education on specific conditions and supports (Alzheimer's Australia, sub. 10, p. 13; Cheryl McDonnell, sub. 79, p. 2; CMHA, sub. 11, p. 4; Cohealth, sub. 50, p. 5; CPSU, sub. PP310, p. 5; Neami National, sub. 63, p. 6; NSW Government, sub. PP230, p. 4; PDA, sub. PP306, p. 3; PWSAA, sub. 112, p. 4; Vision Australia, sub. PP210, pp. 3, 8).

Specialised planners

Study participants also saw a role for specialised planners,[43] such as for people with psychosocial disability. For example, Mental Health Australia said:

> Mental Health Australia supports … a specialised planning team for psychosocial disability. This should be well supported by improved training for planners and oversight of the planning process to ensure consistency and improved outcomes. (sub. PP321, p. 22)

Similarly, Parkinson's Australia argued that scheme participants with progressive neurological conditions would also benefit from specialised planning teams.

> To offer true choice and control [to scheme participants with Parkinson's], NDIS planners must have knowledge of the condition, understand its disabling impact on participants so the unique needs of people living with Parkinson's can be addressed in individual plans. It is strongly recommended that participants with progressive neurological condition[s], such as Parkinson's and atypical Parkinson's conditions, be managed by specialised planning teams that have a good

[43] Study participants who supported planner specialisation included: AASS (sub. PP330); ABF (sub. PP263); Allianz Australia Insurance (sub. PP265); Amaze (sub. PP281); Anglicare Australia (sub. PP339); ALA (sub. PP257); CSSA (sub. PP278); Cohealth (sub. PP261); DAA (sub. PP292); Legal Aid NSW (sub. PP245); Mental Health Australia (sub. PP321); MND Australia (sub. PP255); Noah's Ark (sub. PP328); Neami National (sub. PP347); OPA (sub. PP241); Parkinson's Australia (sub. PP232); Speech Pathology Australia (sub. PP303); Summer Foundation (sub. PP293); Tandem (sub. PP212); Tasmanian Government (sub. PP247); VALID (sub. PP332); VCOSS (sub. PP264); Women with Disabilities Victoria (sub. PP282); and YPINH (sub. PP326).

knowledge and understanding of these conditions and the support and care that is required. (sub. PP232, p. 9)

MND Australia (sub. PP255, p. 7) observed that planners specialising in progressive neurological conditions were used at Victorian trial sites for some time, and believed that this approach worked well.

It is the Commission's view that there is value in having specialised planning teams for some types of disability. This approach is in line with industry practice for insurance companies. For example, Allianz Australia Insurance (sub. 42, p. 6) submitted that, in the context of workers' compensation claims, it employs specific psychological claims teams, given the unique nature of mental health related claims.

The NDIA said that it is currently undertaking work to:

> … enhance workforce capability over the short, medium and longer term. This will include ensuring an enhanced understanding of a wider array of disabilities, as well as employing specialists to work with participants in areas such as intellectual and psychosocial disabilities and degenerative conditions. (sub. PP327, p. 27)

Specialised planning teams will require significant upfront investment, in terms of both the time and resources needed to upskill the planning workforce. However, specialised planning teams have the potential to improve the efficiency of the planning process and lower costs in the medium and long term (in terms of more appropriate supports for participants and fewer unexpected plan reviews from poor planning), especially if appropriate triage processes are put in place. Allianz Australia Insurance said:

> The personal injury sector manages [specialised planning teams] through expertise in triage processes which allow reasonable consideration for the allocation of resources and treatment for an injured claimant. For example, within personal injury claims, insurers may have a team to fast track the management of low touch, minor injuries or a specialist psychological team to streamline the management of resources in an efficient and effective manner … With proper application of triage, the NDIA will benefit from effective resource allocation … (sub. PP265, p. 5)

Matching scheme participants with planners who are suitably trained and knowledgeable about their support needs should also result in better outcomes for participants.

Leveraging industry knowledge

An alternative (or complementary) approach is to leverage expertise from the disability support sector, including specialist disability organisations and service providers. National Disability and Carer Alliance said:

> Consumer-led organisations that specialise in particular disabilities have invaluable experience and expertise that currently remains under-utilised by the NDIA. The NDIA should draw on this expertise in both the development and implementation of training for planners. But beyond planning, this experience could be invaluable in resolving implementation issues more generally

— such as the development of reference packages, in the development [of] further guidance on reasonable and necessary in the operational guidelines, or in effective communication to particular groups of participants. (sub. PP344, p. 7)

And National Disability Services said:

> The quality of planning would improve if disability service organisations were involved. Providers of specialist supports have deep knowledge of disability — and they know their clients. Using this knowledge to inform planning would make sense. This is particularly true for people with complex needs … Planning partnerships between the NDIA and specialist providers should be extended. (2017a, pp. 6–7)

There are a number of ways that sector involvement could be incorporated into planning processes, including:

- having industry and peak bodies provide input or general advice during the planning process (AOPA, sub. PP294, p. 1; Tandem, sub. PP212, p. 9)
- engaging specialist organisations to conduct seminars for planners and NDIA staff about different disability types and supports (APC Prosthetics, sub. PP244, p. 3)
- contracting specialist disability organisations to conduct specialist disability assessments (Macular Disease Foundation Australia, sub. PP243, pp. 2–3)
- greater sector involvement in the development of planning templates or reference packages and the review of assessment tools (Alzheimer's Australia, sub. PP313, p. 5; AOPA, sub. PP294, p. 2).

Leveraging industry knowledge will be especially useful where it is not feasible or cost-effective for the NDIA to develop in-house specialist knowledge (APC Prosthetics, sub. PP244, p. 3; Macular Disease Foundation Australia, sub. 75, p. 5). Such an approach would also mean that the NDIA would not need to compete with others in an already thin market to recruit planners with specialist qualifications or experience.

However, some study participants said that the NDIA was reluctant to involve service providers in the planning process (Anglicare Australia, sub. 157, p. 8; VICSERV, sub. PP284, p. 4). One reason for this reluctance was potential conflicts of interest. For example, APC Prosthetics said that they:

> … offered their services to conduct, free of charge, a half-day seminar for NDIA staff during the Hunter Trial. The offer was not accepted on the grounds of a possible conflict of interest. (sub. PP244, p. 3)

Several study participants also emphasised the importance of ensuring that sound processes for identifying and managing conflicts of interest are in place (Vision Australia, sub. PP252, p. 8; Women with Disabilities Victoria, sub. PP282, p. 6).

It is the Commission's view that the NDIA could make greater use of industry knowledge and expertise. The NDIA should adopt risk-based strategies for leveraging industry knowledge and expertise. This means that measures taken to manage conflicts of interest

should be proportionate to the probability and impact of the risks associated with those conflicts materialising.

A risk-based approach requires a flexible and innovative approach to sector involvement. This might mean that, in some instances, sector involvement is limited — but it also means that bypassing sector involvement is not an appropriate default approach. The overarching consideration for whether and how the sector should be involved should be how it affects outcomes for scheme participants.

Leveraging industry knowledge is relatively common in comparable schemes, such as the Lifetime Care and Support Scheme in New South Wales and the implementation of the NDIS in Western Australia. In many instances, the risks arising from conflicts of interest could be managed by ensuring that the process for involving industry players is transparent and that final decision-making powers are retained by the NDIA.

Performance monitoring

Over the longer term, satisfaction with planners could also be improved through monitoring and assessing their performance (OTA, sub. 15, p. 5; PDA, sub. 38, p. 7). According to the NDIA (sub. 161, pp. 89–90), planner performance is currently monitored through:

- participant satisfaction measures
- complaints, accounting for the volume and substance of complaints
- the National Quality Framework, where monthly audits are conducted on planner records and feedback provided through coaching and supervision.

Regular and public reporting around planner performance could help increase the accountability of planners, and improve community confidence in planners and the planning process.

RECOMMENDATION 5.3

The National Disability Insurance Agency should ensure that planners have a general understanding about different types of disability. For types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or more use of industry knowledge and expertise.

6 Boundaries and interfaces with the NDIS

Key points

- Effective interfaces between the National Disability Insurance Scheme (NDIS), other disability services and mainstream services are essential for good outcomes for scheme participants and the sustainability of the scheme. To provide the right incentives, services available to people who just qualify for the NDIS, and those who just miss out, should be as seamless as possible. This requires coordination of services within and outside of the NDIS.
- The Information Linkages and Capacity Building (ILC) program — designed to connect people with disability to appropriate services — is a key component of the NDIS. It is a false economy to have too few resources for ILC activities, particularly during transition when it is critical that people with disability (including those not eligible for the NDIS) are connected to services.
- For people with disability previously receiving support who are not eligible for the NDIS, the Australian, State and Territory Governments have agreed to provide continuity of support. In practice, there is confusion and uncertainty about what services will continue to be provided and/or funded outside the NDIS. Governments need to be clearer about their approach on continuity of care, and what disability services they will provide for non-NDIS participants.
- The NDIS is meant to work alongside mainstream services, not replace them.
  - The Bilateral Agreements delineate responsibilities for services to be provided by the NDIS and mainstream services.
  - While it is still too early to identify service gaps, there are emerging issues in a number of areas, including justice, emergency, transport and mental health services.
  - Each COAG Council with responsibility for a service area that interfaces with the NDIS should have a standing item on their agenda to address how these services interface with NDIS services.
  - ILC and Local Area Coordinators can play a role in ensuring mainstream services are better informed about their roles and responsibilities.
- There are aspects of the design of the NDIS, and how it interfaces with the aged care system, that create incentives for people to stay in the NDIS after the age of 65 years, and encourage people nearing the age of 65 years to apply for the NDIS. This raises some issues that will need to be addressed, but given the complexity involved, this should be done with the benefit of data from experience at full scheme. It should be reviewed as part of the review of scheme costs in 2023.
- The National Injury Insurance Scheme (NIIS) was envisaged to cover the care needs of individuals who newly acquire a disability through a catastrophic injury or accident. Two of the four streams proposed have been implemented. The contributions by the States and Territories should reflect the cost to the NDIS of participants who were intended to be covered by the NIIS — these will grow over time from a small base.

People with disability, and their families and carers rely on a wide range of services — including mainstream services, specialist disability services and community supports — for their care needs and to maintain the quality of their lives. For the National Disability Insurance Scheme (NDIS) to work efficiently and effectively, the interface between the scheme and other services need to be as seamless as possible. By design, the NDIS is intended to complement these other supports, not replace them. A requirement of any supports provided through the NDIS is that they are most appropriately funded through the scheme and not by other services.

While NDIS funding recognises that previously funding for people with disability was inadequate, the NDIS is not expected to fill *all* of the large service gaps that existed before the scheme was established. Providing services to people with disability remains a shared responsibility between all levels of government.

The interface between all services for people with disability will take time to clarify, but until these interfaces are settled, it is important that governments do not prematurely withdraw from services, as any gaps that emerge will place added burdens on people with disability and their families.

As interface issues become clearer, it is essential that incentives do not exist for individuals to prefer one system over another. It is important that people with disability do not see the NDIS as an oasis of support, surrounded by a desert, where little or nothing is available. Should such a dynamic develop, the financial pressures on the NDIS could be unsustainable, particularly if people feel the need to test their ability to qualify for the scheme, and/or remain in the scheme for as long as possible.

There is still a lot of detail to be worked through. That said, establishing clear and robust boundaries is essential for the financial sustainability of the NDIS and other services. When people are accessing the services they need, the system as a whole should be providing supports at the most efficient and cost effective level.

This chapter first looks at bridging and capacity building services provided under the NDIS (section 6.1), then at how the NDIS interfaces with other disability services (section 6.2). The interface between the NDIS and mainstream services is examined in section 6.3. How the NDIS interfaces with the aged care sector (section 6.4) and the National Injury Insurance Scheme (section 6.5) are also examined.

6.1 Linking people to the right services

About the Information, Linkages and Capacity Building program

The NDIS is just one part of a wider disability system. While the NDIS will benefit all Australians, only a proportion of people with disability will become scheme participants. Of the estimated 4.3 million Australians with disability, about 475 000 (those people with a

'permanent and significant' disability) will receive individualised supports under the NDIS (chapter 1, figure 1.1). As the National Disability Insurance Agency (NDIA) said:

> The NDIS is intended to benefit a wide range of Australians, only a proportion of whom will become participants and receive an individualised plan. … short-term or light touch assistance from the NDIS, in collaboration with a capable and inclusive community and mainstream response, can help them better access mainstream supports, build connections into community supports and strengthen natural supports in order to achieve their outcomes. (sub. 161, p. 53)

The NDIS is just one part of a broader suite of services relevant to people with disability (others include health, housing, education, transport, employment and justice).

Information and referral services are therefore vital to people with disability, their families and carers. For this reason, in 2011, the Commission recommended a bridging and capacity building service, known as Tier 2 supports, to assist anyone with (or affected by) disability, to connect to relevant disability, community and mainstream services (PC 2011, pp. 163-165, 198).

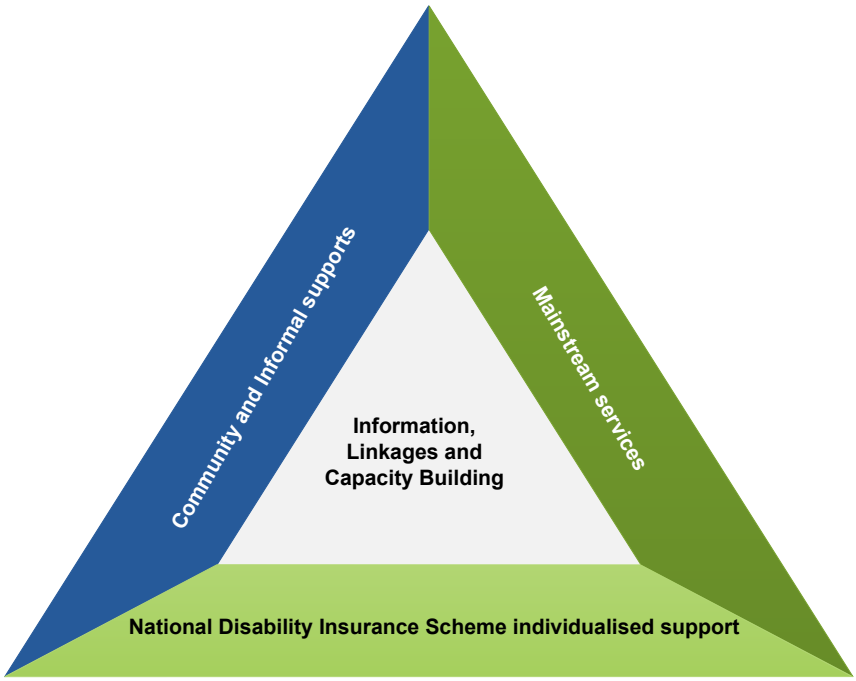
The main goal of Tier 2 supports was to strengthen the links between the community and people with disability. Some examples of Tier 2 supports envisaged by the Commission in 2011 included Local Area Coordinators (LAC) helping to link people with disabilities to local community groups (such as a sailing club), and web services to provide information and educate people about specific disabilities and where to seek help (PC 2011, pp. 13, 163-164).

In July 2017, the NDIA began rolling out the Information, Linkages and Capacity Building (ILC) program (effectively Tier 2 supports). ILC will provide information, linkages and referrals to people with disability, their families and carers, and help them connect with appropriate community and mainstream supports (NDIA 2017h). The focus of ILC is individual development and community inclusion. The NDIA said it is to:

> … build innovative ways to increase the independence, social and community participation of people with a disability. (2016d, p. 5)

ILC will also facilitate capacity building support and greater inclusivity by promoting collaboration and partnership with local communities and mainstream services (figure 6.1).

Figure 6.1 **Bridging services — Information, Linkages and Capacity Building**



Source: NDIA (2015a, p. 4).

ILC is designed to work with individualised supports. As the NDIS Community Inclusion and Capacity Development Program Guidelines put it:

> The NDIS has two parts:
>
> - Individualised NDIS plans for people with permanent disability has a significant impact on their ability to take part in everyday activities; and
> - Information, Linkages and Capacity Building (ILC).
>
> Both parts work together to support people with disability. It is important not to see ILC as something separate to the … success and sustainability of the NDIS. Ensuring people are connected into their communities, using the same services and participating in the same activities as everyone else will mean that, over time, people will rely less on specialist disability support. ILC also has an important role to play in supporting people with disability who do not have an NDIS plan. By providing appropriate support in the community, it will help make sure people only move into the scheme when necessary. (2016d, p. 4)

ILC is an important tenet of the NDIS insurance model, and is expected to reduce costs over time by:

- *reducing the demand for individualised supports* — ILC is a lever to divert people from needing to access individualised packages and instead connect them to the appropriate supports for their needs

- *reducing the need for supports through individualised supports* — ILC can maximise the ability of participants to access mainstream, community and informal supports, which in turn can reduce the need for funded supports (for example, targeted supports to assist a person to navigate the public transport system can reduce the need for funded taxi travel)
- *making supports more effective at helping people achieve their goals* — many supports are more effective in helping a participant achieve their goals when complemented by natural (informal) and community support (for example, a fitness goal is more likely to be achieved if funded support to use gym equipment is complemented by an inclusive gym community or a friend for companionship and motivation) (NDIA, sub. 161, p. 54).

In August 2015, COAG endorsed the ILC Policy Framework (NDIA 2015a). The framework describes five streams to achieve the objective of ILC.

- Information, Linkages and Referrals (activity 1) — connecting people with disability, their families and carers with appropriate disability, community and mainstream supports.
- Capacity building for mainstream services (activity 2) — ensuring people with disability connect with and access mainstream supports.
- Community awareness and capacity building (activity 3) — supporting organisations (such as not-for-profit organisations, local councils and businesses) and people within communities to be inclusive of people with disability, and understand the needs of families and carers.
- Individual capacity building (activity 4) — fostering the principle of choice and control, improving outcomes for people with disability, their families and carers.
- LAC (activity 5) — developing relationships between the NDIS, people with disability, their families and carers, and the local community (NDIA 2015a, pp. 9–13).

In November 2016, the NDIA released its ILC Commissioning Framework to provide guidance around the type of activities ILC will fund and how these will be funded (NDIA 2016f). The framework reflects the ILC Policy activities and identifies five focus areas which are deemed 'priority areas' for funding (table 6.1).

Table 6.1 **ILC Focus Areas**

Focus Area	*Definition*	*Example*
Specialist or expert delivery	Focus on activities that provide specific skills and knowledge in relation to disability — for example, diagnostic specific expertise or expertise in particular models of support or capacity building.	A comprehensive website that provides information about particular disabilities or conditions.
Cohort-focused delivery	Focus on activities for specific groups of people that require detailed cultural or other knowledge to be effective — for example, multilingual activities to assist Aboriginal and Torres Strait Islander peoples or people from culturally or linguistically diverse backgrounds.	A yarning circle (peer group) for Aboriginal women run by local Aboriginal organisations.
Multi-regional activities	Focus on activities that would be inefficient if delivered separately in different local areas — for example, advice or information that is not based on location and could be relevant anywhere.	A community awareness campaign to increase employment opportunities for people with disability.
Remote/rural delivery	Focus on ensuring activities are designed to address local needs, circumstances and conditions in rural and remote locations.	A project that connects young people with disability in a rural area with each other via multimedia or social media.
Delivery by people with disability, for people with disability	Focus on supporting organisations that are run and controlled by people with disability. These are sometimes called user-led organisations.	A telephone information service for people with disability, staffed by people with disability.

Source: NDIA (2016f, p. 18).

The ILC Commissioning Framework developed five strands of outcomes that programs funded through ILC will be measured against. They include the extent to which people with disability:

- participate in, and benefit from, the same community activities as everyone else
- use and benefit from the same mainstream services as everyone else
- have the skills and confidence to participate and contribute to the economy
- have the appropriate information so they can make informed decisions and choices
- contribute to, lead, shape and influence their community (NDIA 2016f, p. 10).

ILC funding

Funding for ILC is made through the Community Inclusion and Capacity Development (CICD) Program. The program consists of grants to support two types of activities:

- ILC Jurisdictional Based Grants — targeted at State and Territory level activities.

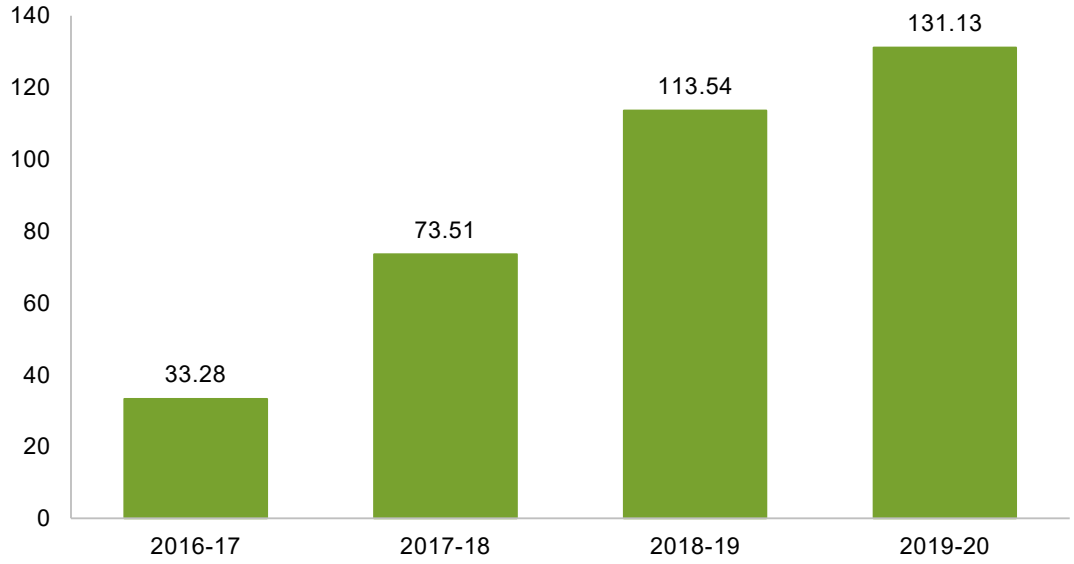
- ILC National Readiness Grants — targeted at activities that can be implemented in multiple jurisdictions or nationally. (NDIA 2016d, pp. 5–6)

The NDIA is taking a staged approach to providing grants in each jurisdiction (full funding across all jurisdictions will apply from 1 July 2019). As part of transitioning to ILC, the NDIA has worked with the Australian, State and Territory Governments to understand what activities currently untaken by the jurisdictions align with the ILC Policy.

Total funding for the CICD Program (which excludes the ILC stream provided by LACs) is $351 million over four years. The funding gradually increases over the transition period from $33 million in 2016-17 to $131 million in 2019-20 (figure 6.2).

Figure 6.2 **ILC Funding[a]**

$ million



[a] These numbers include funding for ILC activities in Western Australia (excluding Western Australia, the budget is about $119 million for 2019-20), but do not include LAC funding for ILC activities in any jurisdictions.

Sources: Australian Treasury (2017d, p. 140); NDIA (2016d, p. 7).

LACs (box 6.1 and chapter 5) are funded separately from the first four ILC activities (through the NDIS Partners in Community Program and with NDIA resources). It is expected about $100 million (or 20 per cent) of LAC funding each year will be for ILC activities.

Box 6.1 Local Area Coordinators

Local Area Coordinators (LACs) play a central role in the delivery of ILC by ensuring people with disability participate in and contribute to social and economic life, and that people with disability receive appropriate services. LACs connect across each of the first four streams of ILC.

LACs also provide support for people with disability to understand their plans and how changes in funding and or the scheme itself are likely to affect them. LACs can help people put their plan into action and help them build capacity to self-manage their plan.

LACs have three main roles:

- to work directly with people who have a NDIS plan by connecting them to mainstream services and community activities, or by helping them put their plans into action (chapter 5)
- provide some short-term assistance to non-NDIS participants and connect them into mainstream services and community activities
- work with the local community to ensure it is more accessible and inclusive for people with disability.

Agreements with LAC partners include that 20 per cent of their effort (and funding) is allocated to the delivery of ILC activities. This is to ensure anyone who approaches a LAC, whether they are eligible for the NDIS or not, are directed to appropriate services (a part of the 'no wrong door' approach, and individual development and community inclusion objectives).

Sources: NDIA (2015a, pp. 13–15, 2017n); NDIA (sub. 161, p. 56).

At the beginning of 1 July 2017, the activities to be funded by ILC Australia-wide and in the ACT were announced (NDIA 2017h, 2017k). The funding allocated to these activities was $14 million and $3 million respectively (NDIA 2017y, p. 45). Some of the successful grants in the ACT included:

- changing the ACT Health Care System to be more inclusive of people with impaired decision making ability
- educating Aboriginal and Torres Strait Islander people about what is meant by the term 'disability'
- establishing a peer support network for people with mild and borderline cognitive disability (NDIA 2017l).

Building the evidence base

As part of the ILC program, the organisations that receive grants — and the NDIA — are required to collect detailed data on ILC activities. This will be important for measuring how effective ILC activities are in achieving outcomes for people with disability. The data will be used by the NDIA to identify and address performance issues, and inform future decisions on the allocation of ILC funds.

Data collected will include: the outcomes and success of activities in the short, medium and long term; the quality and effectiveness of the activities; and performance over time. Data

will be both qualitative and quantitative (NDIA 2016f, p. 27). The data collected will also form part of the ongoing assessment of the broader delivery of NDIS and other disability services (chapter 13).

Is the funding of ILC adequate?

It is difficult to assess the adequacy of current ILC funding …

The adequacy of funding for ILC services was questioned by many study participants given the scope outlined in the ILC Commissioning Framework. For example:

> The PC should consider whether the one per cent cap (of scheme costs) on ILC expenditure should be adjusted to more flexibly accommodate investment in these areas that would generate better participant outcomes. (Victorian Government, sub. 174, p. 11)
>
> It is a widely reported view from the disability sector that there is a significant under-funding of the ILC in order to meet the needs of people with disability. (Speech Pathology Australia, sub. 136, p. 24)
>
> It appears that ILC is significantly underfunded and therefore will not deliver on rising community expectations. (Goldfields Individual & Family Support Association, sub. 13, p. 4)
>
> While some supports may be available through the Information, Linkage and Capacity Building (ILC) framework, it currently is not sufficiently resourced to meet the gaps. (Cohealth, sub. 50, p. 8)
>
> The total funding package for ILC at full roll out … when split across all types of disability is not adequate. (Mental Illness Fellowship of Australia sub. 122, p. 15)
>
> The implementation of the [ILC] framework … is dependent on adequate resourcing. Under full roll out, only $132 million is being allocated to the ILC. This is equivalent to approximately $30 to provide services to each person with a disability as well as to support mainstream services in capacity building. (Down Syndrome Australia, sub. 121, p. 12)
>
> Currently, only $132 million … has been allocated to the ILC. This is not sufficient and means that one of the key foundations on which the NDIS is being built is weak. (Bruce Bonyhady, sub. 100, p. 5)

Others said that the scope of ILC is too narrow to accommodate ILC's intended purpose (box 6.2), particularly in the context of what the Commission proposed would be covered under Tier 2 supports.

Box 6.2 Many participants said the scope of ILC is too narrow

Physical Disability Australia (PDA):

> … it is PDA's understanding that the original tier 2 of the NDIS (that the ILC program replaces) was supposed to boost all non-participants' capacity to access to mainstream services. For example, we envisioned this might involve an 'Access Fund' to support the building of ramps and accessible toilets in the community. As such, PDA finds the current scope of the ILC (and its proposed budget) to be somewhat disappointing. (sub. 38, p. 6)

Australian Blindness Forum:

> … the range and type of services initially promised to be funded under the ILC program has changed substantially. The original proposal was that ILC would reflect the 'Tier 2' programs including block funding and early intervention programs. The goal of this was to continue to provide disability services to those who were not eligible for the NDIS. Now, the way the ILC program has been developed, it is only tools and awareness programs, delivered by mainstream services for a limited time or on an ad hoc basis. (sub. 48, p. 7)

Belconnen Community Service Board:

> ILC does not appear to cover the apparent lack of low intensity early intervention services needed for people who are not eligible for an NDIS package. The limited amount of funding for ILC and the competitive nature of these resources means people living with low to moderate mental health/psychosocial disabilities will struggle to access the supports required to maintain good mental health. (sub. 39, p. 4)

Woden Community Service:

> For the ILC to be able to make meaningful referrals block funded programs will need to continue in parallel with individually funded arrangements. (sub. 159, p. 11)

Allied Health Professions Australia (AHPA):

> AHPA believes the range and types of services proposed for funding under the Information, Linkages and Capacity Building (ILC) program does not currently fit well with the goals of the NDIS, particularly the intention to create and support small and innovative programs. (sub. 37, p. 12)

Centre for Disability Research and Policy:

> The ILC will be an important tool in developing or enhancing services to meet the needs of people where services do not currently exist. This is particularly important in 'thin markets' and within rural and regional contexts. (sub. 55, p. 4)

Psychiatric Disability Services of Victoria:

> … there is no real benefit to mental health services from the ILC because the funding provided through the framework is so minimal; the ILC simply does not have the capacity to provide for the scope of what existing services deliver, whilst also responding to the needs of people who won't be eligible for the NDIS. (sub. 169, p. 9)

Vision Australia:

> The original proposal by the Productivity Commission for Tier 2 services was comprehensive, and offered a meaningful level of supports for people not eligible for the full NDIS. The current ILC program fails to meet this standard, and leaves major gaps in service delivery. One of the key intentions of the original proposal was to address the problems of 'thin markets' — remote, rural and regional areas, and in particular specialist services. (sub. PP210, p. 5)

Macular Disease Foundation Australia:

> … the ILC was intended to fund 'Tier 2' programs including block funding and early intervention programs. The goal of this was to provide access to disability and mainstream services for those who were ineligible for NDIS Individually Funded Packages. (sub. PP243, p 3)

In 2011, the Commission described Tier 2 supports as 'information and referral services (as distinct from funded support)', and said an important role for such supports would be 'to strengthen voluntary links between the community and people with disability — to stimulate 'social capital''[44] (PC 2011, pp. 12–13). The intention was that Tier 2 activities would increase, rather than crowd out existing formal and informal arrangements.

The Commission also said that it would be critical to provide any referral and information services cost-effectively, with strict cost limits, noting that 'the population of potential 'customers' would be very high, but that the overall costs would be small' (PC 2011, p. 12). The Commission suggested $200 million for capacity building (including Tier 1 and Tier 2[45] and Disability Support Organisation funding) (PC 2011, pp. 777, 788).

The question of whether the funding for ILC is adequate is difficult to answer for a number of reasons.

First, the program is still to be fully rolled out. The NDIA said that the timing of ILC funding (as determined by governments) has prevented it from investing in ILC activities and delayed the rollout of initiatives which would allow the infrastructure of a national ILC framework.

> The budget for ILC will increase over time and will reach a total budget of approximately A$131 million. This budget allocation severely hampers the NDIA's flexibility to use ILC at the time when the greatest impact could be realised. … The timing of payments means that the NDIA cannot apply ILC to assist the community or people with disability to prepare for the NDIS in advance of the NDIS rolling out in their area. … The timing of funding, linked to State and Territory contributions also prevents the NDIA from rolling out widespread national initiatives which would allow the infrastructure of a national ILC framework to be established. (sub. 161, pp. 54–55)

According to mapping undertaken by the NDIA of existing programs prior to the introduction of the NDIS, the Australian State and Territory Governments were funding an estimated $200 million of activities that align or mostly align with the ILC Policy. The mapping also showed that these 'legacy' programs were mainly concentrated in activity 1, with gaps in activities 2 to 4 (NDIA, pers. comm., 3 October 2017). Although the NDIA is not obligated to fund legacy programs, some ILC grants will be used to fund these programs. As the NDIA said:

> The effectiveness of ILC funding as an innovative means to increase inclusion of people with disability in the community is constrained by the need to also use this funding for legacy programs to ensure continuity of service delivery (i.e., the funding is also being used to provide transitional funding to States and Territories for existing ILC-like activities in each jurisdiction).

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[44] Social capital relates to the social norms, networks and trusts that facilitate cooperation within or between groups. It can generate benefits to the whole community by reducing transaction costs, promoting cooperative behaviour, diffusing knowledge and innovations, and through enhancements to personal wellbeing and associated spillovers (PC 2011, p. 207).

[45] In 2011, the Commission referred to Tier 1 as covering all Australians (as the scheme provides insurances to everyone against the costs of supports in the event that they or a family member acquired significant disability). Tier 2 covered all Australians with, or affected by, disability (PC 2011, pp. 161–5).

> As a result, the full innovative benefits of ILC funding will take time to measure. (sub. PP327, p. 29)

Second, there do not appear to be any comparable programs, either within Australia or overseas, against which the volume of funding can be assessed. A report prepared by URBIS for the Department of Social Services said:

> The fact that the NDIS is a 'world first' model means there are limited learnings from other jurisdictions as to the level of funding required to achieve intended ILC outcomes. (URBIS 2017, p. 1)

Third, to date there is some uncertainty about exactly what activities are to be funded by ILC. As the New South Wales Government said:

> … there is still a gap in the information presented in relation to the Commissioning Framework not setting out what activities the NDIA will actually fund under the ILC budget for full scheme. (sub. 60, p. 18)

And fourth, there is little evidence on the extent to which ILC is effective in improving outcomes for people with disability who are not eligible for individualised supports, nor if ILC is effective in reducing demand for individually funded packages.

The New South Wales Government pointed to the NSW Ability Links program (box 6.3) as a 'successful, cost effective model of innovation, community based supports to assist people with disability to live independently of specialist supports' (sub. PP230, p 4).

Box 6.3 Ability Links NSW and Early Links NSW

Ability Links NSW (ALNSW) supports people with disability, their families and carers to connect with their local community, to achieve their goals and aspirations, and to live enriched and fulfilled lives. ALNSW 'aims to have a light touch on the people it has contact with, with the locus of control lying firmly with the person with disability'.

ALNSW commenced operation from 1 July 2013 in Hunter (NSW) to coincide with the launch of the NDIS, and was made available state wide from 1 July 2014. The NSW Government has committed funding for ALNSW until 30 June 2018.

Early Links NSW (ELNSW) supports families of children with disability up to eight years old. ELNSW was launched in 2009 (as the Early Start Diagnosis Support Program) and in 2013, steps were taken to align the ALNSW and ELNSW. ELNSW has similar components and objectives to ALNSW — in particular, both programs focus on local area coordination to improve outcomes for children with disability, their families and carers.

The latest URBIS benefit and costs analysis, commissioned by the NSW Government, found that over the 2015-16 period there were a number of economic benefits from ALNSW and ELNSW, including increased participation in education and employment (such as work experience and volunteering), new business activity, and increased welfare for carers through a reduction in carer hours required. URBIS also identified some social benefits (such as greater links to, and participation in the community, leading to improved self-esteem and social networks).

Source: (URBIS 2016).

Other evaluations of LAC programs (including in Western Australia, the United Kingdom, Scotland and New Zealand)[46] also found improvements for individuals and families in terms of access to information about services, ensuring people and families have the help and support they need, greater choice, capacity building and increased awareness of disability.

But the evidence base is very thin. With regard to ILC, upon reviewing the available evidence, Urbis concluded that:

> Due to the lack of a comparable case study which incorporates both individualised funding and ILC-type activities in the same system; it has not been possible to explore, in depth, the concept of ILC as a 'safety net' (for those who are not eligible for more intensive support). The evidence suggests that funding directed to Activity Areas 2 and 3 will further enhance outcomes for individuals. Over time, this may even reduce the required funding for Activity Area 5 (Local Area Coordination). (URBIS 2017, p. 6)

… but additional funding is critical in the short term

It is a false economy to have too few resources for ILC activities in the transition period. It is critical to have structures in place to ensure that people eligible for individualised supports can access the NDIS, and those not eligible can access supports outside the scheme. As the NSW Disability Network Forum said:

> … the level of resources allocated to the ILC is not commensurate with the demands on the ILC. Simultaneously, Local Area Coordinators are not fulfilling their community development functions due to the demands of planning work. … This approach will increase cost pressures on the NDIS as people who are unable to access information and capacity building in the ILC will need to include capacity building as part of reasonable and necessary support in their NDIS plan, thereby increasing package size. In addition, there is concern that the lack of widely available capacity building support to those who are not NDIS participants may ultimately lead to an increase in the number of people eligible to become NDIS participants. (sub. 18, p. 4)

The NDIS Independent Advisory Council also noted that:

> The risk for the sustainability of the Scheme is that the lack of capacity building opportunities through the ILC will spill over into increased demand for capacity building as part of reasonable and necessary support, thereby increasing package size. There is also concern that the lack of widely available capacity building support may ultimately lead to an increase in the number of participants eligible to become participants. (sub. 149, p. 10)

State and Territory Governments withdrawing from ILC type activities may have an impact on the supports available. In relation to ILC and LACs funding, the NDIA stated that:

> The success of this [ILC and LACs] strategy will … be heavily reliant on the quality and availability of such supports that largely remain the responsibility of state and territory governments to fund. The experience of trial is that this is not a certain or consistent base upon which the NDIS is building. (sub. 161, p. 53)

[46] See (Kingfishers 2015; Stalker et al. 2007; Western Australia Disability Services Commission 2003).

Although directing additional funds to ILC in transition could crowd out State and Territory 'ILC like' activities, the grants process by which organisations receive ILC funding means these activities can be targeted to where they are needed most. There could also be a risk of duplicating services, but the risk of service gaps appears a much more likely prospect under current arrangements, particularly as determining precisely what ILC should cover is unclear at the operational level.

In the position paper, the Commission recommended funding for ILC be increased to the full scheme amount of $131 million each year during transition. Many stakeholders supported this recommendation (box 6.4). The accelerated funding should be geared towards National ILC activities, to ensure that all people with disability have access to adequate information and are better equipped to gain access to disability services as the NDIS rolls out in their region.

Some study participants suggested greater flexibility around what ILC can fund. The National Mental Health Commission, for example, said:

> There are … concerns about the scope and function of the ILC as it is currently designed and deployed. If the ILC is to succeed in one of its key objectives — ie to reduce pressure on 'Tier 3' individually funded supports — it needs to have a much stronger role in funding services that provide outreach and engagement with people affected by disability … (sub. PP319, p. 3)

And the DSS said:

> The NDIA may require a greater degree of flexibility around how much of the current ILC and participant plan budget is spent on ILC to improve early outcomes for people with disability through an early intervention approach and reduce longer term Scheme costs. (sub. PP318, p. 9)

However, without an evidence base, it is hard to determine what ILC should fund. As the DSS pointed out:

> … ILC investment needs to be targeted to areas that have a strong evidence base for greatest effectiveness, while being careful not to replace mainstream services which are a State responsibility. (sub. PP318, p. 9)

An evidence base needs to be built and used to inform future decisions on the activities to be funded through ILC. The evidence base should provide information on how effective, and by how much, ILC activities improve the outcomes for people with disability and reduces their need for, or reliance on, individualised supports. This information can then be used to better fund activity areas where there is a shortfall in services, and where it is best value for money.

Box 6.4 Participants support increasing ILC funding in the transition period

South Australian Government:

> SA supports this draft recommendation [5.1], recognising the importance of Information, Linkages and Capacity Building (ILC) to Scheme sustainability over time and in promoting community inclusion and participation for all people with disability. Given that only 20% of LAC funding is for ILC activities, it is important that the other four ILC activity streams are adequately funded to build the capacity of people with disability, families, communities and mainstream services. (sub. PP354, p. 5)

The Department of Social Services:

> DSS agrees ILC is an important insurance element of the Scheme to assist all Australians with disability and their families and carers, including those people moving into the NDIS. Monitoring of the level of ILC funding required will continue as part of standard budget processes for the Commonwealth. (sub. PP318, p. 9)

National Disability Insurance Agency:

> … the NDIA supports the Commission's view that it is a 'false economy' to have too few resources for ILC activities during Transition. A well-functioning ILC program should help improve participant outcomes, while contributing to Scheme sustainability. (sub. PP327, p. 6)

Parkinson's Australia:

> An accelerated and enhanced rollout of the Information, Linkages and Capacity Building Program (ILC), including an increase to the full ILC amount of $131m, is strongly supported. (sub. PP232, p. 11)

Women with Disabilities Victoria:

> [Women with Disability Victoria] strongly endorses the Commission's view that ILC funding should be accelerated and maintained until the scheme is fully established and a proper review can take place. (sub. PP282, p. 7)

Early Childhood Intervention Australia:

> ECIA fully supports the recommendation that the ILC funding be increased to the full scheme amount of $131 million for each year during transition and form part of the next COAG review in five years time. (sub. PP249, p. 5)

Orygen:

> Orygen supports the Productivity Commissions Recommendation 5.1 that funding for the ILC should be increased to the full scheme amount during transition as this could potentially improve outcomes. (sub. PP254, p. 5)

The requirement for organisations to collect data as a condition of receiving an ILC grant will help build this evidence base. The NDIA said:

> While the evidence base for the choice of effective ILC intervention is still evolving, it is clear that the absence of ILC infrastructure poses a Scheme sustainability risk, and the NDIA is committed to ensuring this evidence is developed and reflected in future ILC expenditure decisions. (sub. PP327, pp. 29–30)

The agreed review of NDIS costs in 2023 — as outlined in the Heads of Agreement — provides an opportunity to review the effectiveness of the ILC program, including the scope of the ILC Policy and Commissioning Frameworks, and the magnitude of any benefits from increasing its funding. It is reasonable to expect that there will be more data on ILC by this

time, and that many transitional issues which may be exacerbating concerns about the adequacy of ILC funding will be resolved.

FINDING 6.1

It is a false economy to have too few resources for Information, Linkages and Capacity Building, particularly during the transition period when it is critical to have structures in place to ensure people with disability (both inside and outside the National Disability Insurance Scheme) are adequately connected with appropriate services.

RECOMMENDATION 6.1

Funding for Information, Linkages and Capacity Building (ILC) should be increased to the full scheme amount of $131 million for each year during the transition.

The effectiveness of the ILC program in improving outcomes for people with disability, the adequacy of its funding, and its impact on the sustainability of the National Disability Insurance Scheme should be reviewed as part of the next COAG agreed review of scheme costs in 2023. The ILC budget should be maintained at a minimum of $131 million per annum until results from this review are available.

6.2 The NDIS and other disability services

Prior to the NDIS, the delivery and funding of disability services was primarily governed by the National Disability Agreement (NDA). The NDA, of which the Australian Government and all State and Territory Governments are signatories, was established in 2009 and revised in 2012. It features clear roles and responsibilities for each level of government and nationally agreed objectives and outcomes for people with disability, their families and carers (COAG 2012c).

The NDA also establishes that the Australian Government is responsible for providing income support and employment services for people with disability. States and Territories are responsible for the delivery of specialist disability services such as supported accommodation, family support and community support services, therapy, early childhood interventions, life skills and case management (SCRGSP 2017, p. 15.3).

Other services available to people with disability, prior to the introduction of the NDIS, included (but were not limited to):

- home and community care
- residential aged care (provided to people under the age of 65 years)
- taxi and transport subsidy schemes
- psychiatric disability community supports.

While the scope of these services and their eligibility requirements varied by jurisdiction, they typically included programs that covered both people eligible and not eligible for individualised supports under the NDIS. Continuity of service and program interfaces are therefore critical to ensuring that people with disability do not 'fall between the cracks' when services are split between NDIS and non-NDIS provision.

How does the NDIS affect other disability services?

As individuals transition to the NDIS, many existing services will be defunded, with previous funds used to offset the cost of the NDIS. Funds transferred from these services to the NDIS are calculated on a predetermined per person basis. The funds move with the individual when they transition to the NDIS, as agreed in the Bilateral Agreements. However, not all individuals will meet the NDIS eligibility criteria and not all services will be funded by the NDIS. Consequently, some services provided under the NDA and other avenues will need to continue.

Unless agreed otherwise, the responsibility of governments to provide services under the NDA remains (part 2, subsection 16 of Bilateral Agreements). The Australian, State and Territory Governments have also agreed in the Bilateral Agreements to continuity of disability support services for:

- people who receive support but do not meet the access requirements outlined in the *National Disability Insurance Scheme Act 2013* (Cwlth) (NDIS Act), or are receiving supports that do not meet the definition of reasonable and necessary support in the NDIS Act
- funding for supports attributed to a program/service that will cease when the NDIS is introduced.

All State and Territory Governments agreed to provide continuity of support to people receiving state and territory administered disability programs/services. The Australian Government is responsible for providing Commonwealth administered disability programs/services (Bilateral Agreements schedule D). As part of annex E of the Continuity of Support Agreement (COAG 2013), the Australian, State and Territory Governments are also obliged to make clear their policy approach to providing continuity of support.

On the basis of the agreements that are in place, if the Australian, State and Territory Governments adhere to their responsibilities there should be few, if any, gaps in disability services for existing users (or at least the funding for these services). People previously receiving a disability service will continue to receive a similar level of service — either through the NDIS or from other services funded by the Australian, State and Territory Governments.

Continuity of support is less straightforward in practice

In practice, access to continuity of support varies.

Continuity of support for people shifting to the NDIS

Continuity of support means that people who meet the eligibility criteria for the NDIS will, at a minimum, continue to receive support that enables them to achieve the same outcomes as their previous support — this could be through the NDIS alone, or through a combination of the NDIS and other services.

However, the NDIS supports need to be reasonable and necessary (chapter 5). This means the supports that a scheme participant receives through the NDIS, and what they received prior to entering the scheme, may not necessarily 'match' one to one.

There is no continuity of support arrangements for new scheme participants (that is, those who were not receiving specialised disability services prior to the introduction of the NDIS), as they will be receiving disability care and support for the first time.

Continuity of support for people not in the NDIS

Where programs are transitioning into the NDIS and there are people on these programs not eligible for the NDIS, these clients should receive services under continuity of support arrangements. However, there is significant uncertainty about how continuity of support arrangements will operate in practice (box 6.5). And what supports will be available for people who newly require disability care and supports is even less clear. Further exacerbating the problem is that funds saved from transitioning services will be used to offset the costs of the NDIS, and so each jurisdiction's willingness, and/or capacity to provide additional services may be reduced.

Box 6.5 Participants point to uncertainty around continuity of support

Flourish Australia:

> People not eligible for the NDIS are already experiencing uncertainty and confusion. Continuity of support arrangements are still not finalised, so it is unclear whether they will be able to continue to access the services they currently receive, post full Scheme rollout. The concern is that if people currently accessing support in the community have this support 'switched off' at a future point, their needs and circumstances could be exacerbated, pushing up demand for the NDIS. (sub. 74, p. 9)

National Mental Health Commission:

> It is not clear how continuity of support for carers will be addressed through the NDIS. For example, the NDIS does not include direct provision of respite support for carers. Anecdotal evidence indicates that some applicants are being encouraged not to include family support in order to enhance their chances of getting a package. (sub. 153, p. 4)

Department of Health:

> The continuity of support commitment has been raised as a concern by service providers. It is currently unknown the proportion of program clients that will be deemed ineligible for the NDIS. Further information is needed of this cohort to inform continuity of support planning, such as the reasons for the ineligible access decision and the type of supports that individuals are currently accessing. (sub. 175, p. 5)

Mental Health Australia:

> All governments are nominally committed to providing continuity of support to clients of programs that are being rolled into the NDIS. Implementation of that commitment is impeded by a number of factors, including … a failure to recognise that many existing programs do not 'map' to the NDIS, … a lack of reliable and publicly available data on the number of clients affected in each program, at both levels of government … and a lack of transparency about funding flows as programs wind back (sub. PP321, p. 13).

There is varying detail on what disability support services will continue after the full rollout of the NDIS, and who will fund them. The New South Wales and ACT Governments — signalled that they intend to cease providing specialist disability services (ACT Government 2017; New South Wales Government nd).

Where it is clear that services will continue, the detail on what will be provided varies. For example:

- the Queensland Government said that they will continue providing some disability services (Queensland Government 2017)
- the Department of Social Services (DSS) stated publicly that 17 DSS and Department of Health programs will be affected by the introduction of the NDIS (DSS 2016g).

Rather than having a clear framework around the continuity of support, there seems to be some signs of brinkmanship, with governments holding off implementing policies (perhaps until other jurisdictions act, or waiting for gaps to emerge before engaging in renegotiations).

In addition to disability care and support, all individuals will continue to have access to mainstream services, regardless of which system they fall under. However, the interface between mainstream services and the NDIS must function well and this is often not the case. Boundary issues between the NDIS and mainstream services are discussed in section 6.3.

While the Commission heard concerns about the quantum and nature of supports that will be provided outside the NDIS across a number of areas, mental health is an area where concerns were particularly pronounced (box 6.6). In this case, the non-clinical supports that will be available for people with mental health disability who are not eligible for the NDIS is very unclear (box 6.6). State and Territory Governments have primary responsibility for mental health services — in 2014-15, state spending accounted for 83 per cent of all spending on community mental health services, with the Commonwealth accounting for 17 per cent (DSS, sub. 146, p. 16).

In March this year, the Disability Reform Council (DRC) agreed to focus on mental health to ensure mainstream systems are effectively supporting people with disability in Australia (DRC 2017a, p. 2). In the most recent budget, the Australian Government also allocated $80 million over four years for support services for people with mental health illnesses who do not qualify for the NDIS, contingent on State and Territory Governments matching this contribution (Australian Treasury 2017b, p. 120). This should go some way to addressing support gaps, but continual monitoring will be required to ensure that people with significant needs are not missing out because they do not satisfy the NDIS eligibility criteria. Through COAG, Health Ministers have also agreed to establish a working group to:

> … progress the Commonwealth's National Psychosocial Supports program. This will have the objective of developing bilateral agreements to support access to essential psychosocial supports for persons with severe mental illness resulting in psychosocial disability who are not eligible for the NDIS. (COAG Health Council 2017, pp. 2–3)

The Commission's recommendation to establish a psychosocial gateway (recommendation 4.4) seeks to provide both a dedicated entry pathway into the NDIS for those eligible for the scheme and to direct people who are not eligible to other relevant services. The gateway should also help to identify gaps in service provision that need to be addressed.

Box 6.6 Mental health — an area where uncertainty abounds

Many participants to this study raised concerns about people with severe mental illness missing out on services. In 2011, the Commission assumed that about 57 000 people with psychosocial disability would be eligible for individualised supports under the NDIS (PC 2011, p. 190). The NDIA has since revised this number to 64 000 people with a primary disability of psychosocial disability (NDIA 2016b, p. 26).

The National Mental Health Commission's report on Mental Health Programs and Services estimated that about 700 000 Australians experience severe mental illness in any one year (and there are estimated to be over three and a half million people in Australia (aged 16 to 85 years) with some sort of mental ill-health in any one year) (NMHC 2014, p. 5). The Department of Health (sub. 175, p. 4) submitted that through their internal modelling, about 282 000 people aged 0-64 years have severe psychosocial disability requiring supports, and about 92 000 (aged 18-64 years) would 'most closely align' with the NDIS (although this did not involve modelling against the NDIS eligibility criteria per se).

For people with psychosocial disability not eligible for an individualised package under the NDIS, it is intended that mainstream or other disability support will assist them. However, many submissions to this study pointed to current uncertainty around what services and supports will be provided to individuals with psychosocial disability outside the NDIS. For example, Mental Illness Fellowship of Australia said:

> While there have been assurances under the principle of continuity of service, in practice there is no clear indication of who and how the system will provide for those not eligible for the NDIS yet in existing programs, and more generally, those who were never Commonwealth clients to begin with. Members have reported emerging evidence of cost-shifting and ambiguities in responsibility, resulting in program uncertainty. (sub. 122, p. 12)

The National Mental Health Commission:

> A particular concern is that there seem to be many people in existing community mental health programs at the Commonwealth and the State and Territory level who are being found ineligible for the NDIS, and while governments' commitment to continuity of support for existing clients is welcome (subject to the details of how such support is to be provided into the future), there appears to be no clear strategy for dealing with future cohorts of people who would otherwise have accessed such programs but who are not eligible for the NDIS. (sub. 153, p. 6)

And the Mental Health Community Coalition of the ACT said:

> … there is a need for both the NDIS and a mental health system. One is not a substitute for the other. However, since the introduction of the NDIS, the intersection between these systems has become very unclear and difficult; as well as inconsistent between States and Territories.
>
> - States and Territories made different decisions about what was in and out of scope for the NDIS.
> - Further, these decisions were made very early in the process when detail of scheme design was limited — it's fair to say that in many cases decisions would now be different given how the scheme has evolved. (sub. 135, p. 15)

The DSS (sub. 146, p. 16) also noted that service gaps in this area have been known for some time. The implications of gaps are significant — uncertainty about what supports will be provided is distressing for people who rely on them and places an additional call on the generosity of informal support. Service gaps can also threaten the sustainability of the scheme by encouraging scope creep, or by forcing those who are unlikely to meet eligibility requirements to test their access.

Continuity of support arrangements need to be made public

The DSS called for the States and Territories to demonstrate that they are delivering on continuity of supports:

> As governments refocus significant proportions of their disability expenditure towards funding the NDIS, there is the potential for services that are expected to remain in the mainstream to be withdrawn, creating service gaps for people who are not eligible for the NDIS. The States need to demonstrate they are delivering their undertakings to provide continuity of support to clients not eligible for NDIS. (sub. 146, p. 27)

While the DSS recognised that measuring and reporting on service gaps is difficult, and that the agreed development of a new reporting framework for the *National Disability Strategy* could assist, it also argued for better cross-system reporting to make any moves away from services more obvious (and therefore more difficult to shift costs).

An important first step to ensuring an effective interface between the NDIS and other disability services is for governments to set out what disability services outside the NDIS they will fund, including the value of supports and number of people covered. Without this, it is impossible to understand where the gaps are and where any cost-shifting may be occurring.

In the position paper, the Commission proposed that a detailed schedule of continuity of support arrangements (including the value of supports and number of people covered) be included in the upcoming full scheme Bilateral Agreements. Responses to this proposed recommendation were mixed.

The Queensland Government considered it reasonable that information about continuity of support services be provided in the Bilateral Agreement for full scheme (sub. PP345, p. 11). The DSS also said that the disclosure of continuity of support arrangements will help people understand what governments will provide (sub. PP318, p. 9).

The South Australian Government argued that it is difficult to accurately quantify continuity of support requirements until existing clients' transition into the scheme (sub. PP354). Similarly, the Tasmanian Government said:

> [W]hether continuity of support is required outside the NDIS may be subject to the NDIA's decisions on reasonable and necessary supports and may not be able to be predicted before an individual accesses the scheme and undergoes planning. … It therefore may not be possible to fully describe or anticipate continuity of support arrangements in full scheme agreements as proposed by the [Productivity Commission], especially where interface issues are still being tested and detailed policy is yet to be determined. (sub. PP247, p. 7)

Arrangements for the continuity of supports need to be made clear by governments — and before the full rollout of the NDIS — to ensure there is certainty about supports for those not eligible for the NDIS. It is the Commission's view that high level commitment to the continuity of support arrangements should remain in the Bilateral Agreements for full scheme. However, rather than constrain the Australian, State and Territory Governments to

fixed values and supports, reporting at the operational level should sit outside the Bilateral Agreements. To ensure continuity of support arrangements are made public, and for a centralised discussion to occur, governments should report their operational level arrangements to DRC.

To assist in identifying gaps as they emerge or cost shifting behaviour occurring, there should also be better data collection at the operational level, and ongoing reporting and evaluation. The data will allow for analysis in trends and the ability to identify where future funds can most efficiently and effectively be allocated. Reporting of disability services at the operational level will encourage discussions between the NDIA, mainstream and disability service providers (including governments, local communities and businesses).

The Commission therefore recommends that the NDIA should collect and report regularly to DRC information on boundary issues. The Australian, State and Territory Governments should also collect data on, and publicly report to DRC, the number of people covered by their disability programs pre and post NDIS, and the value of these services (state and territory's responsibilities are further discussed in section 6.3 and recommendation 6.3). The data will form part of the broader collection of disability data across Australia (chapter 13).

ILC programs and LACs could also assist in identifying any gaps and report them to the NDIA, the Australian, State and Territory Governments and DRC.

In the position paper, the Commission recommended reporting of boundary issues be made quarterly to DRC, however the NDIA argued that annual reporting is more appropriate (sub. PP327, p. 31). The Commission does not have a strong view about whether reporting should be done on a quarterly or annual basis. What is more important is that the reporting is perpetual and made publicly available, and that the first series is made available as soon as reasonably practicable.

RECOMMENDATION 6.2

The Australian, State and Territory Governments should make public — through the COAG Disability Reform Council (DRC) — their approach to providing continuity of support and the services they intend to provide to all people with disability (including the value of supports and number of people covered), beyond supports provided through the National Disability Insurance Scheme. Arrangements for continuity of support should be made clear before full scheme implementation.

The National Disability Insurance Agency should report annually to the DRC on boundary issues as they are playing out on the ground, including identifying service gaps and actions to address barriers to accessing disability and mainstream services for people with disability. The reporting should be used for ongoing monitoring, evaluation and improvements.

6.3 The interface between NDIS and mainstream services

A key requirement of any support provided under the NDIS is that the support is most appropriately provided and funded by the scheme and not by another service or system.[47] The NDIS is not designed nor funded to replace mainstream services. For the NDIS to be successful and financially sustainable, there must be clear lines of responsibility between mainstream services and the scheme. Also, as people with disability can require supports across a number of service systems, it is essential that service systems work well together so that people receive the right services and achieve the best possible outcomes.

In theory, the boundary between the NDIS and mainstream services is clear. The *National Disability Strategy 2010–2020* sets out the guiding principles around the supports to be provided by mainstream services (box 6.7). The Strategy's Second Implementation Plan (Driving Action 2015–2018) states that:

> While the NDIS is a significant step forward for many people with disability, the strategy remains the key to achieving improvements in access to mainstream services and support for all people with disability, regardless of age or type and level of support required. (DSS 2016c, p. 6)

However, as the NDIA (sub. 161, p. 57) stated, 'the Strategy is an overarching framework rather than a binding agreement for action'. It does not include 'substantial commitments, key performance indicators or targets' and 'there are limited identifiable consequences for governments if there is a lack of action'.

The Australian Government has also entered into bilateral agreements with State and Territory Governments. These agreements delineate the types of support to be provided and funded by the NDIS and mainstream services (table 6.2). COAG has endorsed *Principles to Determine the Responsibilities of the NDIS and other service systems*, which are to be used to determine the funding and delivery responsibilities of the NDIS. The Principles provide guidance on decisions about what constitutes 'reasonable and necessary' by the NDIA by being incorporated in the *National Disability Insurance Scheme (Supports for Participants) Rules 2013* (Schedule 1).

[47] NDIS Act subsection 34(f).

Box 6.7 National Disability Strategy 2010–2020

The *National Disability Strategy 2010–2020* provides a ten-year national policy framework for improving the lives of Australians with disability, their families and carers. It represents a commitment by all levels of government, industry and the community to a unified, national approach to policy and program development. The vision of the Strategy is for 'an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens' (COAG 2011, p. 8).

The Strategy was endorsed by the Council of Australian Governments in February 2011. It guides public policy across all level of government and aims to bring about change in mainstream services, specialist programs and services, and community infrastructure to meet the needs of people with disability, their families and carers. It is the first time the Australian, State and Territory Governments have agreed to such a wide range of policy directions for disability. The Strategy sets out six priority policy areas for action. They are:

- inclusive and accessible communities
- rights protection, justice and legislation
- economic security
- personal and community support
- learning and skills
- health and wellbeing.

The first implementation plan, *Laying the Groundwork 2011–2014*, established the foundation for reform in the planning and delivery of both mainstream and disability-specific programs and services. The Strategy's second implementation plan, *Driving Action 2015–18*, outlines new priority actions and builds on ongoing commitments to improving outcomes for people with disability across the Strategy's six policy outcome areas. Additional areas of national co-operation include: NDIS transition to full scheme; improving employment outcomes for people with disability; improving outcomes for Aboriginal and Torres Strait Islander people with disability; and communication activities to promote the intent of the Strategy throughout the community.

In September 2016, the Disability Reform Council reaffirmed its ongoing commitment to the *National Disability Strategy*.

Sources: COAG (2011); DSS (2016c, p. 2, 2017d).

Table 6.2 **What the NDIS covers and what mainstream services provide**

	What the NDIS covers	*What mainstream services provide / what the NDIS does not cover*
Health	Support to enable a person with disability to undertake daily activities, including 'maintenance' supports (from clinically trained or qualified health practitioners) directly associated with the person's disability.	Access to health services, such as diagnosis and clinical treatment of health condition, as required by National Healthcare Agreement and Commonwealth Disability Discrimination Act.
Mental Health	Non-clinical supports that focus on the person's functional ability to undertake daily living.	Clinical support related to mental health and any residential care and rehabilitative care.
Early childhood development	Individualised support or early intervention, specific to a child's disability or developmental delay, targeted at enhancing the child's functionality to engage in daily activities.	Early childhood education and care needs, health system, child and maternal health services and any supports clinical in nature.
Child protection and family support	Support for the child, family and carer as a direct result of the child's disability, to enable participation in the community.	Promoting the safety of children from abuse and neglect, and providing parenting programs, counselling and other supports for families.
School education	Supports related to the functional impact of a student's disability to undertake activities of daily living, such as personal care and transport to and from school.	Personalising learning and support related to educational attainment, including teaching, learning assistance, school building modifications and transport between school activities.
Higher education and vocational education and training	Functional support related to the student's disability to undertake daily activities, including personal care and transport to and from education.	Learning and support needs of students that primarily relate to their educational and training attainment, and transport between education, training and employment venues.
Employment	Assistance to take part in the workforce and support in the person's functional capacity to work, such as training in workplace relationships and communication skills.	Employment services to support people with disability to prepare for, find and maintain a job, and employers to hire people with disability in their workplace (e.g. workplace modification, training and funding assistance).
Housing and community infrastructure	Assist individuals with disability to live independently by building their capacity to maintain tenancy, such as home modifications for accessibility, specific to their disability.	Accommodation for people in need of housing assistance, access to housing and homelessness services and any previous infrastructure responsibilities.
Transport	Funding support to enable independent travel, including aids and equipment and training to use transport. Cover reasonable and necessary costs for those not able to travel independently.	Ensuring transport options are available to people with disability. Other parties are still responsible for transport infrastructure as part of universal service obligation, including managing disability parking.
Justice	Continue to fund the full NDIS support related to the person's disability impairment.	Meet the needs of people with disability in line with the *National Disability Strategy* and existing legal obligations, such as ensuring the system supports accessibility for people with disability and a secure environment for those in prison.
Aged care	Those under age 65 can choose to purchase support from an aged care provider and the NDIS will fully meet these 'reasonable and necessary' costs.	Responsible for access to quality and affordable aged care and carer support. Cater for individuals aged over 65 years, unless they qualify to remain in the NDIS.

Source: COAG DRC (2015b).

Interfaces are not so clear at an operational level

At the operational level, the lines of responsibility between the NDIS and mainstream services are not clear. The NDIA reported that during trial and transition it faced three key challenges in relation to mainstream supports, including:

- lack of clarity around some interfaces
- different understanding of mainstream obligations, by each jurisdiction and the NDIA
- difficulty in holding mainstream services accountable (sub. 161, pp. 59–60).

State governments also pointed to the need for further work on achieving greater clarity. For example, the South Australian Government said:

> There remains a lack of clarity in relation to roles and responsibilities across the NDIS and mainstream services in some areas. South Australia believes that there is still extensive work to be done in defining mainstream interface boundaries. (sub. 203, p. 6)

The New South Wales Government said:

> Extensive further work is required by the States and the Commonwealth to scope, agree and communicate service boundaries. Any movement of boundaries (existing responsibilities) between the NDIS and other service systems should be implemented with associated resourcing considerations. (sub. 60, pp. 13–14)

A lack of clarity around responsibilities between the NDIS and mainstream services has the potential to impact on NDIS costs, and on the effectiveness and efficiency of service delivery in multiple ways, including: scope creep; cost shifting from mainstream services to the NDIS and vice-versa; gaps in service provision; inconsistent support access decisions; and duplication of services.

An added complexity is in-kind support arrangements (a program may have been agreed as in-kind but some people receiving the program may not be eligible for the NDIS and not all supports within the program may align with reasonable and necessary supports) (chapter 7).

Some emerging interface issues

Interface issues are starting to emerge. The NDIA reported instances of possible cost-shifting, scope creep and service gaps, including:

- providers trying to extend the amount of therapeutic (health) interventions through use of NDIS funding
- reports that mainstream services are refusing entry to people who are likely to be eligible for the NDIS
- issues around a lack of accessible public transport options, particularly in regional, rural and remote areas, which means NDIS participants seek transport funding through the

NDIS despite having the capacity to travel independently where transport options are available (sub. 161, pp. 59–60).

State and Territory Governments also reported instances of cost shifting. The South Australian Government, for example, said:

> As policies and eligibility have been clarified over the trial/transition period, there are a number of emerging issues which are, or are expected to result in costs for the state in areas which were originally assumed to be part of the scheme. … South Australia is keen to ensure that all appropriate costs are met by the NDIS to avoid any potential of states effectively paying twice for services. (sub. 203, pp. 7)

The ACT Government also said:

> The ACT has experienced a cost pressure associated with the fact that what is 'in scope' for the NDIS has moved over time. (sub. 156, p. 9)

Some of the examples provided by the ACT Government include:

- a narrowing of the eligibility criteria for Early Intervention has meant that some children who were deemed eligible for the scheme and have not implemented plans are being reviewed by the NDIA and referred back to mainstream services
- the lack of clarity from the NDIA about what is considered as parental responsibility and what is reasonable and necessary to fund student transport means that a tightening of scope by the NDIA will shift costs to States and Territories
- the NDIA being insistent that supports for people with forensic disability[48] where their behaviour manifests as a public safety issue is the responsibility of mainstream services. The ACT Government did not anticipate that it would be required to meet such costs, given that they relate directly to the participant's ability to live in the community (sub. 159, pp. 9–16).

While many submissions to this study raised concerns about how the NDIS interface was working with mainstream services, particular concerns were raised in the areas of the justice system (box 6.8) emergency and health services (box 6.9) and transport (box 6.10).

[48] A forensic disability client is an individual who has an intellectual or cognitive disability who has been ordered to be detained for treatment or care (Forensic Disability Act 2011(Qld) s. 10).

Box 6.8 Interface between the NDIS and justice services: views of study participants

Participants to this study expressed a number of concerns about the interface between the NDIS and mainstream criminal justice disability services. While there are specific NDIS rules that deal with the interface with the justice system (NDIS (Supports for Participants) Rules), there are some concerns that these rules are not clearly defined and that differences in interpretation will create inconsistencies. The Office of the Public Advocate, for example, said:

> On the intersection with the justice system, the COAG principles outline that the NDIS 'will continue to fund the reasonable and necessary supports'; a statement that is vague and subject to differing interpretations. Moreover, some of the responsibilities accorded to the justice system in the COAG principles have seldom been available in the pre-NDIS environment; for example, 'specific interventions to reduce criminal behaviours' and intensive case coordination — both of which are attributed to mainstream services — are not currently provided by the justice system and it is unlikely that they will be under the NDIS. (sub. 46, p. 2)

Participants also expressed concern that delineation between the NDIS and State and Territory responsibilities is resulting in the withdrawal of some community justice programs and creating inconsistencies between jurisdictions and gaps in service provision. Disabled People's Organisations Australia submitted:

> There is an assumption that States and Territories are providing the appropriate supports to people with disability through the mainstream or their own specialist disability support systems. In some cases, States and Territories are entirely withdrawing funding and services for disability support while others are retaining a residual role in specialist supports. This creates inequity in programs within different jurisdictions. For example, NSW is ceasing its funding of specialist disability criminal justice programs based on the rationale that this should be the purview of the mainstream criminal justice system. (sub. 165, p. 11)

A further issue was the ability of people in custody to access NDIS support. Sisters Inside, for example, said:

> In our view, the unique and 'complex' needs of women in prison pose a significant challenge for the current NDIS model. We are concerned that most criminalised women will not be eligible for NDIS services. Even if eligible, many criminalised women can be expected to avoid the application process and services provided by mainstream (institutional charity) organisations. (sub. 16, p. 1)

In particular, access to disability services for people moving in and out custody is viewed as problematic. Neami National submitted that an:

> … issue occurs when participants move in/out of justice settings. For example, in preparation for discharge from a forensic mental health unit, extensive preparatory work and relationship building is provided through in-reach of community mental health disability support. This is not funded under the NDIS and will compromise the capacity of justice services to facilitate safe and timely discharge for people, again increasing overall cost pressures on the health and social care systems. (sub. 63, p. 9)

Similarly, Leanne Dowse, Melinda Paterson and Mike Sprange said:

> … as the NDIS implementation is only partially complete in NSW, it is hard to comment on how the interface between the NDIS and mainstream services has been working. What is clear has come from areas where trial implementations of the NDIS have occurred, such as in the Hunter region.
>
> In the area of Justice, there are some reports that the transition out of custodial sentences for people with disability who may be eligible for the NDIS, or even already in it, is problematic. It is likely that in relation to the mainstream area of Justice, many complex issues will arise in the interface. (sub. 114, p. 7)

Box 6.9 Emerging gaps in emergency and health services

Responsibility for funding emergency services

A gap in emergency response funding was identified by a number of study participants. For example, the ACT Government (sub. 156, p. 24) pointed out that there is currently no provision for emergency supports, such as accommodation, for:

- children with challenging behaviours who may not be able to live with their parents all of the time
- participants being discharged from a psychiatric inpatient unit
- participants unable to leave hospital without a modified or supported accommodation option.

It is unclear whether the NDIS or State and Territory Governments are responsible for funding this service. For example, in the ACT, the government has 'cashed out' on disability services related to emergency care (the ACT Government (2017) wound up 'Disability ACT' on 30 June 2017) under the expectation that the NDIS would fund these services. On the other hand, the NDIA has claimed that providing emergency accommodation falls under the State and Territory responsibility of child protection, public housing and health sector respectively.

Uncertainty in some health services

There are also cases where individuals are being turned away from specific state funded health services, and there seems to be uncertainty around who should provide these services.

- Audiologists report confusion around the funding of services for people experiencing tinnitus, with one practitioner being told that supports for tinnitus would no longer be funded by South Australia Health as this program would move over to the NDIS. However, young and adult clients with severe tinnitus are being advised that they are ineligible for the NDIS (Allied Health Professions Australia, sub. 37, p. 11).
- The Australian Physiotherapy Association (sub. 93, p. 10) reported feedback from consumers that rehabilitation services have 'closed their books' to NDIS package holders.
- The Australian Physiotherapy Association also noted cases of individuals being discharged early from hospitals:

  > … there are increasing incentives for 'early discharge' from public and private hospitals resulting from the introduction of the NDIS … There is little incentive, for example, for hospitals to ensure optimal pre-discharge functioning of a participant, compared with early hand-off and the transfer of the responsibility for achieving optimal functioning into the hands of the participant, their NDIS budget and community-based providers. (sub. 93, p. 10)

Box 6.10 Taxi subsidy scheme varies across jurisdictions

As part of the transition to the NDIS, some State and Territory Governments, such as South Australia, Tasmania and Queensland, have cashed out their taxi subsidy scheme for NDIS participants, on the expectation that transport requirements for people with disability will be covered by the scheme.

Since the rollout of the NDIS, some scheme participants have received less transport assistance than they did under the previous taxi subsidy scheme. Some State Governments argue that the NDIA is not providing sufficient transport support. As Queensland's Minister for Disability Services Coralee O'Rourke said:

> Together with other jurisdictions, we have been making representations to the Commonwealth Government since earlier this year, expressing concern that people are not getting sufficient provision for transport in their plans from the NDIA. (Bailey and O'Rourke 2017)

The South Australian and Tasmanian Governments have announced they will temporarily reinstate the taxi subsidy scheme for NDIS participant (Mullighan 2017; TDSG 2017), while continuing to provide a cash transfer to the NDIA. The Queensland government reinstated their taxi subsidy scheme for the remainder of the transition period. This will be treated as an in-kind contribution, replacing what was a cash contribution (Bailey and O'Rourke 2017).

There appears to be discrepancies in services received by individuals, depending on which jurisdiction they live in and how their government interprets their responsibilities – this is not desirable in a system striving to be nationally consistent.

While the Commission considers these interface concerns are highly significant, it is not in a position to review the boundaries per se (though it has devised a process to address these issues going forward — discussed below). As the New South Wales Government said:

> … at this early stage, NSW considers reviewing scheme boundaries by the PC to be of limited value given extensive work is still required by governments to define and agree boundaries. (sub. 60, p. 14)

A number of Administrative Appeals Tribunal (AAT) cases have tested the boundaries of the NDIS (box 6.11), but given the narrow focus of these cases to date, their use in defining boundaries between services is limited. As more decisions are tested through the AAT, it can be expected that boundaries may be clarified. Importantly, however, the fact that a support is ruled to be best provided by a mainstream service does not always mean that the support will necessarily be provided.

Box 6.11 **AAT Cases — whether a support is most appropriately funded by the NDIS**

The following are examples of Administrative Appeals Tribunal cases that look at whether the requested NDIS support item is most appropriately funded by the NDIS or mainstream services. The cases have generally focused on specific claims for medical equipment and disability care.

- *Young and the National Disability Insurance Agency* [2014] AATA 401 — Young applied for a portable oxygen concentrator and insulin pump to be funded through the NDIS. The AAT found that the oxygen concentrator and insulin pump were not clinical treatments, and are most appropriately provided by the health system.
- *McCutcheon and the National Disability Insurance Agency* [2015] AATA 624 — McCutcheon's NDIS support package did not include chiropractic care, which she appealed. The AAT found that the chiropractic treatment can amount to good practice for the purposes of NDIS Act s 34(1)(d). The AAT found that the chiropractic treatment was related to McCutcheon's ongoing functional impairment and was therefore most appropriately funded by the NDIS.
- *Fear by his mother Vanda Fear and National Disability Insurance Agency* [2015] AATA 706 — On behalf of Fear, his parents applied for certain equipment (pulse oximeter and oral suctioning machine) as part of his individual support package under the NDIS, but they were not included in his plan. The AAT found that the oximeter and oral suction machines are more closely related to clinical treatment for Mr Fear's health and were the responsibility of the health system.

Interface issues require ongoing action

While there are various governments involved in delivering services to people with disability, there will be interface issues. It will take considerable effort and goodwill to resolve these issues, and as programs for people with disability continue to evolve, interface issues will never be fully 'resolved'.

It is therefore essential that robust processes are in place to clarify interface issues between the NDIS and mainstream services before they appear (if possible — but some issues will only become apparent through experience), or as they arise. The Commission is aware that governments are undertaking substantial work to clarify these issues, but this is complex and will take time. A more formal process is therefore needed to maintain the momentum for this critical work.

The Commission considers that the most appropriate vehicle for the discussion and monitoring of NDIS and mainstream service interfaces is COAG. A standing item should be introduced for each COAG Council that is responsible for services that interface with the NDIS, so that there is a regular discussion, and actions devised, on how best to address the interface of mainstream services with the NDIS.

There were mixed reactions to this recommendation in the position paper. Some study participants were supportive, for example:

> … Victoria would support a standing item on the agenda of each COAG Council that interfaces with the NDIA (Draft Recommendation 5.3). A necessary first step is to put in place public reporting on how the scheme as a whole is progressing. This would identify whether there is a need for further reporting by the states that can be efficiently and effectively progressed through existing COAG avenues. (Victorian Government sub. PP298, p. 22)

> NDIS should be a standing item on the agenda of every COAG ministerial council that has responsibility for services that interface with the NDIS. This would help foster regular discussions to resolve uncertainties about service gaps, duplications and other boundary issues. (National Disability Services sub. PP295, p. 5)

The New South Wales Government, however, raised concerns about this resulting in fragmented decision making:

> NSW does not consider it appropriate for other COAG Councils to resolve boundary or interface issues with the NDIS. Devolving this responsibility to separate COAG Councils will potentially result in a fragmented approach to decision making, and decisions being made without reference to broader NDIS design/impacts. Rather, the Disability Reform Council should have responsibility for considering and agreeing NDIS boundary and interface issues in consultation with other COAG Councils. (sub. PP230, p. 5)

And the DSS suggested that the standing item agenda should be broadened to include a discussion on improving outcomes for people with disability:

> The COAG DRC now lists the NDS as a standing agenda item for its ordinary meetings, Should this option be more broadly pursued it would be important that the standing agenda item be extended to include a broader focus on improving outcomes for people with disability, consistent with the Strategy, to help drive improved outcomes for all people with disability, including those who will not be NDIS participants. (sub. PP318, p. 11)

The Commission agrees broadly with these views and recommends that the standing item for each COAG Council (that is responsible for services which interface with the NDIS) should put forward issues and proposed solutions to the DRC, rather than having each COAG Council resolve interface issues directly. The discussions on boundary issues should also consider how interactions between services affect outcomes for people with disability.

The DSS suggested specific disability reporting across COAG Councils:

> Monitoring and reporting through COAG infrastructure could be strengthened by specific disability reporting across relevant COAG Councils, specifically on the effectiveness of mainstream systems in supporting all people with disability; and improving the interfaces between mainstream services and the NDIS.
>
> DRC could consider proposing this through its regular reporting to COAG, starting with the three agreed priorities for the *National Disability Strategy*:
>
> - mental health services outside the NDIS
> - health services for people with disability

- over-representation and lack of support for people with disability in the criminal justice system. (sub. 146, p. 28)

The *National Disability Strategy* should be strengthened to improve government accountability. There should be more detailed reporting around the boundaries of the NDIS and the implications for mainstream service provision. Specific commitments, key performance targets and outcomes should be established. This should be pursued through review points of National Agreements and National Partnership Agreements under the Federal Financial Relations Intergovernmental Agreements.[49]

As the DSS said:

> Translating the National Disability Strategy into tangible results for people with disability, their families and carers is a major factor in successful implementation of the NDIS. (sub. 146, p. 5)

RECOMMENDATION 6.3

Each COAG Council with responsibility for a service area that interfaces with the National Disability Insurance Scheme (NDIS) should have a standing item on its agenda to address how these services interface with NDIS supports. The standing item should cover service gaps, duplication and other boundary issues, including ways to improve outcomes for people with disability. Each Council should put forward issues and proposed solutions to the Disability Reform Council for action.

At review points of National Agreements and National Partnership Agreements under the *Intergovernmental Agreement on Federal Financial Relations*, parties should agree to specific commitments and reporting obligations that are consistent with the *National Disability Strategy*. The Agreements should be strengthened to include more details around how boundary issues are being dealt with, including practical examples.

As the system evolves, and providers of services to people with disability better understand the NDIS and its interfaces, staff will be better able to work collaboratively, identify gaps or duplications and re-direct people with disability to the most appropriate services. A number of study participants said that cross-system co-ordination is poorly implemented and more needs to be done in this area (box 6.12).

Cross-system co-ordination differs to that of support co-ordination (chapter 10) — rather than connecting scheme participants with complex needs to appropriate services, cross-system co-ordination will ensure that service providers themselves are better equipped to work with one another, and that the best outcome is achieved for *all* people with disability.

Having better co-ordination can help, but of course only if responsibilities are clearly delineated. ILC and LAC can also play a role in ensuring mainstream services and the NDIS

[49] An important commitment by governments under the Disability Reform Strategy was to use the review points of National Agreements and National Partnerships as an opportunity to assess their consistency with the aims and objectives of the Strategy.

are better informed about their roles and responsibilities, and help identify problems and solutions.

Box 6.12 A need for better cross-service co-ordination

Victorian Healthcare Association:

> In some cases the roll out of the NDIS has led to fragmented management of care recipients by creating artificial barriers between 'health' needs and 'disability' needs — rather than treating clients holistically and providing integrated care. (sub. 172, p. 4)

Victorian Council of Social Services:

> To help people with disability achieve their aspirations, they need to be treated holistically and receive coordinated support. This is particularly the case for NDIS participants who face a range of complex issues such as experiencing chronic health conditions, homelessness, family violence, child and family services and substance abuse.
>
> There is a role for state and federal governments to better coordinate mainstream systems with the NDIS and to meet their commitment under the National Disability Strategy 2010–2020. (sub. 176, p. 25)

National Mental Health Commission:

> For people living with mental illness, the service landscape is complex and fragmented, as services are both cross-sectoral (health and disability, as well as other sectors such as housing) and cross-jurisdictional (Commonwealth and state/territory). To meet the needs of people with a psychosocial disability, coordination across these sectors and jurisdictions is required to ensure no gaps in services emerge from the implementation of the NDIS. (sub. 153, p. 7)

Flourish Australia:

> To ensure an integrated system that takes a holistic approach and is responsive to the differing needs of people with mental health issues, it is important that the NDIS has strong links to and collaborates with other parts of the system. From our perspective, it would appear that the priority at the moment is the rollout of the Scheme, not smooth transition, collaboration or integration with other relevant service systems. This is problematic. (sub. 74, p. 9)

6.4 Interface with aged care

An important issue in the design of the NDIS is the interface between the aged care and disability systems. As people with disability age, they are likely to experience age-related conditions, such as increasing frailty, or the onset of age-related neurological conditions (such as Alzheimer's). At the same time, a person may develop a non-age related disability later in life.

Under the NDIS, a scheme participant:

- under the age of 65 years can choose to purchase supports from an aged care provider and the NDIS will fully meet these 'reasonable and necessary' individualised support costs

- has the choice to stay in the NDIS, or transition to the aged care system, once they turn 65 years old
- ceases to be a participant when they enter a residential care service or start being provided with home based care on a permanent basis, but only after they turn 65 years old (DRC 2015b, p. 26).

There are aspects of the design of the NDIS, and how it interfaces with the aged care system, that create incentives for people to stay in the NDIS after the age of 65, and encourage people nearing the age of 65 to apply for NDIS access (and have their needs met through the scheme, rather than through the aged care system). For example, there are differences in the objectives, financial contributions, and the level of supports provided under the two systems (box 6.13).

Box 6.13 Incentives to remain in, or seek access to, the NDIS

Varying objectives

The NDIS is intended to support the independence of people with disability, provide reasonable and necessary support and has an insurance based focus of lifetime care for the participant. In contrast, the aged care system focuses on minimising a person's loss of autonomy, and acknowledges that 'if you live long enough, you will need some form of care and support because of frailty' (PC 2011b, p. 147).

This can result in different supports provided by the two systems.

Financial incentives

A NDIS participant is provided care and support at no cost, whereas a person accessing the aged care system may be subject to a means tested co-contribution. As noted by one participant (Name withheld, sub. 5, p. 1) as long as the market for providing services to NDIS participants is operating effectively, it is difficult to see why people would choose to transition from the NDIS to aged care.

Aged care is capped and rationed

The NDIS provides all eligible participants a package of supports which is uncapped, provided these supports are deemed to be reasonable and necessary. In contrast, the aged care system has a limited number of places, and packages have a capped amount of government funding. For example, an NDIS participant with a spinal cord injury has an annual average package of about $109 000 (excluding shared supported accommodation — chapter 2), whereas the largest Home Care and Residential Care packages (excluding supplements) are about $50 000 and $80 000 per year, respectively (Department of Health 2017a).

These incentives raise some issues that need to be addressed. However, given the infancy of the NDIS, and in the absence of adequate data on the characteristics of people aged 65 years and over in the scheme, it is too early to determine the best approach to take.

Some of the policy options that could be worth exploring (as more data become available) include:

- changing the NDIS entry cut-off age — possibly to align with changes in the age pension age (transitioning from 65 to 67 years by July 2023)
- removing the NDIS entry cut-off age altogether — some participants suggested that an age cut off is inequitable and discriminatory (Disabled People's Organisations Australia sub. 165, pp. 11–12 and Motor Neurone Disease Australia sub. 45, p. 7)
- introducing a co-contribution for people aged over 65 years in the NDIS (this was suggested by the PC in 2011)
- better aligning the aged care and NDIS systems.

The Commission considers that, in light of new information, the Australian Government should review the interface between the NDIS and the aged care system as part of the 2023 review of NDIS costs.

6.5 Interface with the National Injury Insurance Scheme

In 2011, the Productivity Commission also recommended that a National Injury Insurance Scheme (NIIS) be established and operate in parallel to the NDIS. At the time, the Commission considered it a priority to establish a no-fault lifetime care and support scheme for catastrophic injuries, as many Australians acquiring such injuries were receiving poor care and support because they were unable to find an at-fault party to sue. (PC 2011, pp. 851-854)

Under the model proposed by the Commission, the NIIS was to fully fund health, rehabilitation and care and support costs for all newly acquired catastrophic injuries. As such, lifetime care and support needs of people with newly acquired catastrophic injuries would be met through the NIIS and not the NDIS. However, the care and support needs of people with existing catastrophic injuries, and not covered under any no-fault arrangements, would be met through the NDIS.

The NIIS, as proposed by the Commission, was to operate as a federation of individual state-based no-fault insurance schemes. It was recommended that the NIIS be in full operation in 2015, or before the full rollout of the NDIS. This was on the basis that there were well-established schemes in place that could form the blueprint for the design of schemes and the number of people affected was relatively small (about 1000 people a year) (PC 2011, p. 863).

Implementation of the NIIS is overseen by the Australian Treasury (2017f) and has been investigated across four streams:

- motor vehicle accidents
- workplace accidents

- medical treatment injuries
- general accidents (occurring in the home or community).

Of the four streams, motor vehicle accidents is complete, and workplace accidents is in the process of being completed — a consultation Regulation Impact Statement has been released and progress is being made towards setting minimum benchmarks (Australian Treasury 2015).

Progress on the other two streams — medical accidents and general accidents — has been slower. In June 2017, COAG agreed not to proceed with the medical accident stream. COAG is also seeking advice from Treasurers, in consultation with the DRC, on a general accident stream of the NIIS (COAG 2017, p. 3).

As there is no agreement in place by the State and Territory Governments to commit to the funding for — or establishment of — the medical and general accident streams, anyone who acquires a catastrophic injury from a medical or general accident will receive supports through the NDIS. This will have a direct impact on NDIS costs.

A number of study participants pointed to the costs to the NDIS.

> Not proceeding with the medical or general streams of the NIIS will have a direct impact on the NDIS by increasing overall Scheme costs. … Any additional cost, not adequately funded by the States, is a risk to the Commonwealth. (DSS sub. 146, p. 26)
>
> The sustainability of the NDIS depends on a complete NIIS that, in providing no fault insurance for catastrophic injury, removes the significant cost drivers of these injuries from the NDIS. (Young People In Nursing Homes National Alliance, sub. 187. p. 4)
>
> Without the NIIS in place, further cost-pressure will be placed on the NDIS. (NDIA sub. 161, p. 113)

The DSS argued that the funding obligation should sit with State and Territory Governments:

> Contingencies are needed if the full NIIS is not delivered, as this would move costs onto the NDIS. … If the NDIS were to pick up responsibility the funding obligation would sit fully with the States, which have responsibility for implementing the NIIS. (sub. 146, p. 5)

And:

> The States should bear the consequential NDIS costs if the NIIS remains only partially implemented. This is consistent with the *Intergovernmental Agreement for the National Disability Insurance Scheme (NDIS) Launch* and the transition agreements between governments, reflecting the original intent of the NIIS to reduce the cost of the NDIS. (sub. PP318, p. 11)

However, a number of State Governments disagreed. For example, the Queensland Government said:

> The terms of Queensland's 2013 Heads of Agreement with the Australian Government do not require implementation of NIIS streams for medical or general accidents. The recent COAG

> decision to not proceed with a medical NIIS at this time should not put Queensland at risk for liabilities of NDIS participants who might otherwise have been covered by a NIIS. (sub. PP345, p. 12)

And the South Australian Government said:

> Negotiations regarding the establishment of a NIIS for medical and general injuries are occurring between the Commonwealth and the states and both levels of government have recommended to COAG that the medical NIIS not proceed at this time. … The NDIS cost implications arising from a failure to establish NIIS arrangements are not clearly a state responsibility, given states' lack of involvement in these fields of insurance, the joint decision making process underway between both levels of government to assess feasibility and the relatively stronger ability of the Commonwealth to raise revenue from efficient taxes. (sub. PP354, p. 7)

The cost implications to the scheme may be lessened by the NDIA's ability to seek compensation from other parties (chapter 5 of the NDIS Act).[50] The NDIA can seek a share of compensation from medical indemnity and public liability payouts related to disability care and support. The NDIA's CEO can also require a person take action to obtain compensation if another party is at fault.

The number of people entering the NDIS, who would otherwise be covered by the medical or general accident streams of the NIIS in any one year is expected to be relatively small — across both streams the Commission (PC 2011, p. 793) estimated there to be about 400 people.

But over time, as new people enter each year, there is a cumulative effect. To illustrate, modelling undertaken by the NDIA suggests that the cost to the NDIS of the medical and general schemes not operating would amount to about $23 million in 2018-19. But, would increase to about $226 million in 2025-26 and to about $1.3 billion in 2040-41 (table 6.3). These numbers take into account the NDIA seeking compensation.

[50] In Western Australia, the motor vehicle accident stream allows participants to take their benefits as a lump sum. This has raised some concerns about its potential impact on NDIS costs should Western Australia join the NDIS. For example, if a participant exhausts their lump sum they could access the NDIS. Queensland's motor vehicle NIIS contains provisions of similar effect to that of Western Australia, whereby a participant can seek a lump sum compensation through common law. However, *National Injury Insurance Scheme (Queensland) Act 2016* (Qld) s. 17(4) allows a person to further seek compensation from NIIS Queensland should they exhaust their funds after five years. This means there is minimal impact on NDIS costs. If Western Australia joins the NDIS, a similar provision of NIIS Queensland Act would need to be included in Western Australia's *Motor Vehicle (Catastrophic Injuries) Act 2016* (WA) to negate the impact on the NDIS costs.

Table 6.3 **Medical and general accidents costs to the NDIS**
$ million

	2018-19	*2019-20*	*2020-21*	*2025-26*	*2030-31*	*2035-36*	*2040-41*	*2045-46*
Medical	1	3	7	33	71	121	186	271
General	4	19	42	193	417	712	1 098	1 597
Total	**5**	**23**	**49**	**226**	**488**	**833**	**1 284**	**1 868**

Source: Commission estimates based on NDIA modelling.

One of the key goals of the NIIS is to deter high-risk behaviour and reduce local risks that can contribute to accidents. For this reason, in 2011 the Commission argued that premiums and State and Territory funding should be used to send price signals and encourage greater incentives for safety (PC 2011, p. 865).

The Commission acknowledged that the appropriate funding source for no-fault coverage of catastrophic injuries following medical treatment is more complex than for other accidents. A key consideration is to build on existing incentives to minimise risk by:

- motivating the systematic collection and analysis of data that may decrease risks
- varying premiums depending on whether practitioners (or the health sector more broadly) follow best practice protocols and have the appropriate training and credentials (PC 2011, p. 877).

For general injuries, accidents can have a range of causes, such as environmental factors (for example, maintenance of footpaths and safety of play grounds) and the nature of activity being undertaken (such as participating in riskier recreational activities). Local governments are in the best position to put in place incentives to minimise the risk of accidents (such as proper signage around dangerous areas) and to collect revenue to fund the NIIS (including, for example, a levy on local government rates).

Because the States and Territories have greater control over implementing risk reducing programs (and therefore, indirectly, the costs of the NIIS), they should bear the costs of the NIIS if it remains only partially rolled out for an extended period.

To provide incentives for State and Territory Governments to take steps to reduce the incidence of catastrophic accidents, the mechanism chosen to determine funding for the NDIS (to account for the NIIS being only partially operational) would need to ensure governments with lower rates of accidents pay less than governments with higher rates of accidents. Such a mechanism would be complex and it may be difficult to secure unanimous agreement to the parameters that would be involved. The NDIA provided a possible approach, including ways to collect data and apportion costs (box 6.14).

Alternatively, some kind of base adjustment could be made to the general contributions to the NDIS from the States and Territories. Under this approach, the adjustment should reflect

an estimate of the costs incurred by the NDIS in respect of each jurisdiction as a result of the NIIS not being fully operational. Such an adjustment would have the benefit of simplicity (the value of transparent funding arrangements is discussed in chapter 12), but the incentives for risk reduction by the States and Territories would be lost relative to the option discussed above.

Box 6.14 The NDIA's proposed approach to account for partial NIIS

The NDIA's proposed approach to recoup the costs of providing care to people who otherwise would be covered by a fully functioning NIIS involves three steps:

- *Collecting sufficient data:* appropriate data is required to calculate costs intended to be covered by the NIIS, such as past and new compensations as well as data on participants who enter the scheme with a catastrophic injury
- *Apportioning the costs*: using the data collected, the NDIA can apportion costs accordingly (such as accounting for compensation, the injury stream and which state they originate from), and project future injuries and the cost implication on the NDIS.
- *Paying the costs*: as the full scheme funding mechanism is yet to be determined by the Commonwealth, States and Territories, an additional annual or monthly amount could be paid to the NDIA (sub. PP327, pp. 33–34).

The funding mechanism to account for the cost impact on the NDIS of the NIIS not becoming fully operational will be a matter for negotiation between the Australian, State and Territory Governments.

RECOMMENDATION 6.4

If the medical and general accident streams of the National Injury Insurance Scheme are not implemented, then State and Territory Governments should bear the additional costs borne by the National Disability Insurance Scheme because of the absence of these streams.

7 Provider readiness

Key points

- Providers play an important role in meeting the needs and goals of National Disability Insurance Scheme (NDIS) participants, and improving their lives. However, the transition to a market-based system means that providers need to change the way they provide disability supports. To survive in this new environment, providers need to become more efficient, innovative and responsive to participants.
- Scheme costs are affected by the supply of disability supports. Insufficient supply will mean scheme costs are lower in the short term because participants' supports are underutilised, but higher in the longer term because timely supports can reduce participants' costs of care over their lifetimes.
- While the market-based approach will increase providers' incentives to deliver supports in areas previously undersupplied, there will continue to be 'thin markets' where there are few, if any, providers. Arrangements to deal with thin markets (including Provider of Last Resort arrangements) need timely and considered attention because shortages, less competition and poorer participant outcomes may persist.
- Given the individualised needs of participants and specific circumstances that can lead to thin markets, no approach (including block-funding) should be ruled out by the National Disability Insurance Agency (NDIA) when seeking to address situations where the market is not supplying reasonable and necessary supports. Ongoing public reporting, monitoring and evaluation of thin markets are also crucial.
- Services provided 'in-kind' by the Australian, State and Territory Governments can hinder market development, and reduce choice and control for participants. However, some in-kind services are necessary for continuity of support. Careful, cooperative and consistent approaches between the NDIA and governments are needed to end in-kind services as quickly as practicable.
- Study participants pointed to barriers to providing NDIS supports, including: the cost of moving to fee-for-service; the administrative burden of the NDIS; and the risk of less collaboration between providers. While these are likely to be transitional issues, ongoing monitoring can ensure that they do not become entrenched or systemic issues.

National Disability Insurance Scheme (NDIS) costs are affected by the supply of disability supports. If there are not enough providers and workers to deliver the supports allocated by the National Disability Insurance Agency (NDIA) to participants, this will lead to underutilisation of supports, lower than expected costs to the scheme in the short term, but poorer outcomes for participants and their families.

Costs should be considered from a long-term perspective. When reasonable and necessary supports are allocated to participants under the NDIS's insurance-based approach, the

package of supports should minimise the long-term cost of care to the community. If supports are not available, the costs of supporting participants may be higher in the long term — because of more services demanded through the NDIS, through other government services, or through informal carers. There are also costs to participants and their families from reduced wellbeing.

The impact on the wellbeing of a person with disability from not being able to access supports will vary by support type. For example, not being able to find a carer to provide core supports (like an attendant carer to provide assistance to get out of bed and with personal daily activities) is likely to impose a higher cost on a person with disability than not being able to find a provider for community-engagement activities. The use of the community-engagement support is also likely to be contingent on being able to find someone to provide core supports, and vice versa.

The focus of chapters 7–10 is on how ready the market (providers, workers and participants) is, and how this will affect scheme costs. This chapter looks at how existing and new providers are responding to the increased demand for supports under the NDIS.

- Section 7.1 provides a snapshot of the current state of the disability support sector and the expected growth required to meet the demands of the NDIS.
- Section 7.2 looks at where the market supply for disability supports could be limited and result in 'thin markets'.
- Section 7.3 examines the effect of in-kind services.
- Section 7.4 discusses other transitional matters affecting provider readiness.
- Chapter 8 considers the pricing of disability supports.

7.1 The changing disability support market

People with disability have different wants and needs (including personal care, therapy, community participation, and assistance with cleaning and household chores), which require a variety of supports. And the cost of providing supports varies by region and the degree of competition. This means that there are a number of submarkets within the aggregate disability support market. As explained by one provider, there are particular characteristics of the disability support market that distinguish it from a conventional market.

> The disability support 'market' is not a normal or 'perfect' market in classical economic terms. It is about providing a range of customised supports, human and technological, paid and unpaid, to meet complex and often poorly-defined human needs and wants. Outcomes are often hard to measure and report. Information is unbalanced. Regional, rural and remote markets are 'thin'. The 'buyers' of services and their local situations are diverse and heterogeneous, not homogeneous. Many are vulnerable. (House With No Steps, sub. 104, p. 1)

It is within this context that the NDIS is driving market-based competition between disability support providers, at a time when the size of the aggregate disability support market needs to significantly increase to meet NDIS demand. These changes include:

- a shift away from a block-funded, welfare model of support to a fee-for-service, market-based approach
- an increase in funding for the sector from about $8 billion in 2015-16 to at least $22 billion by 2019-20 (SCRGSP 2017; chapter 12)
- assessing and meeting the reasonable and necessary needs of about 475 000 people by 2019-20 (chapter 2)
- about 70 000 additional workers (or about 20 per cent of all new jobs created in Australia) in the three-year transition period to full scheme (Bonyhady 2016, p. 5; chapter 9).

As the NDIA said:

> In the first year [of transition], to meet projected Scheme demand, growth in supply needs to be around eight per cent. By the second and third year respectively, growth must reach 30-40 per cent, although … the supply needed to meet funded participant demand varies depending on location. (2016i, p. 8)

The market for disability supports is diverse and difficult to characterise in general terms. Some providers specialise in providing supports for those with specific disability, while others specialise in providing particular types of supports (such as accommodation or therapeutic supports). Others provide a much more general service.

The data on disability support providers are patchy. The most comprehensive data were collected by Martin and Healy (2010). More recent work by National Disability Services (NDS) and Curtin University's Not-for-profit Initiative contains data on provider characteristics and financial performance.[51] Notwithstanding the data limitations, the data provide some insights.

- Many providers are small.
  - About 40 per cent of disability service outlets employed 10 or fewer disability workers (Martin and Healy 2010, p. 122).
  - The NDS estimated that about 58 per cent of providers are either small or very small (with a turnover of less than $5 million) (Gilchrist and Knight 2017a, p. 10).
- Most disability providers (about 80 per cent of survey respondents) are not-for-profit (NDS 2016, p. 7).

[51] The National Disability Services' (NDS) State of the Disability Sector Report 2016 is based on the fourth wave of the National Business Confidence Survey of 549 disability service providers, of whom 486 were NDS members and 63 were non-members (NDS 2016, p. 7). The NDS has also undertaken a financial benchmarking project for disability services (NDS nd). This work was commenced by Curtin University and is now being done in partnership with the University of Western Australia (Gilchrist and Knight 2017b).

- Most providers do not just provide disability services.
  - About 57 per cent of providers surveyed by the NDS provided services in other areas, such as aged care, mental health and homelessness (NDS 2016, p. 13).

How will the sector need to change under the NDIS?

While a lack of data prevents a comprehensive evaluation of the current state of the sector, envisioning how the future disability sector will look under the NDIS is even more difficult. Some of the supports required by participants will be provided by existing providers who expand, while others will be provided by new entrants. However, what is not certain is:

- how many providers will be needed — and the proportion of new and existing providers
- what the proportion of for-profits, not-for-profits and government service providers will be
- whether there will be greater specialisation by disability, type of support, or both
- how long it will take for these changes to occur.

This uncertainty is reflected in estimates on the number of providers needed under the NDIS. The Australian National Audit Office (2016, p. 68) estimated that between 13 500 and 40 000 providers will be needed by the end of the transition period in 2020. Understanding how existing providers are responding to, and whether new providers are entering, the NDIS market is therefore important.

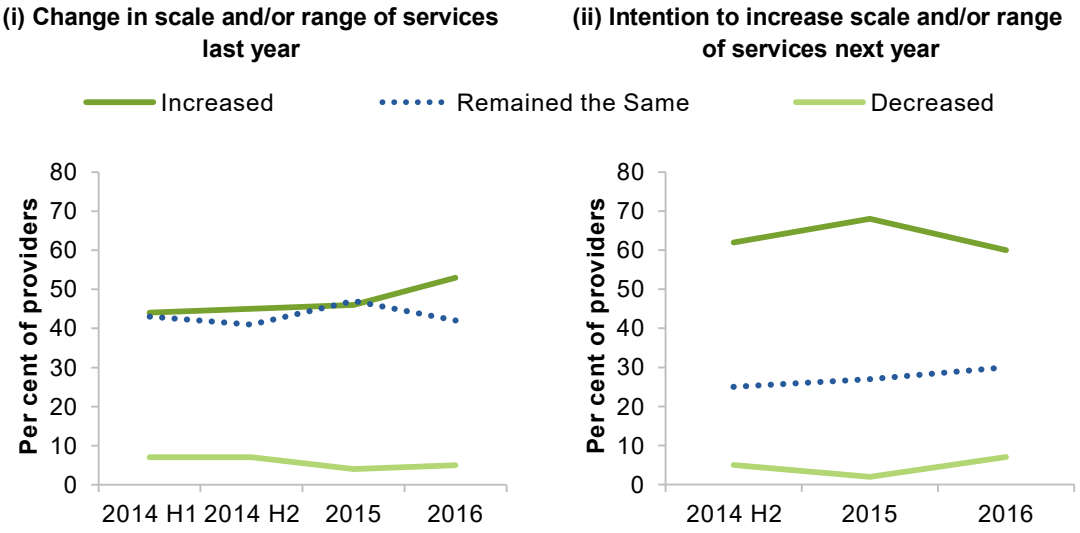
The NDS survey of providers gives some insight on how existing providers are responding. The majority of providers surveyed in September 2016 reported that they had expanded their services last year, and that they intended to expand in 2017 (figure 7.1). Providers reported increasing their services, particularly in the areas of therapy, early intervention, and planning and coordination supports (NDS 2016, p. 11), but the amount of additional supports is unclear.

However, some providers reported plans to reduce or stop supplying services in other areas, and that they are entering new markets (outside of the disability support sector) (NDS 2016, pp. 12–13). The financial position of providers is also variable, and in turn, the strength of existing supply (NDS 2016, pp. 14–15).

It is more difficult to determine the size, scope and number of new providers who are entering the market in response to the NDIS. Data are available on the number of providers *registered* with the NDIA to provide supports under the scheme, which includes both existing and new providers (figure 7.2).

While registrations increased by about 30 per cent between the March 2017 and June 2017 quarters, about 54 per cent of registered providers are not yet active, and the largest 25 per cent of active registered providers currently account for about 80–90 per cent of the value of payments made by the NDIA for participant supports (NDIA 2017y, p. 41).

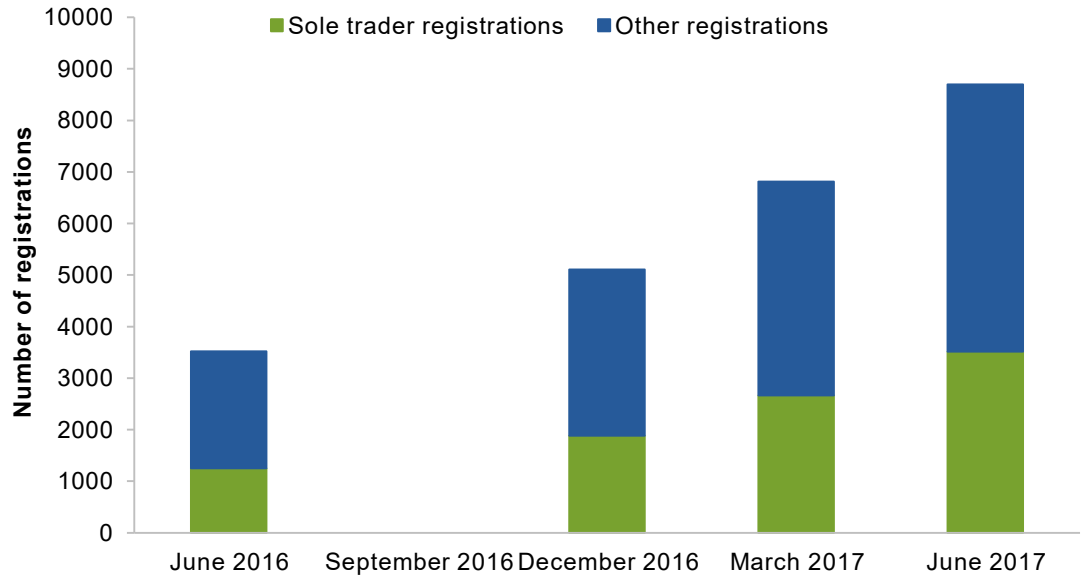
Figure 7.1 **Providers' response and intention to increase supply[a]**



[a] H1 and H2 refer to the first half and second half of the calendar year respectively.

Source: Gilchrist and Knight (2017a, p. 16), who surveyed 492 respondents.

Figure 7.2 **Cumulative number of NDIA-registered providers by quarter[a]**



[a] Data for September 2016 are unavailable.

Sources: Commission estimates based on NDIA (2016p, 2016q, 2017y, 2017z).

This is consistent with NDS data, where 77 per cent of providers surveyed had registered, but only about half had provided services under the NDIS (Gilchrist and Knight 2017a, p. 5).

One explanation could be that some providers are registering to provide services ahead of the NDIS rollout in their location (NDIA 2017y, p. 43; DSS, sub. 146, p. 36).

Growth in registrations of those providing therapy supports — usually allied health professionals — has been strong. In the quarter ending 30 June 2017, allied health professionals accounted for about half (48 per cent) of the increase in registrations (NDIA 2017y, p. 43).

While the scale of market growth to date is uncertain, many providers who made submissions to this study identified the main challenges to developing the market for disability supports as:

- the effect of price controls for supports set by the NDIA (chapter 8)
- concerns that some markets will be too small to be profitable
- government-provided disability services
- other transitional issues affecting provider readiness.

7.2 Thin markets and the Provider of Last Resort

The market-based model for disability supports under the NDIS is designed to encourage greater supply of the supports that people with disability want and need compared with previous arrangements (PC 2011, pp. 111–156). However, there continue to be cases when the disability support market remains too small (in terms of the number of providers or participants) to support the competitive provision of services. This outcome is known as a 'thin market'.

There are a number of negative consequences of thin markets. Insufficient supply may lead to higher prices, less variety, lower quality services and unmet demand. In the disability support sector, thin markets can result in poor participant outcomes, increased demand for mainstream services, and greater pressure on informal carers. Scheme costs are also affected — while they may be lower in the short term (due to underutilisation of supports), they may be higher in the long term if participants are not receiving the right supports at the right time. For these reasons, governments often need to — and do — intervene in thin markets to ensure the supply of disability supports for people with disability.

When will thin markets arise under the NDIS?

Thin markets can arise in places or for particular disability supports when demand is limited and the cost of supply is high. Some have noted that thin markets are most likely to occur in rural, regional and remote areas, for Indigenous and culturally and linguistically diverse (CALD) cohorts, and for specialised supports, such as aids and equipment (DRC 2015a,

p. 19; NDIA 2016i, p. 15). Study participants also identified access problems for particular groups of people with disability, including for some participants:

- living in outer regional, remote or very remote areas[52]
- with complex, specialised or high intensity needs, or very challenging behaviours, such as those with psychosocial disability or who require 24-hour care[53]
- from CALD backgrounds (ECCV, sub. 31)
- who are Aboriginal and Torres Strait Islander Australians[54]
- who have an acute and immediate need (crisis care and accommodation).[55]

Given the early stage of the transition, it is difficult to tell *where* thin markets are under the NDIS, and whether they are diminishing, persisting or growing. And where there are thin markets, it is not necessarily the case that they are occurring because of the NDIS. Thin markets were a feature of the previous disability support arrangements, and are a feature of many other human services (PC 2011, pp. 115–156, 2017b). What is important is that the policies are put in place in a timely manner to minimise their incidence and impact on participants and providers. This is especially the case as the interface with other mainstream services evolves (chapter 6). Thin markets will remain a feature of some disability supports under the NDIS (box 7.1).

52 For example: the AFDO (sub. 180); APC Prosthetics (sub. PP244); Australian Red Cross (sub. PP258); The Benevolent Society (sub. PP334); Cheryl McDonnell (sub. 79); Commonwealth Ombudsman (sub. 137); CTO (sub. PP280); Deaf Australia (sub. 183); EACH (sub. PP276); ECIA NSW/ACT (sub. 190); GIFSA (sub. 13); MAV (sub. PP343); Mental Health and NDIS Facebook Support Group (sub. 8); MND Australia (sub. PP255); MTHCS (subs. 6 and PP222); Northern Territory Government (sub. 205); OPA Victoria (sub. 46); OPG (sub. 143); QAI (sub. 115); Quality Living Options Bendigo (sub. PP220); Queensland Government (sub. PP345); RDAMR (subs. 12 and PP231); and South Australian Government (sub. 203).

53 For example: ABF (sub. PP263); Carers Australia Victoria (sub. 131); Cohealth (sub. PP261); Department of Health (sub. 175); DSA (subs. 9 and PP256); Leadership Plus (sub. 128); Legal Aid NSW (sub. PP245); MHCSA (sub. PP308); Neami National (sub. PP347); NSWCID (sub. PP234); PWSAA (sub. PP228); Tandem (sub. PP212), VALID (sub. PP332); Vision Australia (sub. PP252); Women with Disabilities Victoria (sub. PP282); and Youngcare (sub. PP253).

54 For example: Anglicare NT (sub. PP340); First Peoples Disability Network Australia (sub. PP355); Flourish Australia (sub. PP246); GIFSA (sub. 13); Northern Territory Government (sub. 205); MJD Foundation (sub. PP233); OPG (sub. 143) and VACCHO (subs. 162 and PP223).

55 For example: Anglicare Tasmania (sub. 145, pp. 46–47); DSA (sub. PP256, p. 3); MS Australia (sub. PP283, p. 8); and Youngcare (sub. PP253, p. 2).

Box 7.1 Evidence of thin markets under the NDIS

Thin markets for disability supports have long been an issue for some groups and in some regions. The structure of these thin markets means that many will persist under the National Disability Insurance Scheme (NDIS). For example, the DSS (sub. 146, p. 37) said that there was early anecdotal evidence of thin markets for personal care supports, supports for participants with complex needs, early childhood supports and employment supports. In particular, thin markets are likely to exist for people with disability who live in rural and remote areas, which appears to be confirmed by early evidence from the scheme.

- The NDIA (2016c, p. 34) deemed the supply risks for therapy supports (a specialised support) to be more acute in regional areas in southern New South Wales.
- A National Institute of Labour Studies survey found that unmet demand was experienced more by NDIS participants living in rural and remote areas in the Victorian trial site and by older NDIS participants, particularly by those living in regional areas (Mavromaras, Moskos and Mahuteau 2016, p. xi). These findings were similar to those of a survey of participants living in the Victorian trial site by the Melbourne Social Equity Institute. It found that underutilisation of supports was particularly evident among participants living in regional areas, or those needing highly specialised services and supports (Warr et al. 2017, pp. 30–31).
- In some service regions, the increase in the value of support packages is forecast to grow more quickly than the growth in participants (NDIA 2016l, pp. 10–12, 2016x, pp. 10–12). This could reflect a lack of supports and more unmet demand for these participants.
- In South Australia, almost one-third of NDIS participants are expected to reside outside of Adelaide (NDIA 2016u, p. 25); however, the NDIA observed that there was a lack of provider choice in remote and very remote areas in South Australia, with participants often dependent on a key support worker (NDIA 2016u, p. 26).
- Participants in the Barkly region in the Northern Territory had the third highest level of unutilised funding — 41 per cent of committed supports in 2014-15, and 64 per cent in 2015-16 (NDIA 2017v, p. 29). However, underutilisation may be due to a number of factors other than unmet demand (chapter 2).
- In the Northern Territory, there appears to be a shortage of supports for physical disabilities. At the end of June 2016, only one per cent of active registered providers in the Northern Territory provided physical wellbeing services, but 27 per cent of participants with an approved plan in the Barkly trial region were identified as having 'other physical disabilities' (NDIA 2017v, pp. 10, 22). The NDIA noted that:

  > Given the much higher level of physical disability in the Territory as compared to … [Victoria and New South Wales], the number of providers registered to provide physical wellbeing supports appears to be low. (2017v, p. 21)

How should thin markets be addressed?

One of the challenges of addressing thin markets is that while they share some common characteristics, often they have very specific and different causes. A 'one-size-fits-all' approach will not to be feasible or effective. A more tailored response that considers the complexities of dealing with the wide variety of thin markets is required, taking into account issues such as the presence of CALD and Aboriginal and Torres Strait Islander communities,

quality of infrastructure, weather events and population density.[56] In practice, it means that standardised approaches to pricing may not be effective to encourage supply in some thin markets. This is reflected in the diversity of options that can be used to address thin markets (box 7.2).

However, there are costs associated with government intervention to minimise underprovision of disability supports in thin markets. To address thin markets, it is necessary to balance the trade-off between providing services that are not only cost-effective, but also as flexible as possible to enable participant choice and control. For example, the NDIA's Rural and Remote Strategy (NDIA 2016t), and Aboriginal and Torres Strait Islander Engagement Strategy (NDIA 2017b) both reflect the need to provide disability supports in a way that allows for as much choice and control for participants as possible, and to encourage innovative methods of service delivery.

Such an approach is also reflected in the Bilateral Agreement between the Northern Territory and Australian Governments on the transition to the NDIS, as the Northern Territory has historically faced particular challenges in providing human services due to thin markets (PC 2017b). It was agreed that the Northern Territory's approach to the transition would be guided by the following principles:

- place-based, tailored solutions to planning, market development, access to services and risk management
- a coordinated, client-centred, and tailored approach to the operating model in remote communities, informed by existing effective frameworks that maximise access, engagement and management of risk for individuals
- culturally competent engagement and professional practices
- local planning, market development and risk management strategies informed by timely and appropriate data (Australian Government and Northern Territory Government 2016, p. 4).

It is too early to assess how these principles have been implemented in practice, how effective they have been in addressing thin markets, and whether such approaches are appropriate for other jurisdictions. The NDIS Evaluation Consolidated Report, which is to be released in the latter half of 2017, may provide useful guidance on this issue (Mavromaras, Moskos and Mahuteau 2016, p. 18).

[56] For example, scheme participant density in the Northern Territory (except the Darwin urban service region) in 2020 is expected to be less than five participants per 100 square kilometres (NDIA 2017v, p. 14). Despite remoteness price loadings, some providers in Queensland also reported to the NDIA that recent new providers were concentrated in major population centres such as Townsville, Cairns and Mackay (NDIA 2016s, p. 33). The Commonwealth Ombudsman (sub. 137, p. 16) also noted that some existing providers who specialise in providing services for people with disability who are CALD and Aboriginal and Torres Strait Islander Australians may not be able to make the transition, due to registration barriers and insufficient cash reserves to transition to fee-for-service.

Box 7.2 Different approaches to address thin markets

There are a number of measures that could be used to mitigate the risks of thin markets.

- Partial or full block-funding to commission or procure services (PC 2011, pp. 521–523). Goldfields Individual and Family Support Association (sub. 13, p. 12) said that removing block-funding would likely result in an 'almost complete loss of … services on the very remote Lands'. Many study participants said that block-funding is the most efficient way to ensure that needs are met (Centacare Brisbane, sub. 44; Australian Blindness Forum, sub. 48; Cohealth, sub. 50; Anglicare Tasmania, sub. 145; and Department of Health, sub. PP360).
- Sharing infrastructure, knowledge, skills and experience among providers.
- Facilitating bulk-purchasing arrangements by participants — for example, by pooling participants' funds (Mallee Track Health and Community Service, sub. 6; PC 2017b).
- More collaboration, coordination and integration of services, particularly with existing local and mainstream service providers, community organisations (including Indigenous organisations) — to avoid supply gaps or duplication (CADR 2014, p. 15; RACGP, sub. 200). Providing more hours of support coordination in participants' packages should also be considered, particularly for those with complex needs (Alzheimer's Australia, sub. 10, pp. 9–10). Brain Injury SA (sub. 116, p. 14) and the First Peoples Disability Network Australia (sub. PP355, p. 10) emphasised the need for effective coordination of services among the Australian, State, Territory and local Governments.
- Use of community- or place-based services (PC 2017b) — including greater employment and training of the local workforce where possible. Aboriginal community controlled organisations could also have a role in building community capacity in delivering disability services for Aboriginal and Torres Strait Islander participants living in rural and remote locations (VACCHO, sub. 162, PP223; AMSANT, sub. PP336; JSCNDIS 2017c, p. 46).
- Greater use of information technology — including videoconferencing, telehealth and other technologies, particularly for therapeutic supports (NDIA 2016w, p. 28; APA, sub. 93; Amaze, sub. 160; Livecare Australia, sub. PP217).
- The NDIA providing more detailed and frequent information on market demand (and unmet demand) to encourage providers to enter thin markets. The NSW Government (sub. PP230, p. 7) said that more information on location, type and quantum of demand is required.
- Cultural training, education and awareness programs (Brain Injury SA, sub. 116; Commonwealth Ombudsman, sub. 137) — including greater funding of translators and interpreters (GIFSA, sub. 13; Cohealth, sub. 50; SDN Children's Services, sub. 73; and Companion House, sub. 84).
- More support and respite care for informal carers (chapter 9).
- Greater engagement with the local community to build trust and relationships — including consideration of community feedback on provider performance (PC 2017b) and the development of community plans (First Peoples Disability Network Australia, sub. PP355, p. 9).

What is being done to address thin markets?

Based on the experience of the NDIS trial sites (particularly the Barkly trial in the Northern Territory), the NDIA said that it would consider a range of approaches to mitigate the risk of thin markets, including:

- active and deliberate cross-government collaboration — including the use of locally-based workers, and educating the community about the interface between health services and disability supports
- leveraging established community organisations (such as those already operating in health, aged and community care sectors) that may also deliver disability services
- supporting providers to access supports from business councils, Indigenous Business Australia, or any other organisation in the Aboriginal and Torres Strait Islander business capacity-building sector
- using the hub and spoke model (also known as scaffolded support) — where generalist providers provide support in the rural or remote community, and where needed, can collaborate or seek oversight from an advanced practitioner or specialist centre, either through a visiting clinic or telepresence
- working with existing mainstream providers to expand their services to better meet the needs of participants — such as plan management services by local accounting services and re-purposing underutilised infrastructure (sub. 161, pp. 105–106).

These approaches rely heavily on the commercial decisions of providers (such as the type of workforce, the decision to deliver disability services, and service delivery business models). They also reflect an attempt to make the market-based, consumer-driven approach succeed where possible — with more interventionist alternatives a last resort (such as directly commissioning or providing supports). The NDIA (sub. 161, p. 106) noted that 'some providers are thinking creatively about supply in thin markets', including by diversifying into associated areas to provide additional business income, and forming business relationships between urban and remote businesses.

Study participants had mixed views on the NDIA's proposed approaches, particularly in relation to greater reliance on mainstream providers.

- The NSW Government (sub. PP230, pp. 6–7) cautiously supported the idea of using mainstream providers, but emphasised that 'mainstream government service providers should be the exception, not the norm', as it could stifle the development of a competitive market. It argued that there needed to be a clear strategy and actions to encourage non-government providers to supply services to people with disability.
- Vision Australia (sub. PP252, p. 11) agreed that reliance on mainstream services may be practical and cost-effective. However, it noted that ensuring quality of service would be challenging and that funding through Information, Linkages and Capacity building grants to provide training and support for mainstream providers may be a useful trial.

- Inclusion Australia (sub. PP357, p. 21) was also sceptical about the responsiveness of mainstream providers to the needs of people with disability, given their 'poor track record' in responding to these needs.
- The MJD Foundation (sub. PP233, p. 10) argued that the reliance on mainstream providers has so far not been achievable, and that cross-government collaboration has generally not been successful to improve outcomes for Aboriginal and Torres Strait Islander participants in remote communities.

While the details of how providers are to be encouraged to supply thin markets are not yet clear, the NDIA and DSS are jointly developing a more detailed Market Intervention Framework to address thin markets, which is being negotiated with each jurisdiction (NDIA 2016i, p. 15, 2016t, p. 26). The Commission understands that the NDIA is developing a more detailed Market Intervention Strategy to support the establishment of a more developed NDIA market monitoring system and to facilitate the NDIA's decision-making on market interventions (DSS and NDIA, pers. comm., 4 October 2017). This strategy is expected to be completed in late 2017 (DSS and NDIA, pers. comm., 4 October 2017).

Given that the NDIS is already more than 12 months into the transition phase, there is a risk that thin markets will persist or worsen in the absence of clear and timely strategies and intervention by the NDIA. The NDIA needs to clarify and implement practical measures to mitigate the risks to participants associated with thin markets, particularly with the withdrawal of government-provided disability services (DSS, sub. 146, p. 37; NSWCID, sub. PP234, p. 5). As the Victorian Government said:

> Greater certainty surrounding market intervention and provider of last resort arrangements is also required as thin markets and provider viability could compromise the scheme's capacity to deliver choice to participants … The NDIA is ultimately the market steward: there are significant risks to participants, providers and states if its capability to identify and intervene in thin markets is not in place by full scheme. (sub. PP298, p. 15)

While acknowledging the NDIA's Rural and Remote Strategy, the Joint Standing Committee on the NDIS recommended that:

> … the NDIA in collaboration with the Australian, State and Territory Governments develops a strategy to address the service gaps that exist for rural and remote communities. (2017c, p. 50)

Interventions also need to be tailored to the specific circumstances of each case — such as user characteristics, the broader service landscape, resource constraints and effects on the wider community (PC 2017b). The diversity of user needs means that a 'one-size-fits-all' solution will not be effective to address access issues. And it is inappropriate to automatically default to block-funding, direct commissioning or mainstream services (particularly health and aged care services) unless it is necessary. While it is likely that block-funding will be needed in some cases (PC 2011, pp. 521–523) — such as for services that benefit many people with disability and when isolating the individual cost is difficult (National Mental Health Commission, sub. PP319, p. 12) — care must be taken to avoid crowding out competition.

There is a need for collaboration between the Australian and State and Territory Governments, given the latter's knowledge and experience as funders and providers of disability services. Anglicare South Australia noted that the Exceptional Needs Unit in the Disability SA division of the SA Government Department for Communities and Social Inclusion was a practical example of when block funding, specialisation and government collaboration were appropriate for one thin market — people with disability who have complex needs and comorbidities in South Australia (Anglicare Australia, sub. PP339, p. 7).

Addressing thin markets requires a whole-of-government approach and community involvement, but some experiences to date suggest that this is not occurring in some instances (Anglicare Australia, sub. PP339, p. 9). For example, Anglicare NT reported a lack of collaboration between government departments in aged care and disability, even though in some remote communities they may be the same providers and the same workers.

> The further one moves out from any regional centre into a remote community in Central Australia or the Top End, the greater is the probability that the services for people with a disability and older people will be provided by the same service provider and indeed the same staff! Yet there is little interface between the two Commonwealth Departments that are responsible for funding these services and driving these reforms. Clearly a place based whole of government approach that works to build up a community's capacity is what is required at this time. (sub. PP340, p. 4)

Government and community collaboration are important to provide services in remote Indigenous communities (MJD Foundation, sub. PP233, p. 10; PC 2017b). The Steering Committee for the Review of Government Service Provision's most recent report on *Overcoming Indigenous Disadvantage* noted that the set of 'success factors' include:

- cooperative approaches between Aboriginal and Torres Strait Islander Australians and government — often with the non-profit and private sectors as well
- community involvement in program design and decision-making — a 'bottom-up' rather than a 'top-down' approach
- good governance — at organisation, community and government levels
- ongoing government support — including human, financial and physical resources (2016a, p. 3.18).

The MJD Foundation said that:

> The way forward is to build on established community organisations that have a successful track record in delivering services and who have existing good relationships with families and communities in the remote areas. Collaboration and not control should be the focus (sub. PP233, p. 10).

It will not always be possible to match the price, quality and range of services in the major cities (PC 2011, p. 529). Some participants may need to travel (and in some cases, move) to metropolitan areas to access highly specialised services. This highlights the need for complementary services, such as transport to access specialised disability care, to be provided either in a participant's plan or outside of the NDIS where appropriate (chapter 6).

Improving access to supports for participants in thin markets is a key objective of the NDIS, but it is an ongoing task requiring constant vigilance, monitoring and evaluation (box 7.3).

Box 7.3 Addressing thin markets requires data and ongoing reporting

Mitigating the effects of thin markets (and informing associated funding arrangements) requires more transparent identification, reporting and evaluation of thin markets. Planning, evaluation, monitoring and feedback systems (as well as commissioning practices) are discussed in the Commission's current inquiry on Human Services (PC 2017b). Specific key performance targets and indicators (both outputs and outcomes) need to be developed, and the relevant data collected, to ensure the equity, effectiveness and efficiency of disability supports and thin market strategies. This was recognised by the Joint Standing Committee on the NDIS for services in rural and remote areas. The Committee recommended that:

> … all options to develop a market that provides choice and control for participants in rural and remote areas be explored, and that any additional funding for disability in the Northern Territory to any provider is conditional on measureable increases in service provision. (2015, p. 76)

The Northern Territory Government also emphasised the need for more granular data.

> The availability of more granular data is particularly important to enable monitoring of the Scheme's roll out in remote regions and thin markets — where the NDIS market-based model is most challenging to implement. Detailed regional level data is also important to inform service providers to enable localised market growth and development (e.g. client base, size of market, and service provider gaps). (sub. 205, p. 3)

Information on thin markets (including through Local Area Coordinators and current feedback mechanisms in the NDIS) could supplement current reporting to the DRC under the National Disability Strategy. In particular, reporting in each thin market could better reflect similar measures reported by the Commission as part of the National Disability Agreement, including:

- participation rates — such as the number of eligible participants; the severity and nature of disabilities; and other participant characteristics (as well as their trends and drivers). The Joint Standing Committee on the NDIS (2015, pp. 62–67) noted a lack of data for participants who are from CALD backgrounds, as well as for Aboriginal and Torres Strait Islander Australians
- access or support use by participants — this would map use of existing and future services, such as: plan activation; the frequency and scope of plan reviews; utilisation rates; the number of providers, workers and supports; as well as market concentration
- appropriateness of supports — for example, whether supports were delivered in a culturally and linguistically respectful manner in accordance with the NDIA's Aboriginal and Torres Strait Islander Engagement Strategy
- quality of services — such as reporting the satisfaction rate of participants and carers, and any complaints under the NDIS Quality and Safeguarding Framework (and State and Territory Government quality and safeguard regulations in the interim)
- cost per unit of output — including government and NDIA contribution per participant, and forecasts of future costs per participant (this is consistent with an insurance-based approach)
- participant outcomes — such as choice and control, economic or social participation, and use of other services by people with disability (including mainstream services and informal supports) (SCRGSP 2017, p. 15.1–15.39).

Timely and ongoing data collection is particularly important as the NDIA's online platform (eMarketPlace) is still being developed (chapter 10).

Regardless of the approach taken, it is clear that there is an need for strong market stewardship by governments, as well as a consistent framework against which actions are taken to mitigate thin markets (PC 2017b; NSW Government, sub. PP230, p. 7; chapter 10).

FINDING 7.1

In a market-based model for disability supports, thin markets will persist for some groups, including some participants:

- living in outer regional, remote and very remote areas
- with complex, specialised or high intensity needs, or very challenging behaviours
- from culturally and linguistically diverse backgrounds
- who are Aboriginal and Torres Strait Islander Australians
- who have an acute and immediate need (crisis care and accommodation).

In the absence of effective government intervention, such market failure will result in greater shortages, less competition and ultimately poorer participant outcomes.

What if there is no market? The Provider of Last Resort

The NDIA does not directly supply individualised supports to participants, but there are times when it may take a direct role to ensure that services are provided (for example, by providing or commissioning services). This might occur in very specific and exceptional circumstances when providers are unwilling or unable to supply disability supports under NDIS policy settings, such as when:

- participants cannot access disability supports — there is no provider, or the only external provider is likely to fail in circumstances that would leave participants at risk (such as in remote locations)
- supports are not available at reasonable prices — this might be true for participants with highly complex needs or challenging behaviours, or in emergency situations when supports are needed at short notice
- it is difficult to verify that external providers are genuinely achieving good quality outcomes for participants or their carers
- there are significant economies of scope from combining or coordinating several services together, and when the government has an advantage in supplying the package of services — this might apply to participants who are Aboriginal and Torres Strait Islander Australians, where governments might have to deal with multiple levels of disadvantage (income, housing, health, education, urban amenity, employment, transport and disability) (NDIA 2016i, pp. 26–27; PC 2011, p. 409).

The principles that should govern provider of last resort (POLR) arrangements were considered by the Commission in 2011. The Commission said that the POLR should be subject to the same regulatory oversight and monitoring as other providers in the scheme,

and that block-funding of providers should only be used when fee-for-service was proven to be infeasible to ensure the supply of supports (PC 2011, pp. 523–526).

The Commission also emphasised the need for the POLR arrangements to be contestable and at arm's length from the commissioning body. And, when block-funding is judged to be the preferred method, that the NDIA should develop standardised tendering, contracting, reporting and acquittal requirements in order to reduce compliance costs (PC 2011, pp. 523, 528). It is not the role of the NDIA to support failing providers in thin markets, but to ensure that disability supports for participants are provided in the most effective and efficient way. The overriding aim of the POLR arrangements is to ensure continuity of support and to protect the wellbeing of participants.

The POLR arrangements for the NDIS are still being developed by the NDIA and DSS, but appear broadly consistent with the Commission's views in 2011 (box 7.4). The Commission understands that the NDIA is currently developing participant-centred operational processes to replace the previous POLR system of grants and programs for complex or very complex NDIS participants (DSS and NDIA, pers. comm., 4 October 2017). The NDIA is working with States and Territories to deliver position statements to replace existing POLR arrangements. This phase of the project is due to be completed in December 2017 (DSS and NDIA, pers. comm., 4 October 2017). However, the delay in formalising these arrangements is resulting in some uncertainty for participants, providers and governments. For example:

- The Tasmanian Government (sub. PP247, p. 8) said that the NDIA's POLR arrangements have not yet been negotiated for Tasmania.
- The Victorian Government (sub. PP298, p. 15) reported that work has commenced to construct a range of NDIS market risk scenarios to inform how market risks and crises will be managed under the POLR framework and broader Market Intervention Framework. However, the operational details for Victoria are yet to be worked out.
- The ACT Government (sub. PP312, p. 7) noted that to date, the issue of the POLR had not been addressed in the ACT. In its view, the NDIA had taken an individualised, rather than a systematic, approach to concerns it had raised, particularly in relation to participants with very high needs and challenging behaviours that concern all elements of the human services system.

The NDS stated that the POLR arrangements under the NDIS are:

> … currently poorly articulated and are inadequate. This needs to be addressed, ideally through the NDIA establishing emergency response agreements with a number of disability support providers across the country. (sub. 51, p. 16)

More recently, the Joint Standing Committee on the NDIS emphasised the importance of continuity of support for participants, and recommended that:

> … the NDIA provides details how it is ensuring a provider of last resort is available for all NDIS participants unable to find a suitable service provider, regardless of their location, circumstances and types of approved supports. (2017c, p. 50)

Box 7.4 The NDIA's Provider of Last Resort arrangements

What is the Provider of Last Resort (POLR)?

As a market steward, the NDIA is responsible for the POLR arrangements. When there is a significant risk of insufficient market supply; when no provider is available; or in the event of provider failure (for example, if the *only* local provider for a range of disability support services in a remote community goes into administration), the NDIA may directly commission and procure disability supports for scheme participants. As the NDIA said:

> If local providers are not available, the NDIA may enter into agreements (and at times contracts) with specific providers for provision of services to more remote regions. The contract with a service provider [will] specify how the cost of travel and any other associated expenses in these areas. (2017q, p. 16)
>
> The NDIA is prepared to act to reinforce thin markets where intervention is necessary to ensure market supply, and to act as a Provider of Last Resort where the market fails to provide this supply. (sub. PP327, p. 40)

Triggers are likely to include:

- insufficient, volatile or uneven supply — in a particular geography, market segment or service type, potentially due to lack of scale or lack of providers being active in that market
- evidence of inappropriate use of market power — for example, constraints to competition or lack of consumers exercising choice
- insufficient quality at a reasonable price
- benefits for greater return on investment from arrangements other than individual commissioning.

A provider contracted as a POLR will need to meet agreed quality standards and ensure that services are delivered in an appropriate and culturally competent way. The provider may also need to leverage existing infrastructure. The NDIA considers the POLR policy to be a highly interventionist form of market intervention.

Who is responsible for the POLR?

As the transition leads to full scheme, the NDIA will lead an integrated response jointly with the States and Territories. In the interim, the States and Territories lead as the POLR, and will continue to do so for providers who they fund during transition (except for the Northern Territory, where the NDIA is responsible for ensuring the POLR services even in the transition period pursuant to Schedule K of the Northern Territory Bilateral Agreement). The Agency noted that identification and response to such market failure will require collaboration among all NDIS stakeholders.

What does the POLR involve?

The POLR framework forms part of the NDIA's broader Market Intervention Framework. Both are currently being developed by the NDIA and DSS, and negotiated with each jurisdiction. It was expected that in 2016-17, the NDIA would agree to the POLR processes, and that by 2018-19, there will be a maturity of the POLR capabilities to potentially include a range of response options (such as panels in relevant jurisdictions or sub-markets capable of providing emergency capabilities at extremely short notice) (NDIA 2016i, p. 15, 2016t, p. 26).

Sources: NDIA (2016i, 2016t, 2017q, p. 16).

There is some guidance about the POLR arrangements for scheme participants in the Northern Territory. In the Bilateral Agreement between the Australian and the Northern

Territory Governments on the transition to the NDIS, it was agreed that the NDIA would be responsible for ensuring that the POLR services are in place for all participants in the Northern Territory (Australian Government and Northern Territory Government 2016, Schedule K).

The Bilateral Agreement also includes principles on how these arrangements are to work where there is a 'significant risk of service failure' (Australian Government and Northern Territory Government 2016, Schedule K). These principles include considering risk, transparency, a person-centred approach, non-exclusivity, barriers to entry, supply of services and end of service arrangements. It also stated that 'solutions will be established to avoid inappropriate default to the acute medical system as the provider of last resort' (Australian Government and Northern Territory Government 2016, p. 2, Schedule K).

Some study participants commented that this detail is not sufficient to ensure that the POLR arrangements are in place (nor what they would mean in practice).

> The State Committee is further concerned the POLR commitment is behind in its conceptual and operational planning in line with the rollout schedule and ambiguous to members on what these provisions mean in terms of their own business planning and existing services. We ask that urgent attention be given to clarify the POLR aspect of the NT Bilateral Agreement so as to further mitigate the risk of market failure. (TEAMhealth, sub. 102, p. 22)

> In January 2017, participants in the East Arnhem region commenced transition to the NDIS. It is concerning that the rollout commenced without a clear framework for the Provider of Last Resort (POLR) … Schedule K does not define what constitutes 'service failure' or how it will be recognized or measured by the NDIA, nor when it is necessary for the Provider of Last Resort (POLR) arrangement to be put in place … in 2014–2015 participants in the Barkly region in the NT had the third highest level of unutilised funding – 41 percent. At what point is this recognized as service failure and the need for market intervention? (Anglicare NT, sub. PP340, pp. 1–2)

The Northern Territory Government (sub. PP359, p. 15) said that it is working with the NDIA to develop the POLR framework, which once developed, could have broader application nationally. The Northern Territory Government (sub. PP359, p. 4) also recommended that the POLR include a panel of emergency service providers, and options for short-term block or direct funding arrangements until more permanent arrangements can be established.

There is an increasing need for greater clarity on how the POLR and thin market arrangements more generally are to be put into practice, particularly as governments change their involvement in providing disability and mainstream supports (section 7.3 and chapter 6).

It is critical for the NDIA to clarify how the POLR arrangements are to operate, and how the Agency intends to intervene in the market more generally, by publishing the relevant policies and strategies immediately.

RECOMMENDATION 7.1

The National Disability Insurance Agency should address thin markets by:

- considering a range of approaches, including block-funding
- publicly releasing its Provider of Last Resort (POLR) policy and Market Intervention Framework discussed in the *NDIS Market Approach: Statement of Opportunity and Intent* as a matter of urgency
- collecting and making publicly available disaggregated data, feedback and reports on thin markets, including when POLR arrangements are used.

7.3 In-kind services

Under Bilateral Agreements between the Australian and State and Territory Governments, government funding of the NDIS is a combination of 'in-kind' services and cash contributions, with the proportion differing by jurisdiction. In-kind services are Australian, State and Territory Government programs under existing block-funding arrangements that continue to exist to ensure continuity of support in the short term, and may also partly reflect the long-term contracts involved.

In practice, this means that governments may continue to remain a service provider, or block-fund a provider to deliver services. Under the Bilateral Agreements, most in-kind services will be phased out during transition and replaced by cash contributions where possible, though the timing of this varies by jurisdiction. At the commencement of transition, in-kind contributions accounted for about 19 per cent of total package costs, and at commencement of full scheme, they are expected to account for about 10 per cent (DSS, sub. 146, pp. 22–23).

The withdrawal of in-kind services is consistent with the NDIS objective of a more competitive, consumer-driven and market-based system, with services to be delivered by a wider range of private providers. Governments will no longer provide or procure disability services except in limited circumstances, such as in thin markets and under the POLR arrangements (section 7.2).

In–kind services have many disadvantages …

There are concerns that the continuation of in-kind services may adversely affect:

- the transition by existing providers
- market entry (PC 2017b)
- the quality of supports (PDA, sub. 38, p. 13)
- overall scheme costs.

Providers may delay adapting to the fee-for-service model due to ongoing block-funding under in-kind service arrangements (Mavromaras, Moskos and Mahuteau 2016, p. 45; NDIA, sub. 161, p. 102). In addition, providers may have less incentive to provide or increase services if they are effectively prevented from providing supports to participants where there are in-kind services (NDIA 2016i, p. 7).

The risk of deterring private providers may be higher in regional or remote areas, and other thin markets, where governments may be the main provider with few actual or potential competitors.

> Mr Croker from Keep Moving, was concerned that because the NT Government was the only entity that was able to provide services across all of the region, this left his organisation effectively in competition with the NT Government and begged the question of 'How do you compete as a private enterprise against government departments?'. (JSCNDIS 2015, p. 68)

In-kind services can also hinder innovation and restrict participants' choice and control, as these services must be used where they are provided and available to participants (NDIA, sub. 161, p. 47; *National Disability Insurance Scheme (Plan Management) Rules 2013* (Cwlth), rr. 6.8-6.9). Some in-kind services also cannot be bundled by the NDIA and can only be priced as individual line items (JSCNDIS 2015, p. 33), often at prices higher than the NDIA's price caps (NDIA, sub. 161, p. 101). This limits the potential efficiencies and pro-competitive benefits of allowing providers to bundle supports due to economies of scale or scope. As the NDIA said:

> The NDIA considers that in-kind funding arrangements are limiting choice and control for participants, imposing additional burdens on the NDIA, and may also be limiting growth in certain parts of the market. (sub. PP327, p. 67)

In-kind services also raise broader funding issues, including cost- and risk-shifting between the Australian and State and Territory governments (chapter 12). Funding issues are compounded by a lack of data and transparency on the true, like-for-like cost of providing in-kind services between government and private providers.[57]

… but in-kind services may be necessary in some circumstances

While in-kind services have drawbacks in terms of market development and participant choice, some argued that in-kind services are necessary — in some cases beyond transition — to ensure continuity of support to people with disability. This is particularly the case for those in thin markets and with complex needs. Some study participants, particularly State and Territory Governments, argued that in-kind services may need to persist in a range of circumstances, including where:

[57] Bilateral Agreements between the Australian and State and Territory Governments contain estimates of a jurisdiction's in-kind contribution, and a requirement that in-kind contributions during transition be based on the current cost of delivering services. The price and value of any in-kind contributions at full scheme will be separately agreed by June 2018.

- there is no provider (especially for participants with complex needs)
- the cost of in-kind services reflect economies of scale, or higher quality supports (based on greater supervision, lower casualisation and better training) than what can be supplied in the market
- in-kind services can complement other services to be provided in the scheme, which encourages entry by new providers of those services. (For example, where government housing (provided in-kind) and attendant care (provided by the market) combine to provide supported independent living for participants under the scheme.)
- in-kind services support other people with disability (who are not NDIS participants), or are not easily separated from other service systems
- the administrative costs of dismantling in-kind services are large.[58]

However, some of these arguments are not good reasons to continue in-kind services. Providing services to non-scheme participants is important (chapter 6), but should not be cost-shifted to the scheme through in-kind funding arrangements. Nor should in-kind funding arrangements be used to unnecessarily preserve the high — and potentially inefficient — administrative costs of such services.

The lack of a market, and the nature of the in-kind service provided compared to what is provided in the market, are more complicated — and arguably valid — reasons to continue in-kind supports. This is more likely to be an issue 'in the eye of the beholder', as governments and the NDIA may not agree on whether the market can provide the quality and quantity of supports that are being provided in-kind. The lack of a POLR policy adds complexity about whether governments can phase out in-kind services with confidence that there is continuity of support for participants.

The pace of the rollout is also contributing to concerns about whether the market can supply enough supports while in-kind services are withdrawn. This concern has apparently led the NDIA, in some cases, to request that governments slow down their withdrawal of in-kind services, such as transport and personal care services provided in schools (Tasmanian Government, sub. PP247, p. 11; Queensland Government, sub. PP345, p. 27). The Queensland Government also argued that in-kind services need to continue when the NDIS is unable to manage the transition of a service due to a range of factors, including market and workforce issues in the NDIS.

> … it is important to acknowledge that in some instances in-kind may be required as an extended interim option to maintain services post-transition while longer term and more permanent solutions are being developed and complexities are being addressed. (sub. PP345, p. 27)

[58] HSU (sub. PP316, pp. 9–10); New South Wales Government (sub. PP230, pp. 12–13); NMHC (sub. PP319, p. 17); Northern Territory Government (sub. PP359, pp. 8–9); Queensland Government (sub. PP345, p. 27); South Australian Government (sub. 203, p. 16) and Tasmanian Government (sub. PP247, p. 11).

In-kind services need to be phased out carefully

There are strong grounds to phase out in-kind services, but the phasing out must be done with care and cooperation.

- Care must be taken to ensure continuity of support for participants currently using in-kind services, and that there are arrangements to transfer participants to private providers (in consultation with participants, their families and providers).
- Cooperation between governments and the NDIA is necessary to identify where in-kind services can be safely withdrawn (in the context of a market with sufficient supply to meet participants' needs).

The Commission recommends that in-kind services be phased out as quickly as possible, subject to the following considerations.

- Where there are services that need to be provided in-kind to assure continuity of support, there should be greater public reporting and transparency of the costs and use of these services.
- Governments should publicly report on the cost and quality of services being provided in-kind, publish their reasons and provide evidence on why in-kind services cannot be provided by the market, and a timetable for when in-kind services will end.
- The NDIA should also closely monitor in-kind services and co-operate with governments where the Agency's market intelligence indicates that in-kind services can be 'cashed out' where market supply is available.

RECOMMENDATION 7.2

Bilateral agreements regarding the full rollout of the National Disability Insurance Scheme should only include in-kind funding arrangements for services that are required to ensure continuity of support for existing clients. For in-kind services that persist past transition, a timetable for when they will be 'cashed out' should be included in bilateral agreements.

7.4 Other factors affecting provider readiness in transition

As the NDIS is a new system and is creating a new market, there are several transitional issues affecting the sector's supply response. These include:

- challenges faced by providers who were previously block-funded
- administrative burdens associated with the scheme
- the scheme's effect on collaboration among providers.

Moving from block-funding to fee-for-service

Prior to the NDIS, providers received government funding *before* providing certain supports in 'bulk' to participants (table 1.1). This usually took the form of lump sum payments for each participant under annual contracts that were paid three months in advance (AONSW 2017, p. 7). Providers now claim reimbursement from the NDIA *after* providing individualised supports to scheme participants, unless the NDIA has given prior written approval for prepayments.[59] The majority of support items are based on per hour, or per instance of service provided (NDIA 2017q, 2017r, 2017s, 2017t). This affects the capacity of providers to deliver disability supports under the NDIS.

Providers face significant challenges to adapt to the new fee-for-service model, and some may not be able to make the transition. The shift to the competitive provision of disability services may create upward pressure on production costs for a wide variety of reasons. Providers bear increased financial risk (such as from non-payment and late payment), and in turn, may have a greater need for cash reserves, making it harder to maintain liquidity and solvency (DSS, sub. 146, p. 37). The NDS (2015, p. 17) stated that 'the majority of not-for-profit disability service providers report insufficient cash flow required to transition to the NDIS'. Providers will incur fixed costs to restructure and adapt their business to the NDIS market. Costs may relate to unit pricing, ICT, accounting, advertising, the provision of individualised supports, labour and other input costs.

While these production costs are likely to be significant given the scale and nature of the required changes (particularly for small providers, of which there are many in the disability support sector (box 7.5)), they are better addressed by the price received for supports than the payment method (PC 2011, p. 520).

In general, the need to cover fixed costs is not a reason for government intervention (PC 2011, p. 523). Fixed costs are also likely to be a transitional issue for a number of reasons, and be offset against any eventual gain in efficiency.

- The introduction of innovative payment systems by some financial intermediaries may reduce some of the financial risks of the fee-for-service model and help providers adapt to the new system (Eyers 2017).
- Price deregulation will help providers recover their fixed costs in the longer term, as prices will more accurately reflect the cost of supply, and fixed costs will be driven by consumer preferences (PC 2011, p. 520).
- Providers may be able to use different pricing methods to efficiently recover fixed costs (such as discounts for regular users, or for periods when demand is lower) (PC 2011, p. 521).

[59] Prepayment will only occur in exceptional circumstances such as home modifications and remote area servicing. The NDIA may also approve prepayment for certain assistive technologies where this has been agreed by the participant (NDIA 2017q, pp. 11, 18, 2017r, pp. 12, 19, 2017s, pp. 12, 19, 2017t, pp. 12, 19).

- The experience of providers in adjacent sectors in the economy (including aged care) that moved from block-funding to fee-for-service as part of consumer-directed care reforms also suggests that adjustment can and will take place in the medium to long term (although differences between disability and other sectors make direct comparisons difficult). As the NDIA observed:

  > … aged care providers are undergoing their own reforms related to consumer-directed-care and many businesses are leveraging this experience to build services and products relevant for the disability market. (2016x, p. 5)

Box 7.5 Small providers can face big challenges to transition

A feature of the disability support sector is that many providers are small (Martin and Healy 2010, p. 122). National Disability Services estimated that about 58 per cent of providers are either small or very small (with a turnover of $5 million or less) (Gilchrist and Knight 2017a, p. 10). About 40 per cent of NDIA-registered providers are individuals or sole traders (NDIA 2017y, p. 42). Small providers may have less capacity to make the transition to the NDIS than larger providers. For example, they face challenges from:

- proportionately higher fixed costs of operating in the NDIS, especially as they must incur new marketing and systems costs
- achieving economies of scale or scope, with total costs spread more thinly across fewer hours of support, particularly with the shift to more individualised or tailored supports
- potentially lower and variable revenue from the fee-for-service model, which may require providers to diversify their revenue sources (such as public contributions in the form of volunteering, donations and sponsorships), or services. For example, Riding for the Disabled of the ACT (Pegasus — a provider of horse therapy and equestrian services for people with disability) said that in 2016-17, it received about $18 000 in NDIS revenue. This compared with about $250 000 in annual block-funding from the ACT Government in previous years. As a result, under the NDIS, Pegasus has become more reliant on donations and sponsorship support. Pegasus is also planning on expanding their services to new cohorts (Connery 2017; Riding for the Disabled of the ACT (Pegasus), pers. comm., 28 September 2017).

The scale of these challenges may be inferred by the amount of merger and acquisition activity in response to the challenges of being a small provider. Merger activity and restructuring in the sector provides some indication that this may be the case (NDS 2016, p. 17), although it is unclear whether this consolidation has led to an actual increase in services or substantially reduced competition.

The Commission heard that uncertainty and lack of clarity — particularly about the timing of price deregulation and the withdrawal of in-kind services (ANAO 2016, p. 32) — are causing some providers to delay (or be discouraged from) making changes to their business model, planning and investment. About 75 per cent of providers surveyed by the NDS felt that 'the policy environment is uncertain' (NDS 2016, p. 19). One provider who was surveyed by the NDS commented that:

> The uncertainty around 'how much we will be able to receive' once NDIS is implemented in our region means that the climate for any investment is too uncertain, because we cannot make a reliable business plan. (NDS 2016, p. 10)

The Office of Best Practice Regulation also noted that:

> … ongoing engagement with providers when developing reference prices and maximum prices, particularly for key supports, should help providers during the transition to a fee-for-service based system of disability care. (2015, p. 49)

Better information and communication by the NDIA would assist, as will independent price monitoring and regulation (recommendations 8.2 and 8.3). That said, there are still risks that some existing providers may be unable to transition to a fee-for-service model without some additional assistance in the short term. There could be merit in the NDIA or governments providing short-term targeted assistance where the risks of providers exiting (and a resulting lack of supply) could lead to greater costs to the scheme and participants over the longer term.

Administrative burdens

There is a range of regulatory and other costs to provide NDIS supports. As the NDIA (2016i, p. 9) noted, there are 'high costs to enter the marketplace'. Regulatory costs include the cost of registering with the NDIA, and costs associated with ensuring quality and safety of supports for people with disability. These include:

- professional registration (in the case of specialised services, like therapeutic supports)
- working with children checks
- third-party verification (such as for the safety of new specialist disability accommodation)
- police checks.

These costs are necessary to ensure safe and high quality supports for NDIS participants. The recently developed NDIS Quality and Safeguarding Framework (which will largely only apply to NDIA-registered providers) aims to provide a nationally consistent set of regulations on what providers need to do to provide disability supports (chapter 11). Increased regulatory consistency across jurisdictions should mean lower compliance costs for some providers than under previous arrangements.

Concerns were also raised by a number of study participants about the NDIA's online payment system and communication issues with the NDIA. As Catholic Social Services Australia said:

> Though CSSA [Catholic Social Services Australia] member agencies have been preparing for transition to the NDIS for a long time, the dysfunctionality and un-preparedness of the NDIA has severely affected its capacity to deliver sustainable services through the NDIS. Complex and ongoing issues with the portal (including the system being taken down for weeks at a time with very little notice) means that providers are finding it very difficult to access the funds for services provided. These cash flow issues have restricted providers' ability to invest, innovate and even operate (for example one agency providing significant disability services in a trial site had

> $1 million 'stuck' in the portal in December 2016). This has led to cash flow issues and providers withdrawing due directly to pricing or lack of payment. (sub. 166, p. 9)

The problems associated with the online portal have already been examined in some depth by others (ANAO 2016, pp. 62–71; Conifer and McKinnon 2017; PwC 2016), and were acknowledged by the NDIA (sub. 161, p. 119). The Agency indicated that it is reforming its processes to improve the 'provider pathway', including registration and payment arrangements, and is also delivering tailored information sessions for providers.

> The NDIA is working to improve the quality and amount of information available to providers in all elements of the provider pathway (awareness, commercial assessment, registration process (including the impacts of the move to the national arrangements being led by DSS), service planning and delivery, payment and claiming outcomes) so that providers are better placed to meet expectations and develop their service offer under the NDIS. (sub. 161, p. 102)

Payments to providers need to be timely so that innovation, entry and the supply of disability supports are not hampered. Equally important is for the Agency to maintain open and clear lines of communication with providers to minimise the administrative burden on them. Other schemes, such as NSW Lifetime Care and Support (now part of icare), take a collaborative approach to dealing with providers. This includes: regularly seeking feedback from providers through meetings; workshops and forums; proactive management of provider issues; and having designated staff who deal with any specific problems that arise (icare, pers. comm., 28 September 2017). A relationship of mutual trust, respect and cooperation between providers and the NDIA is needed for the effective operation of the scheme.

Collaboration in the disability support sector

Some disability supports are provided using collaborative and cooperative arrangements, often to ensure better outcomes for people with disability. Some providers were concerned that the increased competitive pressures of a market-based system will reduce collaborative activity (and the associated benefits), and therefore lead to a potential erosion of 'social capital'[60] (Alzheimer's Australia, sub. 10, p. 15; Anglicare Australia, sub. 157, p. 13; and CMHA, sub. 11, p. 14). This could increase provider costs and lead to the withdrawal of some services.

A National Institute of Labour Studies survey found that the introduction of the NDIS had made providers more guarded and that less information was shared due to commercial considerations (which may undermine provider networks), although some collaboration among providers was continuing to occur. One provider who was surveyed commented that:

> I think that's been a sad sort of aspect of the NDIA. When you create a competitive marketplace it's very hard, you know, those old networks that we would have been a part of and shared ideas and things like that have kind of broken down a little bit. (Mavromaras, Moskos and Mahuteau 2016, p. 45)

[60] The relationships and trust that underpin the functioning of society (PC 2010, p. XIX).

A study participant said that:

> There is absolutely no cooperation between providers anymore. They kick out complex clients, saying they do not support clients like that. They do not talk to each other, saying it is not their problem. (Belinda Jane, sub. 80, p. 10)

At the same time, not-for-profit providers may experience lower volunteering and fundraising contributions, due to public perception of their perceived greater 'commercial' focus and competitive behaviour, and that the NDIS is fully-funded (ABF, sub. 48, p. 14; Scope Australia, sub. 72, p. 25). The NDS said that:

> Providers are beginning to report that fundraising revenue is dropping as donors believe that the NDIS will provide all people with disability with all the supports they need. This is clearly a misunderstanding but seems to be becoming more pervasive. (sub. 51, p. 14)

While these contributions may be retained within the disability sector (either redirected to other providers or spread more thinly across all providers), they could also be transferred to other human service sectors, and be lost from the disability support sector.

Conversely, providers may have greater incentives for collaboration in order to increase flexibility and responsiveness to participant demand in an increasingly competitive funding environment (NDS and CADR 2015, p. 13). Collaboration may allow providers to offer services at a greater range of times and locations, and achieve economies of scale or scope that would otherwise be difficult to achieve (particularly in thin markets and for small providers). Market stewards (and regulators) need to monitor such arrangements closely to ensure that collaboration does not reduce competition, choice, efficiency and participant wellbeing.

The NDS data indicate that in 2015-16, the majority of providers surveyed collaborated to advocate for the sector (68 per cent) or for clients (62 per cent), and had agreements to refer or provide services to clients (55 per cent), despite increased competition for both workers and clients (NDS 2016, p. 17). This appears to be broadly in line with previous results, where providers reported that they were forming alliances and joint working relationships with other organisations to offer services at a greater range of times and locations (NDS 2015, p. 38; NDS and CADR 2015, p. 13).

Collaboration is also consistent with the objectives and mission of not-for-profit providers, which typically promote the interests and wellbeing of people with disability. As noted by Centacare Brisbane (sub. 44, p. 3), the degree of collaboration and cooperation between providers under the NDIS will depend on the maturity, interests and skills of each party.

On balance, collaboration is a voluntary and valuable activity undertaken by not-for-profit providers that produces intangible benefits, but has tangible costs when removed. The mixed evidence on the degree of and incentives for collaboration in a more competitive environment suggests that the net effect will depend on whether the increased efficiency of providers offsets the higher costs associated with reduced social capital. The Commission

has previously noted that for the not-for-profit sector, efficiency and effectiveness are central to maximising community wellbeing (PC 2010, p. 18).

While is difficult at this early stage to know how many collaborative arrangements will end and form, the available evidence suggests that some provider collaboration will continue to exist in the NDIS, and is likely to be primarily determined by provider efficiency. Uncertainty about the degree of provider collaboration in the future (and its effect on participant outcomes) highlights the need for strong governance of the NDIA (chapter 11), policy-relevant data collection (chapter 13), monitoring and effective market stewardship (chapter 10).

8 Pricing of disability supports

Key points

- In a mature market, participants' choice and control will determine the price of disability supports. However, temporary price controls are needed to ensure that participants have access to affordable disability supports in the transition period, when the supply of supports is still growing to meet increased demand.
- The National Disability Insurance Agency (NDIA) currently sets the maximum price of disability supports that can be charged by NDIA-registered providers. The NDIA's 2017-18 price review recently concluded. The Agency has also commissioned McKinsey & Company to review its pricing methodology, which will report to the NDIA Board by the end of 2017.
- The NDIA's approach to setting price caps to date has hindered market development and resulted in providers withdrawing from the market for some disability supports. In some cases, the price caps have led to poor participant outcomes, especially for people with complex needs. The benefits of the National Disability Insurance Scheme (NDIS) will not be fully realised if the Agency continues with its current pricing approach.
- NDIS price caps should be set by a body that has relevant capability and necessary resources, and in a manner that is transparent, evidence-based, supported by clear and limited legislative authority, independent and timely.
- To better reflect these pricing principles and ensure that market development receives the necessary attention over the longer term, the Commission recommends that NDIS price caps be deregulated in three stages by:
  - mandating that the NDIS Quality and Safeguards Commission (QSC), when it commences in July 2018, act as an independent price monitor. This will be a 'check and balance' on the NDIA's pricing decisions over the transition period, and should assist with the transparency of pricing — a problem that the NDIA has only partially addressed to date
  - transferring the NDIA's pricing power to the QSC by no later than July 2020. The QSC would also be responsible for determining when supports would no longer be subject to price caps
  - continuing independent price monitoring by the QSC following price deregulation.

Prices of disability supports are a key part of the National Disability Insurance Scheme (NDIS).

- Prices reflect the preferences and relative value that participants place on different supports, which in turn signal to providers the supports to supply. Put another way, prices are signals that are sent to the market when participants exercise choice and control over their packages of individualised supports. Prices affect participant choice, competition, quality, variety, efficiency and innovation.

- Prices affect the purchasing power of participants — the higher the price, the fewer supports participants can purchase using a given package (unless participants can substitute for lower cost supports for a given support type).
- Prices affect the total costs of the NDIS and therefore its financial sustainability.

Prices also affect the allocation of scarce resources and efficiency in the economy — the higher the NDIS price relative to other sectors, the more the NDIS will attract resources from these sectors. Prices can also have spillover effects by driving efficiencies, innovation and growth in the broader economy.

How prices are determined under the NDIS therefore has a direct bearing on participants' (and their families') welfare, provider profitability, scheme costs and the wellbeing of the community.

The National Disability Insurance Agency (NDIA) currently determines 'price caps' or maximum prices that can be charged by registered providers for many NDIS supports.

This chapter examines how prices affect market development, and the choice that participants have over their supports. It focuses on how existing and new providers are responding to the NDIS price of disability supports. Section 8.1 looks at how the NDIA currently sets price caps. Section 8.2 examines the effect of these price caps on the supply of disability supports. Section 8.3 considers whether the NDIA should continue to set prices. Section 8.4 concludes with a discussion of how NDIS pricing could be improved to benefit participants and their families, providers and the wider community.

8.1 How does the NDIA set prices?

The price of disability supports directly affects the supply of quality supports to scheme participants. In a mature market, the choice and control that participants exercise will, and should increasingly, be the main factor determining the price of disability supports. Allowing the market to determine the price of supports is an important feature of the NDIS, as prices affect participant outcomes and the financial sustainability of the scheme. However, temporary regulation of prices in the disability support sector is necessary, and was one of the Commission's recommendations in its 2011 *Disability Care and Support* inquiry (box 8.1).

Box 8.1 Why regulate the price of disability supports?

Governments have historically regulated the price of human services (PC 2016, p. 35), including disability care and support services, on the grounds of equity and efficiency. Without price regulation, the supply of disability supports may be below socially optimal levels for a number of reasons, including ineffective competition and abuse of market power (NDIA 2017a, p. 5).

In particular, there may be too few providers in the market. This is a real risk in the disability support sector. Early data indicate a market concentration of more than 80 per cent in some disability service sub-markets (NDIA 2016l, p. 32, 2016s, p. 29, 2016x, p. 38; DSS, sub. 146, p. 38). This may result in prices that are too high, and limited access to services for some disadvantaged groups. Others have noted the need to maintain price controls in the foreseeable future, as it may take at least a decade for the new market for National Disability Insurance Scheme (NDIS) disability supports to develop (ANAO 2016, p. 54; AONSW 2017, p. 5; DSS, sub. 146, p. 39).

In 2011, the Commission recommended that an early — albeit temporary — task for the National Disability Insurance Scheme Agency (NDIA) would be to set efficient prices to allow providers to recover the costs of providing services (including adequate returns for capital investment), and in turn, ensure the supply of disability supports (PC 2011, pp. 51, 412–414).

While the NDIA has set prices since the beginning of the NDIS trials in July 2013, the Agency said that it does not plan to do so in the long term.

> During transition, the market stewardship role of the Agency will be more active; to facilitate development of the marketplace and as a catalyst for basic market infrastructure. This includes … setting prices and pricing policy …
>
> The setting and reviewing of NDIS prices is a significant market-intervention initiative … for most submarkets it [the NDIA] sees this [price-setting] as a temporary measure to support the marketplace. In the long-term, the NDIA will not set prices to the extent it does now and will instead allow the marketplace to determine the price of supports. (2016i, pp. 18, 26)

An important principle of price regulation is that it should not be distortionary — that is, it should not persist unnecessarily, have excessive scope, or shape the market — such as by benefiting some providers or participants over others.

Given that at least 84 per cent of participants have supports that are subject to NDIS price caps (NDIA 2017y, p. 21), these price controls affect market development. The NDIA acknowledged that it walks a fine line when setting prices.

> The NDIA risks unnecessarily disrupting existing markets through setting prices inaccurately. If price limits are set too high (relative to an efficient benchmark) providers will not face adequate incentives to review practices and operations in an effort to be more efficient. As a result, participants, and the Scheme in general, would not get value for money from expenditure on supports. On the other hand, if price limits were set too low, providers would be unable to recover even efficient costs. This could result in a significant share of providers leaving the sector and/or a lack of new investment in disability services. (2016n, p. 10)

This is reflected in the rationale of price caps, which is to:

- ensure 'value for money' for participants — as the price of supports may be bid up too quickly in the absence of price caps in the period after funding is allocated to participants,

but before the disability support sector has grown sufficiently to meet the increased demand

- encourage the market supply of disability supports by giving providers sufficient incentive to grow and enter the NDIS market (NDIA 2016o).

There are also trade-offs with price controls. Fixing prices could mean lower scheme costs in the short term, but also slower market development and support shortages. On the other hand, deregulating prices could mean higher short-term costs, but faster market growth. In the short term, the trade-off is between potential shortages and disability support price inflation.

The price cap for attendant care is particularly important because attendant care is one of the most common supports used by participants in the scheme. The NDIA currently sets price caps for attendant care using its 'Hourly Rate Model' (HRM).[61] The model seeks to 'define the direct cost elements at a rate that is sufficient to cover the efficient costs of a reasonable quality support provider at a point of time' (NDIA 2014a, p. 2). Prices are intended to reflect an estimate of what the long-term 'efficient' price would be in a competitive, deregulated market, plus an additional margin to reflect both the cost and time needed for existing providers to transition to a market-based system, and to entice new providers to enter the disability support market (transitional pricing). To do this, the HRM makes a number of assumptions about the cost of providing supports, which vary by support (box 8.2).

Prices are currently set by annual reviews conducted by the NDIA. The most recent review was completed in June 2017.

The NDIA's 2017-18 Price Review

The most recent price review was undertaken by the NDIA in the first half of 2017. This was the first price review to include a discussion paper that invited feedback from the public on the validity of the assumptions used in the HRM to calculate prices. The NDIA also considered submissions to this study for the price review.[62] While the NDIA intended to publish the updated price guides in late May 2017 (NDIA 2017a, p. 18), they were released on 28 June 2017, just three days before they took effect.

[61] This model is also referred to as the 'Hourly Return Model' (Bowen 2017a). It was previously called the 'Reasonable Cost Model' (RCM) (NDIA 2014a). Many study participants provided submissions that refer to it under these different names, and as the underlying assumptions of the model appear to have remained largely unchanged, the names are largely interchangeable.

[62] A number of confidential submissions were made to this study that had a direct bearing on pricing, including detailed arguments and analysis about the validity of price assumptions. As these submissions were not public, they were not used by the NDIA in its deliberations.

Box 8.2 The NDIA's Hourly Rate Model

The hourly rate model (HRM) uses a range of assumptions to determine the price cap for a given support type under the National Disability Insurance Scheme (NDIS). The price caps are meant to inform providers about the efficiency levels that should be targeted under the market-based system. To date, price caps have included an additional premium to reflect the costs of transitioning existing providers into the scheme, and to give new providers an incentive to enter the sector.

One support subject to a price cap is the cost of an hour of attendant care — one of the most common supports provided under the NDIS. The HRM assumes the following conditions for an hour of attendant care provided in 2017-18:

- the hourly rate of pay is based on the Social, Community, Home Care and Disability Services Industry Award 2010 pay point 2.3 for employees and 3.2 for managers or supervisors. Pay rates depend on whether the hour worked is on a weekday (6am-8pm or 8pm-12am), Saturday, Sunday, or a public holiday
- employees are employed on a full-time or permanent part-time basis. No allowance for shift work or other allowances are included. Leave entitlements are ten days of paid personal leave; four weeks of paid annual leave at 17.5 per cent leave loading; and 17.98 per cent of employees achieve long service leave of 8.67 weeks.

In terms of other costs, including 'on-costs', the HRM assumes:

- loadings for location (20 and 25 per cent for remote and very remote areas respectively) and the intensity of client needs (about 6 per cent)
- that carers spend 95 per cent of paid time with clients, and that managers spend 90 per cent of time with clients, or dealing with client matters. A manager is expected to supervise 15 employees (for standard needs clients)
- that providers operate with a corporate overhead equal to 15 per cent of total salary, management and non-client facing expenses. There is an additional payment for provider travel costs for travelling between clients (maximum 20 minutes)
- superannuation is 9.5 per cent of total salary costs, and workers' compensation insurance is 4 per cent of total salary costs
- a profit margin of 5 per cent of total costs, as well as an additional margin for the transition pricing period.

The HRM, under these assumptions, results in a price cap of about $45 for an hour of attendant daytime weekday care in metropolitan New South Wales, Victoria, Queensland and Tasmania, and about $46 in metropolitan ACT, Northern Territory, South Australia and Western Australia. About a third of this price is for on-costs.

Most of the assumptions and methodology of the model were initially developed in consultation with National Disability Services; however, the parties did not agree on what assumptions were appropriate for the future efficient price. Many providers who made submissions to this study (and to the National Disability Insurance Scheme Agency's (NDIA) 2017-18 price review) argued that the price caps resulting from the HRM are too low to provide quality supports. The HRM was to be reviewed by the NDIA in the 2017-18 price review. The model is being reviewed by McKinsey & Company (who will report to the NDIA Board by the end of 2017).

Sources: Bowen (2017a); NDIA (2017a, 2017q, 2017r, 2017s, 2017t); NDIA and NDS (2014, p. 16).

The prices announced were designed to keep the price caps of most supports in line with inflation.[63] However, other tasks that the pricing review was to undertake were not completed, such as examining the evidence, assumptions and methodology used to set prices, with a focus on attendant care (NDIA 2017a, p. 8).

Instead, the NDIA announced that it had commissioned a pricing review by McKinsey & Company to gain a better understanding of pricing, including the pathway to deregulation. The review commenced in June 2017, with the final report to the NDIA Board due by the end of 2017 (Bowen 2017a). The review's terms of reference directs McKinsey & Company to:

- Provide recommendations in relations to improved pricing effectiveness, including but not limited to:
  - National versus regional pricing;
  - Pricing of services with different levels of complexity;
  - Pricing of short stay support, and for emergency and crisis supports;
  - Thin and undersupplied markets, particularly in regional and remote areas;
  - Relative provider efficiencies (including overheads);
  - Adequacy of provider returns; and
  - Effectiveness of the Hourly Return approach used to set prices.
- Provide recommendations in relation to the potential early de-regulation of price in more mature sub-markets and the glide path for the eventual de-regulation of price more generally. (Bowen 2017a)

8.2 What is the effect of the NDIA's prices on the market?

Regulating prices is always difficult — regulating a market that is transitioning, still developing and undergoing significant change is even harder, as the past offers little guidance to regulators, and there is an increased risk of disruption caused by regulated prices. Prices are also only one of many factors affecting the willingness and ability of providers to supply disability supports.

63 The outcomes from the 2017-18 price review included: increasing the price of supports for personal care and community participation by 4.5 per cent to reflect both wage and consumer price inflation; increasing the price of other supports (including those related to capacity building) by 1.94 per cent to account for wage inflation; increasing the price of capital-related supports by 2.1 per cent to account for consumer price inflation; and increasing loadings for remote and very remote areas by 2 percentage points to 20 and 25 per cent respectively (consistent with the loading changes made by the Independent Hospital Pricing Authority). There was no change in the price of therapy services, as data from competing sectors examined by the NDIA indicated that no change was required. However, the NDIA changed the cancellation policy to allow providers of therapy services to charge for up to two participant cancellations per year, when it was previously prohibited (Bowen 2017a; NDIA 2016o, 2017ac).

As mentioned earlier, there are trade-offs with price controls. Allowing participants' wants and needs to drive prices, and therefore the supply of supports, is important for participant choice and control, and ultimately, participant outcomes. However, without price controls, a lack of supply could put upward pressure on prices, erode participant's packages and have adverse consequences for participants. Therefore, prices should only be regulated where the benefits outweigh the costs.

Many submissions to this study raised concerns about the prices set by the NDIA. Most concerns were about the assumptions of the model used by the Agency. The NDIA's assumptions around complexity of needs, attendant care and short-term accommodation ranked high among the concerns raised. The Commission heard that the price caps in these areas were creating perverse incentives for providers, and leading to poor outcomes for participants.

The cost of supports for people with complex needs is not well reflected in prices

Under the NDIA's price caps, there is single loading when providing attendant care to participants with complex needs (people who have or are likely to have multiple, episodic or high support needs over their lifetime).

Many study participants commented that people with complex needs are struggling to find providers willing and able to provide services to them (box 8.3).[64] A number of providers also said that they could not provide services to participants with complex needs at the prices derived from the HRM (Anglicare Australia, sub. 157, pp. 11–12, 19; CMHA, sub. 11, pp. 5, 13; Leadership Plus, sub. 128, pp. 3–4; NDS 2017b, p. 4; United Voice, sub. 118, p. 12; VCOSS, sub. 176, pp. 20–21). And this was a consequence of the single complexity loading, base salary rate and supervisory requirements. As the Brotherhood of St Laurence said:

> The existing fixed pricing structures pose some problems for both participants and service providers because they fail to take into account the circumstances of activities. By setting a single price, the provider does not have the option to charge less or more for a tailored service. This has the unintended consequence of reducing the choice and control of people with disability. (sub. 189, p. 20)

[64] Including: ACT Government (sub. 156); Anglicare Australia (sub. 157); Belinda Jane (sub. 80); Disability Services Australia (sub. 9); Disability Services Commissioner Victoria (sub. 35); National Disability Services (sub. 51); Scope Australia (sub. 72); and Victorian Government (sub. 174).

Box 8.3 Study participants' concerns about the complexity loading

Victorian Council of Social Services:

> VCOSS members report pricing limitations are particularly inadequate to meet the costs of delivering services to participants with complex and high support needs … Without adequate resourcing, the NDIS risks creat[ing] disincentives for providers to assist participants with complex needs. This could mean services 'cherry pick' participants and leave some people with disability without services. (sub. 176, pp. 20–21)

Disability Services Australia:

> The premium for complexity is insufficient, and there is a strong risk of market failure in the area of service delivery for complex customers — this includes those with challenging behaviours, and those that require centre-based services. (sub. 9, p. 10)

The ACT Government:

> Providers have also reported 'cherry picking' of service types which are better paid and have 'easier' clients, which opens up market gaps for other services.
>
> These pricing issues are very serious … particularly in the areas of … intensive personal support and support for participants with complex needs … The risk to participants in the ACT from providers who currently support people with complex needs withdrawing from the market is high. (sub. 156, p. 30)

Anglicare Australia:

> … The system is designed with low level personal care as the basis for the pricing and consequently the higher skill and responsibility levels for staff who need to care for those with [psychosocial] disabilities is essentially ignored. (sub. 157, p. 12)

Belinda Jane:

> They [providers] kick out complex clients, saying they do not support clients like that. (sub. 80, p. 10)

National Disability Services:

> Providers are also reporting a growing reluctance to support people with complex conditions (in all service types). The NDIS has some higher prices for complexity but they are inadequate. Without a price increase, a high needs group of participants will increasingly not get the supports they need. (sub. 51, p. 12)

Mental Health Australia:

> Since rollout commenced, mental health providers have repeatedly highlighted that the price of supports is set well below the hourly rate for psychosocial support work currently delivered by suitably qualified people. There is no hourly price for psychosocial support services in the NDIS Price Guide … (sub. PP321, p. 37)

This appears to be especially the case for providers that deliver supports to people with psychosocial disability. Many study participants (including CMHA, sub. 11, pp. 4–5; Mental Health Australia, sub. PP321, p. 37; National Mental Health Commission, sub. PP319, pp. 10–11) argued that the single complexity loading did not sufficiently accommodate the different degrees of complexity of need for people with psychosocial disability, and the need

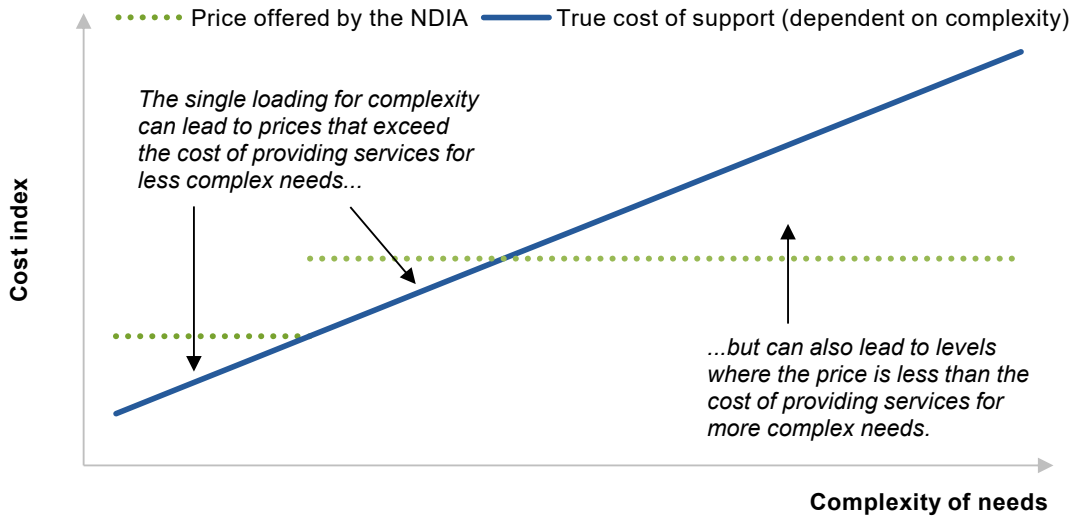
for quality services provided by skilled and qualified mental health workers. For example, the Mental Health Coalition of South Australia said that:

> The cohort for psychosocial disability are at the most complex end of need, yet the Reasonable Cost Model is based on level 2.3 of the SACS award. Skilled mental health peer and support workers attract at least level 3 and often 4. (sub. PP308, p. 3)

It is the bluntness of the single complexity loading that can cause these problems, as it is based on the average, rather than the actual, cost of services. Figure 8.1 shows that as the complexity of needs rises, the actual cost of supplying the support also increases. Yet the price of supports is fixed at two levels — one that includes the complexity loading and one that does not. This creates incentives for providers to provide supports for participants with less complex needs, but a strong disincentive to provide supports to those with more complex needs — resulting in a shortage of supports for these participants.

Given that the cost of supplying supports increases with complexity of needs, a 'one-size-fits-all' approach is not appropriate in the pricing of services for participants with complex needs. A single loading approach is also not consistent with the approaches taken in some other human services, including aged care and public hospital services (box 8.4).

Figure 8.1 **A stylised representation of a single complexity loading**



Box 8.4 Measuring the complexity of human services user needs

Users of human services have needs of varying complexity and intensity. In turn, the cost of delivering services to users will differ depending on the complexity of their needs.

In the aged care sector, the Australian Government pays approved providers a residential care subsidy for each care recipient. The basic subsidy amount is determined by the Aged Care Funding Instrument (ACFI), which consists of 12 questions about assessed care needs, some of which are supported by specified assessment tools and two diagnostic sections (Department of Health 2017b). These questions are rated by the aged care home on a four-point scale of A, B, C or D, which are then used to determine an individual's ACFI rating (Department of Health 2017b). The ACFI consists of three funding categories: activities of daily living, behaviour and complex health care (DHS 2017). Funding in each of these domains is provided at four levels — nil, low, medium or high. This means that there are 55 different rates corresponding to different ACFI classifications (DHS 2017).

The Australian Government also funds public hospital services, jointly with State and Territory Governments. Major determinants of the level of funding are the National Efficient Price (NEP) and National Efficient Cost (NEC) as determined by the Independent Hospital Pricing Authority (IHPA). The NEP also provides a price signal or benchmark for the efficient cost of providing public hospital services (IHPA 2017a). The NEP Determination is used to calculate activity-based funding for in-scope public hospital services, while the NEC Determination covers block-funded services (IHPA 2017c, p. 7). In practice, NEC is higher than NEP, because NEC is for hospitals with activity levels that are too low to be suitable for funding on an activity basis, such as small rural hospitals (IHPA 2017c, p. 34).

In determining the NEP, the IHPA uses classification systems to classify types of patients, their treatment and associated costs. The IHPA then groups patients who have similar conditions and cost similar amounts per episode together (IHPA 2017c, p. 13). Currently, there are six patient service categories — admitted acute care, subacute and non-acute care, non-admitted care, mental health care, emergency care, and teaching, training and research (IHPA 2017c, pp. 13-19). For example, admitted acute care is classified according to the Australian Refined Diagnosis Related Group (AR-DRG) patient classification system. The AR-DRG consists of about 800 patient classes with each patient being classified based on their diagnoses, interventions and other routinely collected data (IHPA 2017b).

Attendant care price caps may be too low to achieve safe and quality outcomes

Many providers presented anecdotal evidence to this study about NDIS price caps for an hour of attendant care being too low. Estimates of the shortfall between what was needed and what the cap offered (as a percentage of the current price cap) varied considerably. For example:

- House with No Steps (sub. 104, p. 3) said that there was a shortfall of about 10 per cent against what it considered to be a more sustainable price cap. This is equivalent to a shortfall of about 11 per cent against the current price cap
- Belconnen Community Service Board (sub. 39, p. 1) suggested a shortfall of between 10.5 and 16 per cent

- Cohealth (sub. 50, p. 11) said that there was a shortfall of 49 per cent for those with mental health needs.

While there is a wide range of views on the pricing of attendant care, more thorough analysis of the assumptions underpinning the HRM highlight the challenges faced by providers to supply supports.[65]

- The Samaritans Foundation applied alternative assumptions that they considered were more reflective of existing practices and the efficiency gains that they believed could be realised in the disability care sector. It found that the price cap on an hour of attendant care would have to increase by between 13 and 25 per cent for providers to continue to provide reasonable quality care (Samaritans Foundation, in Anglicare Australia, sub. 157, att. 4, p. 1).
- A survey of 129 registered NDIS providers and 738 disability support workers examined how the pricing model affected disability support workers. It found that the NDIS price of attendant care under the NDIA's Reasonable Cost Model did not enable minimum Award conditions to be met, and prevented employers who offer above-Award conditions from meeting their legal obligations. The researchers found that the pricing model under-classified support workers and supervisors; underestimated the time needed to deliver quality and safe services to NDIS participants, especially to participants with complex needs; and underestimated a range of other costs that providers must incur to develop and maintain quality staff and services (Cortis et al. 2017).

Short-term accommodation is another area of concern

Short-term accommodation is a core support that provides integrated support for self-care, accommodation, food and activities in a centre or group residence, for people with disability for short periods (NDIA 2017q, pp. 27, 40). It can involve irregular days and may include funding to provide substitute support 'respite' in a group-based facility or in-home support.[66] As respite is important to maintain the ability of informal carers to provide support to participants (chapter 9), short-term accommodation for people with disability is vital to participants, their carers, and the financial sustainability of the scheme. Currently, the price cap for short-term accommodation applies on a flat day rate, which includes all expenses in a 24-hour period with no additional loading (NDIA 2017a, p. 16).

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65 The Commission did not make any findings or recommendations on the prices of particular supports, though some study participants suggested that there would be merit in the Commission doing so (for example, HSU, sub. PP316, p. 6 and Victorian Government, sub. PP298, p. 23). The NDIA provided the Commission's study with a copy of its HRM, but it was provided too late for the study to examine in detail. That said, many of the assumptions in the HRM that was provided to the Commission appear similar or identical to those stated in the NDIA's Price Controls Review 2017 Discussion Paper and 2017-18 Price Guide.

66 Some participants in this study said that the term 'respite' is pejorative and preferred the term 'family care'. The Commission is sensitive to this issue, but has used the term 'respite' for clarity — both because it is included in the NDIS Price Guide (NDIA 2017q, p. 28) and most study participants, including people with disability, used the term in their submissions.

Some study participants argued that the price of short-term accommodation has several flaws. These include: the flat daily rate that does not allow for any complexity loading or penalty rates for weekends or public holidays; and the NDIA's assumptions about the occupancy rate (NDS, sub. PP295, pp. 8–9; Cerebral Palsy Alliance, sub. 163, att. 1, p. 4).

These assumptions are beginning to shape market supply responses.

- The CSSA (sub. PP278, p. 5) reported members not opening on public holidays; long wait times; large providers withdrawing services; and cherry picking participants — leaving vulnerable participants with complex needs without adequate and timely support.
- According to the NDS (sub. PP295, pp. 8–9), some providers are considering shutting down these services (and converting them to Specialist Disability Accommodation). An emerging risk is that more participants will move into full-time Supported Independent Living (a more expensive option) or Specialist Disability Accommodation.
- The HSU (sub. PP316) said that it had received reports of providers refusing to provide services on weekends and public holidays.
- Some providers are reducing or closing down their respite services in response to NDIS price caps. For example:
  - Marymead, an ACT provider, initially announced that from 26 October 2017, it would significantly reduce its overnight respite services to young people with disability with high needs (Bourchier 2017; Groch 2017a, 2017b). On 3 October 2017, Marymead announced that an agreement had been reached with the NDIA, with the support of the ACT Office of Disability, to allow Marymead to charge for its respite services at a price higher than the NDIS price cap for the next six months (Groch 2017c). As a result, Marymead (2017) said that it would continue to provide these services to scheme participants.
  - Disability Trust, the last remaining provider of overnight respite care for young people with disability in the ACT, indicated that it was reviewing its services, and could not guarantee respite services after Christmas (Groch 2017a)
  - CatholicCare Sydney is no longer providing respite care and short-term accommodation because in its view, the NDIS flat daily rate does not reflect penalty rates and other costs (Morton 2017).

The view more broadly

Most, if not all, of the concerns about pricing raised by study participants related to the assumptions of the HRM,[67] and the limited opportunity for providers (and participants) to have input to the pricing process.

[67] The Commission also had access to 46 of the 84 submissions to the NDIA's 2017-18 Price Review. These submissions expressed similar concerns about the assumptions in the NDIA's price model, as did many of the submissions made to this study.

In response, the NDIA said that:

> Some providers have raised concerns that NDIS price levels are too low, particularly for personal care and community supports, but have generally not supported these arguments with clear evidence. Other providers have suggested that current price levels are appropriate. These contradictory views within the provider population might be evidence that some are struggling to adjust to a funding model that is based on market principles. There is also evidence of a wide variation in operating costs under pre-NDIS approaches where efficiency was not a key consideration. It also might reflect changes in volume as well as the extent of cross-subsidisation of services that previously existed.
>
> The NDIA effort to set maximum prices has incorrectly been taken by many in the sector to authorise an 'NDIS price' for their services, which is often inflated above actual costs. (sub. 161, p. 101)

The NDIA acknowledged that there remain divergent views on pricing.

> More generally, divergent facts and views were presented. Some providers argued that existing prices do not allow adequate recovery of their costs, impeding their ability to make a return and acting as a barrier to market growth. On the other hand, some participants argued that providers are overpricing supports in some categories. More detailed work is required to gain a deeper understanding of these divergent perspectives. (Bowen 2017a)

While further work is required to arrive at an appropriate pricing model, it is clear that some prices are having a negative effect on the sector. A survey by the NDS, in partnership with Curtin University (now conducted with the University of Western Australia), found that:

- 67 per cent of respondents were worried that they would not be able to provide services at the prices being offered under the NDIS
- 46 per cent said that to provide services at the prices being offered by the NDIA, they would have to reduce the quality of service (NDS 2016, p. 20).

While 55 per cent of disability support organisations reported making a profit in 2015-16, only 40 per cent of respondents budgeted to make a profit in 2016-17 (NDS 2016, p. 14).

Evidence presented to this study also suggests that other care sectors are beginning to look more attractive than the disability support sector. For example, the ACT Government said that:

> The current Fixed Pricing Structure for NDIS services has affected the overall development of sustainable business models. There appear to be services that are not, or are perceived to not be financially viable. … others have begun to diversify and others have made decisions about withdrawing from (or not entering) the disability services market. ACT providers have also expressed concern that fixed pricing is compounded by the extensive administrative burden and delays when dealing with the NDIA. Some providers have made a decision to leave disability service provision and will instead focus on aged care. (sub. PP312, pp. 7–8)

The Commonwealth Ombudsman also reported that:

> … at a recent consultation a provider told us they could bill around $10 per hour more for providing in home domestic assistance for aged care clients than they could for providing the same service to an NDIS participant. They suggested it was difficult to understand the rationale for this difference and said it created a risk that service providers would focus their service provision on areas that were more financially sustainable, leaving NDIS participants with even fewer choices. (sub. 137, p. 14)

The NDS called for the NDIA to immediately review its prices, and not wait for the McKinsey & Company review.

> Providers are making these decisions now, to get out of certain disability services, and the (NDIA) needs to respond now rather than wait for that review. (Baker in Morton 2017)

This sentiment was echoed by the Victorian Government, which called for the NDIA to urgently review its prices.

> Victoria considers that there is also an immediate need to consider areas where NDIS pricing may be inhibiting market growth or risking provider failure (particularly in areas or services in which there are thin markets). In some areas, the NDIA appears to have applied flawed assumptions to its calculation of prices. Examples include low allowances to train, supervise and recruit direct support staff, unrealistic assumptions around the amount of time staff need to spend undertaking non-client facing functions, and low assumptions around the proportion of overall costs devoted to overheads (particularly during the transition period). Victoria considers that these areas should be corrected as soon as possible. (sub. PP298, p. 3)

Divergent perspectives on the adequacy of prices are currently leading to uncertainty and low confidence within the sector. This is not conducive to the scale and scope of market development (and increase in provider capacity) that is needed to provide supports for NDIS participants.

There is a serious risk that both existing and potential disability support providers will choose to provide their services elsewhere. Some providers in the ACT have said that they have deregistered with the NDIA (or are considering doing so) as a result of the NDIA's price caps (Hermant 2017). Some participants with particularly complex needs may not be catered for under the scheme. This may result in an inappropriate increased reliance on carers, Provider of Last Resort services (including crisis supports), in-kind services and other mainstream services. Under the NDIA's current pricing approach, the benefits of the NDIS scheme will not be fully realised.

FINDING 8.1

The National Disability Insurance Agency's approach to setting price caps to date has hindered market development by discouraging the provision of some disability supports. In some cases, it has led to poor participant outcomes, especially for those with complex needs. The benefits of the National Disability Insurance Scheme will not be fully realised if the Agency continues with its current pricing approach.

8.3 How should price caps be set?

Prices must send a clear signal to the market to encourage the supply of supports, promote competition and innovation. Without this, many of the problems experienced under the previous system — unmet demand, unclear decision-making and unfair allocations of supports — will continue or reoccur, and lead to poor participant outcomes. In the context of the NDIS, the challenge for the price regulator is to find the right balance between market development, the financial sustainability of the scheme and participant outcomes. It is this balance that the NDIA currently aspires to in setting price caps (NDIA, sub. PP327, pp. 36-7).

The Commission's concern is that the NDIA has not achieved the right balance. Comments by the NDIA (sub. PP327, p. 36) that price setting is inseparable from financial sustainability, and by the former Chair of the Agency (Bonyhady, sub. PP333, p. 13) that 'the NDIA's 'efficient prices' … are calibrated to the expected full costs of the NDIS of $22 billion', suggest that financial sustainability could be prioritised over other objectives.

If the financial sustainability of the scheme is given priority over the other objectives of market development and participant outcomes, then the scheme's objectives will not be achieved. As pointed out by Victorian Legal Aid (sub. PP367, p. 3), 'the scheme cannot function predictably, transparently or fairly if financial sustainability looms large over every decision', and it is difficult to reconcile such a position with the scheme's objective to provide reasonable and necessary supports for participants.

Others suggested that one body attempting to achieve this balance of multiple objectives through pricing is not possible or desirable. For example, both the Harper Competition Review and the OECD emphasised the value of having regulators — including price regulators — being at arm's length from other decision-making and functions (Harper et al. 2015, pp. 227–229; OECD 2014, p. 47). Many State and Territory Governments[68] — funders of the scheme — also suggested that price-setting should be more independent than is presently the case. The Department of Social Services (DSS) (sub. 146, p. 39) also indicated that there could be merit in moving price regulation to an independent body, albeit not immediately. The Australian National Audit Office (ANAO) (2016, pp. 30–31) raised the concern that the NDIA could be conflicted in its dual market roles as both price-setter and purchaser of supports.

Regardless of whether there is a conflict, or how a balance is to be achieved, it is clear that the current pricing approach needs to be improved quickly.

At its heart, pricing policy should reflect the objectives of the scheme and address the concern that without price regulation for a period, participants will be adversely affected by unaffordable support costs. Value for money for participants needs to be considered with financial sustainability of the scheme in the short term, but with an eye to market

[68] See for example: Northern Territory Government (sub. PP359, p. 2); Queensland Government (sub. PP345, p. 13); Tasmanian Government (sub. PP247, p. 8); and Victorian Government (sub. PP298, pp. 3, 22–4).

development to render price controls unnecessary over the longer term. If price caps are set inappropriately, there is a risk that pricing decisions will distort or 'make the market', rather than allowing the market to develop in a way that reflects the needs (and goals) of participants.

To realise the benefits of the scheme for participants, NDIS price caps should be legislated to be evidence-based, set transparently, and determined independently (box 8.5).

Box 8.5 Best practice principles for price regulators

The UK National Audit Office observed that government authorities setting prices for public services in markets should adhere to eight principles for value for money. They should:

- understand national supply and demand and intervene to remedy problems
  - this includes: the patterns of regional variation (including levels of spare capacity); the likely impact of policy reforms; and possible future scenarios
- understand the national market structure and intervene in the event of market failure
  - this understanding should include: market size and concentration (including 'difficult to replace' providers); degree of exposure to publicly funded users; and price and quality variations and trends
- understand the role of, and work with, the competition authorities and relevant quality and sector regulators to raise awareness, standards and enforce rules and the right market behaviour
- understand the authority's impact on local public and private markets as a purchaser of services, and how to encourage the right market behaviour
- know the costs of service provision
- ensure the price sustains supply at acceptable levels
- ensure quality is acceptable
- ensure users are well informed about quality (NAO 2013).

More generally, the OECD's seven principles for good governance of regulators are:

- role clarity
- preventing undue influence and maintaining trust
- decision making and governing body structure for independent regulators
- accountability and transparency
- engagement
- funding
- performance evaluation (OECD 2014).

Evidence and transparency are essential, but lacking

As the NDIS disability support market is still developing, the data and information needed to determine the appropriate price controls are limited. This is reflected in the NDIA's approach, which includes consulting with the disability support sector.

> In the roll-out phase of the NDIS, the NDIA is adopting a cautious approach to price controls in the absence of information on the competitiveness of markets for supports. (NDIA 2017a, p. 5)
>
> Price control decisions are informed by significant input from market stakeholders through regional forums, targeted workshops, individual discussions and responses to discussion papers. (NDIA, sub. 161, p. 100)

This approach is consistent with the Office of Best Practice Regulation's recommendation that the NDIA should:

> … continue to make its decisions about the setting of reference prices transparent, continue to work with the NDS to collect information on the costs of providing supports, and continue to monitor the impacts of reference prices on existing providers. (2015, p. 43)

There is some evidence that the NDIA has responded to market circumstances and feedback. For example, the NDIA increased price caps for personal care and community supports by about 10 per cent in 2014 and 2015 at some NDIS trial sites (ANAO 2016, p. 47). However, some providers argued that to date, they have not had any real opportunity to provide feedback on pricing decisions.

House with No Steps (sub. 104, p. 4) said that there was a 'lack of real consultation by the NDIA with service providers', and that (prior to the 2017-18 price review) they had never been formally consulted on any matter (including prices), despite being one of the largest providers nationally.

> Our frustration is that this pricing is relatively easily and transparently modelled in an Award environment. Such modelling, if publicly shared, would move the discussion from the inadequacy of a 'black box' number to an informed discussion around cost drivers such as staffing mix, management spans of control and overhead levels. We understand such modelling has been carried out by the NDIA and independent actuaries and, if so, do not understand why the output of those modelling exercises has not been made public or reflected in NDIA pricing. (sub. 104, p. 3)

Similarly, Interaction Disability Services was concerned about the Agency's lack of engagement with providers on pricing issues.

> Our most significant concern is that the NDIA has developed non-contextual pricing. In our view, this has happened because of what we believe is a failure to engage wholly with service providers on planning and pricing. This is a misplaced philosophical position based on assumptions that service providers will inflate prices. These assumptions have never been tested. (sub. PP213, p. 1)

These frustrations extend to a lack of usable information about prices needed to provide meaningful feedback.

> The NDIA's process for pricing services of various kinds has been difficult for non-government stakeholders to understand or contribute to … Providers have also been largely unable to provide detailed advice in response to any consultations either during or subsequent to the RCM's [Reasonable Cost Model] development. To build the NDIA's evidence base for 'a market price' for psychosocial services, Mental Health Australia asked the NDIA to check the assumptions in the model with providers, but to our knowledge this did not occur. (Mental Health Australia, sub. 155, p. 22)

The lack of transparency has also led some providers to question the NDIA's independence. For example, Autism Association of Western Australia said that:

> Given the lack of transparency and evidence surrounding the populating of the RCM [Reasonable Cost Model], it is more accurate to describe it as a funding tool rather than a pricing tool with all that this would imply in relation to market-based evidence. (sub. PP219, p. 3)

Concerns about a lack of transparency and consultation were shared by many others (not just providers) — including the HSU (sub. 132, p. 10), the ACT Government (sub. 156, p. 27) and the ANAO (2016, p. 13). For example, the DSS said that:

> … greater transparency, appropriate benchmarking and independence are required in price regulation under the Scheme. Better communication is required to improve stakeholder understanding and provide greater market certainty, particularly about the pre-conditions for price deregulation. (sub. PP318, p. 14)

As part of its most recent price review, the NDIA said that it had received feedback from stakeholders that there was:

> … a lack of transparency on the assumptions and methodology used to calculate price controls (which could affect discussion about how price arrangements relate to other parts of the NDIS, as well as debate about the price controls themselves). (2017a, p. 7)

To address this lack of transparency, the NDIA (2017a) released additional information about pricing as part of the latest pricing review. The NDIA Board also commissioned a pricing review by McKinsey & Company.

> Reflecting the NDIA's market stewardship role, the NDIA has also commissioned McKinsey and Company to undertake an independent Price Review which will provide the evidence and transparency to ensure that any future price settings for supports and services underpin the critical objectives of the NDIS. (Bowen 2017b)

That said, the NDIA's price-setting process remains largely opaque. Submissions to the price review are not made public, nor is it clear how the material is used or assessed. And details about the operation of the HRM are not in the public domain.

The lack of transparency around prices is at odds with the practice of independent price regulators and authorities in other sectors.[69] It is also inconsistent with the Commission's 2011 recommendation that the NDIA's recommendations to change prices should be transparent, if the Agency is to set prices (PC 2011, p. 412).

As a first step to improve transparency, the NDIA should make public a summary of the McKinsey & Company price review, once it is completed. The NDIA should also use existing work, such as the provider benchmarking study currently being run by the NDS and the University of Western Australia.

Transparent price controls are important to impose discipline and public accountability in setting prices, as well as to increase credibility and certainty of price signals, which assists with forward planning, investment and entry by providers. There are reports that some new providers (including aged care providers) may be delaying entry to the sector because of ongoing uncertainty regarding price deregulation and profitability (Whyte 2017).

A number of State and Territory Governments agreed that independent, transparent and evidence-based price controls are necessary to facilitate market development (for example, Tasmanian Government, sub. PP247, p. 8). As the NSW Government pointed out:

> A well-functioning market requires a robust and transparent pricing framework. This provides certainty in relation to revenue potential for providers, which, in turn, provides an incentive for investment in service offerings (if prices are set at the right level). This work must be prioritised. (sub. PP230, p. 5)

Transparent price controls are particularly important for providers of Specialist Disability Accommodation, as large upfront capital investment ('patient capital') is required, which may be debt-funded and is usually recovered over a 20-year investment period (NDIA 2016v, p. 19; NSW Government, sub. PP230, p. 5). Transparency around price controls also extends to disseminating relevant market information ('non-price signals') to complement and improve the effectiveness of price signals. Power Housing Australia commented on the lack of data on disability housing demand from NDIS participants across Australia.

> … there is little transparency about where people with disabilities and those needing Specialist Disability Accommodation tend to live, and what types of disability housing are needed across Australia … To ensure affordable housing with appropriate modifications are available into the future, information about current and future projections around the location, types of disability, and housing required for NDIS participants is recommended … (sub. 139, p. 6)

Transparency creates greater incentives for new providers to enter the disability support market, and helps build community trust and confidence that the prices for supports are fair

[69] For example, aged care (Aged Care Pricing Commissioner and Aged Care Financing Authority), electricity and telecommunications (Australian Competition and Consumer Commission), energy (Australian Energy Regulator), minimum wages (Fair Work Commission), public hospitals (Independent Hospital Pricing Authority), and the Independent Pricing and Regulatory Tribunal NSW.

and reasonable for providers, participants and taxpayers. A lack of transparency can erode this confidence, and put the scheme at risk.

Clear and limited statutory authority to regulate prices

Transparent price regulation also requires that the legal authority for price regulation is clearly defined and stated in legislation. Having clearly specified objectives ensures that the regulator has 'sufficient context to establish priorities, processes and boundaries for its work' (OECD 2014, p. 31). In other words, clearly defined statutory limits are necessary for pricing powers to be exercised transparently, predictably, independently and fairly.

Clearly defined roles for price regulation also promote public accountability and the rule of law, by ensuring that regulators only operate within the scope of powers given to them by the legislature. This means that the regulator's objectives, functions and powers should be made clear to the regulator's staff, regulated entities, citizens and other stakeholders (ideally through principle-based legislation) — with regulators not being assigned competing or conflicting objectives or functions (OECD 2014, pp. 32–38). A regulator with clear roles is more effective in achieving desired policy objectives, and fosters public trust and confidence in its decision making, resulting in greater certainty and stability. A lack of clarity can impair a regulator's performance and lead to poor community outcomes.

Currently, the NDIA's power to set prices is not expressly specified in the NDIS legislative framework (the *National Disability Insurance Scheme Act 2013* (Cwlth) and NDIS Rules). Nor are the objectives or functions of its price regulation powers clearly stated in the legislation (making administrative review of its decisions difficult). This is notably different to the legislative arrangements for other price regulators.[70]

Without clear limits set on price regulation, there is a risk that the NDIA could exercise its pricing powers inappropriately (for example, constraining scheme costs to the detriment of market development). Unless pricing functions, powers and objectives are clearly specified, the Agency may also have less incentive to act transparently, particularly if it is not empowered or required by law to act transparently in the exercise of these functions.

Strong support for independent price regulation

The transition period of the scheme provides an opportunity to consider a number of issues, including any concerns around how the NDIA balances different objectives of the scheme, the lack of transparency in how price caps are set, as well as the need to define the price-setting role in legislation. It is also an opportunity to provide greater certainty to

[70] For example, the Independent Hospital Pricing Authority's objectives, functions and powers (including matters that the Authority must consider) to determine the national efficient cost and price for health care services provided by public hospitals are specified in the *National Health Reform Amendment (Independent Hospital Pricing Authority) Act 2011* (Cwlth).

providers about how and when price deregulation will occur, which is a key milestone in moving to a market-driven approach.

Most study participants agreed with the need for an independent price regulator (box 8.6).

There was support across a range of stakeholders, including people with disability, providers, community organisations and governments.[71]

However, the NDIA (sub. PP327, pp. 35–9) argued that an independent price regulator would put the scheme at risk. The Agency (sub. PP327, pp. 35–6) perceived its situation not as a conflict of interest, but a 'necessary and deliberate' tension between promoting participant outcomes, market development and financial sustainability.

Balancing the objectives of the scheme, including market development and financial sustainability is important, but does not preclude moving to an independent price regulator. Just as in other price-regulated industries, and like any other stakeholder, the NDIA would be able to make public submissions to a regulator on how price changes could affect the scheme's financial sustainability and other scheme objectives (and include any confidential market data held by the NDIA about relative efficiencies and benchmark costs of service provision), and be able to recommend its own set of prices to the regulator to inform the latter's decision making.

The NDIA (sub. PP327, pp. 36–7) also said that if its pricing powers were moved to an independent price regulator, the Agency would no longer be able to perform its market stewardship role effectively. But the responsibility for effective market stewardship and the management of market risks is already shared among a number of governments (and does not always require price controls). The Agency would still be able to influence market development by providing information and other resources to the market. Delivering better quality plans (chapter 5), supporting participants to navigate the market, and achieving the outcomes of the proposed eMarketPlace (chapter 10) will shape demand, and in turn, the supply response in the disability support sector.

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[71] Including: Activ (sub. PP302); ADACAS (sub. PP260); AFDO (sub. PP325); Anglicare Australia (sub. PP339); APC Prosthetics (sub. PP244); ABF (sub. PP263); AOPA (sub. PP294); Australian Unity (sub. PP273); Autism Association of WA (sub. PP219); BCCM (sub. PP329); Carers Australia (sub. PP224); cohealth (sub. PP261); CSIA (sub. PP251); CSSA (sub. PP278); CYDA (sub. PP358); Flourish Australia (sub. PP246); HSU (sub. PP316); HSU, AU and UV (sub. PP272); Jenny Harrison (sub. PP236); Legal Aid NSW (sub. PP245); MAV (sub. PP343); Mental Health Australia (sub. PP321); MIFA (sub. PP338); MJD Foundation (sub. PP233); MS Australia (sub. PP283); NDCA (sub. PP344); NHMC (sub. PP319); Neami National (sub. PP347); NDS (sub. PP295); Noah's Ark (sub. PP328); Northern Territory Government (sub. PP359); OTA (sub. PP285); One Door Mental Health (sub. PP266); Prader-Willi Syndrome Association of Australia (sub. PP228); PDA (sub. PP306); Queensland Government (sub. PP345); Richard Madden (sub. PP307); Summer Foundation (sub. PP293); Tasmanian Government (sub. PP247); VALID (sub. PP332); VCOSS (sub. PP264); VHA (sub. PP337); Victorian Government (sub. PP298); and Vision Australia (sub. PP252).

Box 8.6 Many study participants support independent price regulation

Autism Association of Western Australia:

> For the sake of the sustainability of the Scheme, and the quality of services delivered to participants, pricing needs to be undertaken by an independent umpire who is not conflicted in their approach; and who has no other interest but to set objective prices based on true market conditions for the work under consideration. Only in this way will the Scheme be scalable and sustainable. (sub. PP219, p. 6)

Flourish Australia:

> Integral to the long-term success of the NDIS is the need to get pricing right. Available evidence suggests that a significant number of providers are struggling under the current regime. In the lead-up to deregulation, the price setting process requires specialist expertise, a robust methodology, independence and transparency, and comprehensive consultation with and input from service providers. (sub. PP246, p. 7)

Australian Federation of Disability Organisations:

> … would like to see independence and transparency for such issues as setting the pricing cap that an independent pricing regulator would enable. This is vital in the context of providing a degree of financial certainty … which may allow for more providers to enter the marketplace or existing providers to develop sustainable business models … AFDO is aware of sector wide concern that the financial realities of disability service provision are not given the weight they should. (sub. PP325, p. 17)

Australian Unity:

> … supports the establishment of an independent pricing regulator … Australian Unity is concerned that the current pricing formula does not sufficiently recognise the core costs associated with providing services under the NDIS. We agree that the establishment of an independent pricing regulator is likely to enhance current arrangements, and will ensure that the pricing arrangements for the NDIS align with other parts of the human services sector. (sub. PP273, p. 2)

National Mental Health Commission:

> … acknowledges that the NDIA has been given an extremely difficult task. Implementing a reform of the scale and nature of the NDIS was always going to be challenging; implementing it with a curtailed timetable, reduced resourcing and under shared accountability arrangements where different governments have different expectations. For these reasons the NMHC supports … the separation of the pricing function from the Agency. (sub. PP319, p. 5)

Queensland Government:

> There is merit in introducing an independent price regulator to avoid a potential conflict of interest with the NDIA both setting prices and being responsible for the financial sustainability of the scheme. (sub. PP345, p. 13)

Catholic Social Services Australia:

> … strongly supports … the establishment of an independent price monitor to conduct an immediate review of NDIA price caps, transitioning to an independent price regulator … (sub. PP278, p. 4).

Victorian Government:

> More confidence in NDIA pricing is required as soon as possible to encourage growth in supply and incentivise market transition. Victoria welcomes the recommendation to move to an independent price regulator … (sub. PP298, p. 22).

The NDIA (sub. PP327, p. 38) argued that a new body would result in additional costs, increased fragmentation and inefficiency, and any regulator would hold less useful data and information than the Agency. On access to data, there do not appear to be any significant

barriers to the data sharing between the Agency and the private firms engaged to assist the Agency with its pricing response (for example, the McKinsey & Company price review). The Agency also shared data and information with the Commission for this study. And in terms of additional costs, these will be minimised if the NDIA's pricing powers are transferred to an existing body, particularly if pricing functions are relevant and complementary to its existing functions relating to the NDIS.

Moving towards independent price regulation

As with any price regulator, there are costs and benefits to its operation, and the need for open channels of communication between the regulator, regulated firms, consumers and others affected by such regulations. There is a compelling case to legislate for an independent price regulator that can set price caps independently, transparently and in an evidence-based manner. This will give providers and the community greater certainty (and participants certainty that they will receive the services that they need), and in turn, encourage new and existing providers to supply disability supports. The ultimate objective is for the supply of supports, innovation and efficiency to be driven by price signals that reflect participants' wants and needs through the exercise of their choice and control.

To achieve this, the Commission recommends that price deregulation should occur in three stages (figure 8.2).

In the first stage, the NDIA would temporarily maintain its role of price regulator (given that it is not possible to set up a new price regulator immediately), but an independent price monitor would be introduced with responsibilities, including to:

- examine how the market is responding to price caps set by the NDIA
- review the NDIA's price caps based on the available evidence, including submissions made to the NDIA's price reviews, and making comparisons with prices in other care sectors (including aged care)
- report publicly on its assessment of the NDIA's price controls with regard to market development and participant outcomes.

This monitor should be put in place quickly to serve as a 'check and balance' on the NDIA's pricing decisions over the transition period. The monitor will improve transparency around how price caps are set, and in turn, lead to greater accountability to participants, providers and the wider community.

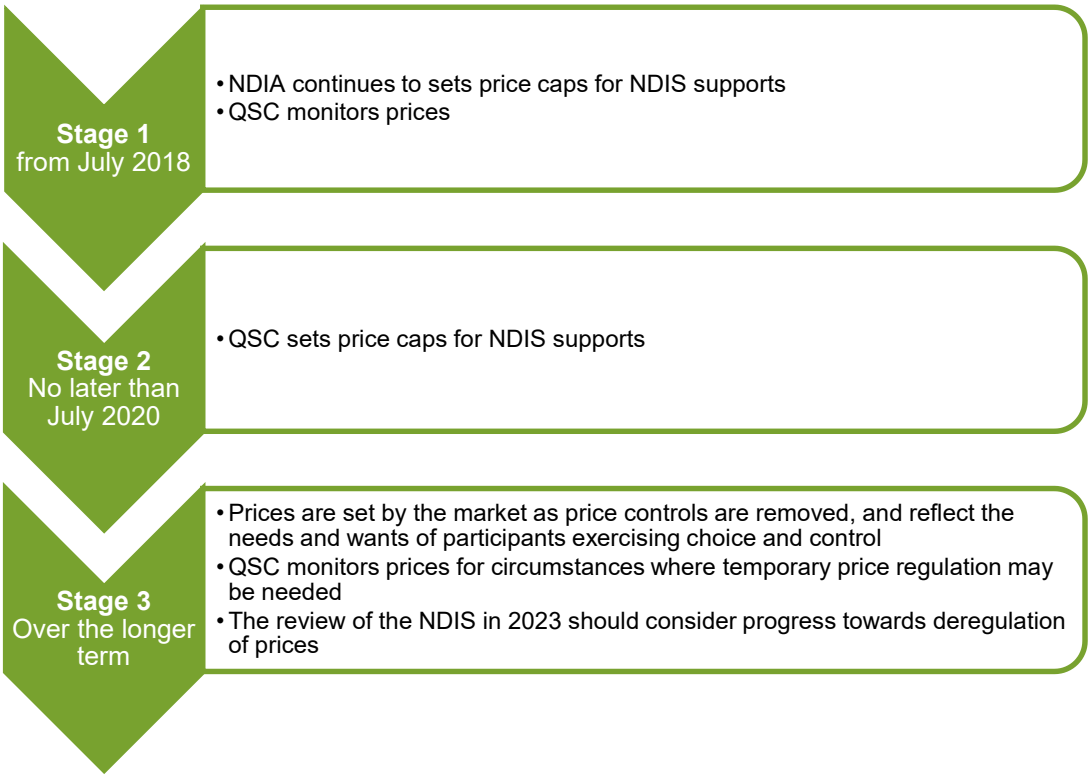
The Commission considers that the NDIS Quality and Safeguards Commission (QSC) (box 8.7) is an appropriate body to *monitor* NDIS prices in the first stage. The QSC's role will include the assessment and enforcement of quality and safety standards to protect participants — which itself will have a strong bearing on prices. Put simply, price and quality are intertwined in the NDIS. The QSC will also have regular communication with

stakeholders, including providers and the NDIA, as part of its provider registration, quality and safety regulation functions.

The QSC should begin price monitoring when it commences in July 2018 to enhance the transparency of the NDIA's price setting over the short term. The full report of the McKinsey & Company price review should be provided to the QSC when it is completed.

The second stage is to transfer the NDIA's price-setting powers to the QSC in July 2020. This would allow the NDIA to focus on its core responsibilities of delivering and administering the NDIS, and remove any concerns about a conflict of interest or how the Agency balances its objectives. It will also help address concerns about a lack of transparency in price regulation. Given the expectation for price regulation to persist for at least the next decade (ANAO 2016, p. 54), it will be necessary to place increasing emphasis on market development to deliver safe and quality supports — a role that the QSC is best placed to undertake, rather than the NDIA. The benefit of having an independent price regulator is that it would provide a credible, independent and transparent evidence base upon which pricing decisions could be made. The QSC would consult with, and accept submissions from all interested parties on its pricing decisions, including the NDIA.

Figure 8.2 **The PC's recommended path for NDIS price deregulation**



Box 8.7 The NDIS Quality and Safeguards Commission

The Australian Government announced that it will establish the National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission (QSC) to oversee quality and safeguards for all scheme participants, and set standards for NDIS providers. It is expected to commence operations in July 2018, with its enabling legislation currently before Parliament.

The Productivity Commission considers that the QSC is best placed to act as a price monitor in the short term, and to act as a price regulator for NDIS supports over the longer term, because its functions are consistent with the Commission's proposed pricing principles.

The QSC is to be evidence-based and transparent

The QSC is to be evidence-based in its legislated role and use its best endeavours to support and maintain a diverse and sustainable NDIS market. By law, the Commissioner will be required to:

- contribute to the National Disability Insurance Scheme Agency's provider benchmarking and to provider quality ratings, as well as monitor, review and report on the effectiveness of the NDIS, including market trends and the quality of outcomes achieved
- actively monitor those providers who would be 'hard to replace' if they ceased trading, including prudential oversight of financial viability
- form a national perspective on markets, using data and information generated by consumers and providers to identify trends in provider practice and wider market responses that may require action
- engage in, promote and coordinate the sharing of information to achieve the objectives of the NDIS Act.

The QSC is also to be transparent in its dealings with the community. The Commissioner is to have powers to initiate inquiries into systemic issues connected with supports or services provided under the NDIS. The Bill also makes clear that the Commissioner may consult and co-operate with a broad range of people, organisations and governments, including people with disability. Further, one of the Commissioner's core functions is to provide advice or recommendations to the National Disability Insurance Agency (or its Board) in relation to the performance of the Agency's functions — a function consistent with a price monitoring role.

The QSC is to be independent and well resourced

The QSC is to be an independent statutory body, with the Commissioner to hold broad-ranging powers in the exercise of his or her functions, and be accountable to the Australian Parliament. While the Minister for Social Services may give the Commissioner general directions in the exercise of their functions, the Minister is prevented from giving specific directions about particular providers, groups or individuals. The Australian Government has allocated $209 million between 2017-18 to 2020-21 to establish the QSC with about 300 staff. To support the Commissioner, the QSC is envisioned to have subordinate members including the NDIS Registrar (responsible for registering NDIS providers) and a Complaints Commissioner (responsible for complaints and reportable incidents). Adding a Pricing Adviser to assist the Commissioner in price regulation roles could be a sound approach to transfer pricing responsibilities from the National Disability Insurance Agency to the QSC.

Sources: Australian Treasury (2017b, p. 154); DSS (2016d, 2017f); National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017 (Cwlth); Porter (2017); and Porter et al. (2017).

Across both stages, the body tasked with price regulation for scheme supports should have relevant capability and necessary resources[72] to perform its functions, including to:

- collect and publicly report data on providers' characteristics and costs — public reporting of this data would provide a benchmark for providers, inform public debate about prices, and facilitate relevant research by external parties
- communicate with disability support providers, participants and the NDIA to transparently set prices at regular intervals, with sufficient time for providers to phase in price changes. Providers (and participants) should be given at least 60 days' notice of price changes before they are to take effect
- periodically review and publish its price model for transitional and efficient prices in a transparent and comprehensive manner
- send granular and targeted price signals — that is, provide prices at the state and territory level, with an expectation that prices could be set at a more disaggregated regional level where possible. This would include the timely provision of supporting market information on all States and Territories (to date, the NDIA has not produced a market position statement for Western Australia (NDIA 2017p)), as well as more disaggregated data on committed supports where possible
- determine — on the basis of transparent consultation and evidence — when prices for particular NDIS supports in each region should be deregulated, and evaluate whether there is a need for price controls. To enable efficiencies to be driven by the market wherever possible, the price regulator should presume that it is appropriate for prices to be deregulated — that is, to only have price controls when there is clear evidence that unregulated prices are likely to lead to inflation that would harm participants. The review of the NDIS costs in 2023 should consider the state of market development, including progress towards price deregulation.

The third stage of deregulation will occur when the price of a given disability support is deregulated, but is still subject to subsequent monitoring. The QSC would maintain an ongoing watch on pricing, collect data, and publicly report on emerging market issues that affect the purchasing power of scheme participants. The QSC's pricing role would gradually diminish (and revert to a price monitoring role) as the market develops over time.

[72] For example, as at 30 June 2016, the Independent Pricing and Regulatory Tribunal NSW had 133 full-time equivalent employees (IPART 2016, p. 7) and the Independent Hospital Pricing Authority had 51 employees (IHPA 2016, p. 37). The NDIA had a total of 1505 employees (NDIA 2016b, p. 85), but data on how many employees were in the Markets and Pricing division are not publicly available.

RECOMMENDATION 8.1

The body responsible for regulating the price of supports under the National Disability Insurance Scheme should have relevant capabilities and the necessary resources to set price caps in a manner that is:

- transparent, with wide public consultation and publicly available information, including all assumptions used in any pricing models
- evidence-based
- supported by clear and limited legislative authority
- independent
- timely, particularly in giving providers sufficient time to phase in changes and be responsive to market conditions.

RECOMMENDATION 8.2

The Australian Government should amend the *National Disability Insurance Scheme Act 2013* (Cwlth) to require the National Disability Insurance Scheme Quality and Safeguards Commission (QSC), upon its commencement in 2018, to monitor, review and report on the price caps for scheme supports set by the National Disability Insurance Agency (NDIA). This should include appropriate funding for the QSC to undertake price monitoring of scheme supports, and to continue the business characteristics and benchmarking study currently undertaken by National Disability Services and the University of Western Australia.

The Act should require the NDIA to provide any relevant data and information that is required by the QSC in its price monitoring functions. The NDIA should make public a summary of the report of the 2017 McKinsey & Company price review upon completion, and provide the full report to the QSC.

RECOMMENDATION 8.3

The Australian Government should amend the *National Disability Insurance Scheme Act 2013* (Cwlth) to transfer the National Disability Insurance Agency's (NDIA) power to set price caps for scheme supports to the National Disability Insurance Scheme Quality and Safeguards Commission (QSC) by no later than 1 July 2020. The Act should require the NDIA to provide any relevant data and information that is required by the QSC in its price regulation functions.

Prices should only be regulated as narrowly and for as short a time as possible. As part of its price regulation functions, the QSC should:

- collect, de-identify and publicly release data on providers' characteristics, including the price, profits, costs and quality of services
- set price caps for supports at least at a state and territory level, which should be made public no less than 60 days before prices take effect
- comprehensively review and make public its price model on at least an annual basis. This review should be transparent, have wide public consultation, be evidence-based and evaluate the effectiveness of prices in meeting clearly defined objectives
- determine when to deregulate prices for supports, with particular regard to the type of support and region.

Progress towards price deregulation should be considered by the independent review of scheme costs in 2023.

9 Workforce readiness

Key points

- The disability care workforce will need to roughly double from its 2014-15 level to meet the increased demand for National Disability Insurance Scheme (NDIS) supports. This will mean that about 1 in 5 new jobs (net) forecast to be created in Australia over the transition period will need to be in disability care. While the disability care workforce has already grown considerably, it is unlikely to meet this target under current policy settings.
- There are a number of challenges to growing the disability care workforce. These include: the effect of price caps for NDIS supports on wage growth; finding carers to meet high participant demand at particular times of the day; ensuring that there are enough qualified carers to provide a reasonable quality of care (including allied health professionals); and increasing rates of retirement of workers from the sector as they age. There are also regional challenges — the workforce will need to triple or even more to meet demand in some areas.
- Policy changes that would help to address some of the workforce shortages over the transition period include:
  - taking advantage of the preference of many workers in the disability care sector to work more hours
  - using a targeted approach to immigration to address persistent skill shortages
  - trialling different approaches to help fund volunteer organisations to provide participant supports.
- Over the longer term, there needs to be a clearer delineation of roles and responsibilities for developing workforce policy for a more coordinated response to meeting the workforce needs of the NDIS. Building the evidence base on the number of workers in the sector, and their conditions and working arrangements, would be a sound investment to develop more effective workforce policies in the future.
- The way respite services are provided under the NDIS — participants are required to include it in their plans, and there are caps on the amount of respite — could be creating a disincentive for providers to supply these services. This may reduce the ability of participants' family members and friends to provide informal care. A lack of respite and informal care will increase demand for formal carers and scheme costs.

The state of the disability care market's readiness to deliver National Disability Insurance Scheme (NDIS) supports will affect scheme costs. Market readiness depends on, among other things, whether there are enough workers to provide NDIS supports.

As recognised by the National Disability Insurance Agency (NDIA), any workforce shortages are a risk to the scheme.

> A major concern for the NDIA is that the speed in growth of demand cannot be met by a commensurate speed in growth of supply. The availability of workforce is a significant factor in the ability of the market to supply the needs of people with disability. (sub. 161, p. 95)

While workforce shortages will have a direct effect on scheme costs, the NDIA's pricing policies will also affect workforce growth and scheme costs. For example, without price regulation (in the short term), increased competition for care workers could bid up wages and increase scheme costs. However, with price regulation, the workforce may not grow quickly enough. This could lead to unmet demand for participants, which will put a brake on scheme costs, but could also undermine the objectives of the scheme by restricting access to reasonable and necessary supports.

This chapter examines the question — can the disability care workforce grow quickly enough to supply the increasing demand for services under the NDIS?

Section 9.1 looks at the current state and characteristics of the disability care workforce. Section 9.2 discusses the size and scope of the workforce that will be needed when the NDIS is fully rolled out. Section 9.3 examines policy options for developing the workforce, and ways to reduce the number of workers required to provide NDIS supports. Section 9.4 examines policies for informal carers that may reduce calls on the formal care workforce.

9.1 The disability care workforce

The disability care and support workforce is diverse. It includes disability support workers that provide daily care and allied health professionals that provide specialised care. As the NDIS is rolled out, the size and scope of the workforce will increase — both to cater for more participants, and to embrace new roles driven by the market-based system as participants exercise greater choice over their supports.

To understand how the workforce will need to change requires an understanding of what it looks like now. It is difficult to measure the disability care workforce as it is usually classified in the same category with aged care workers in regularly published statistics (box 9.1). With this in mind, a number of broad conclusions about the disability (and aged care) workforce can be drawn.

- Disability care workers are older than the workforce in general (figure 9.1) — about 22 per cent of workers are aged 55 years and older (NDS, sub. 51, p. 9).
- About 80 per cent of employees in the disability care sector are women (compared with about 46 per cent of employees for all occupations).[73]

[73] Commission estimates based on ABS (*TableBuilder*, Education and Work, May 2016).

- About 60 per cent of employees in the disability care sector work part time (compared with about 30 per cent of employees for all occupations).[74]
- The majority of workers in the disability care sector hold a certificate-level qualification (figure 9.2).

Box 9.1 Measurement issues: the disability care workforce

Data on workers in Australia are collected regularly by the Australian Bureau of Statistics based on the industry of employment (the Australia-New Zealand Standard Industry Classification (ANZSIC)) and the occupation of the worker (using the Australia-New Zealand Standard Classification of Occupations (ANZSCO)) (ABS 2006, 2013). However, neither of these classifications are well suited to identifying those working in the disability care sector, or those working in disability care roles.

For example, the most disaggregated — that is, the level of finest detail — ANZSIC classification that includes disability carers is '8790 Other Social Assistance Services', which also includes aged care assistance services, marriage guidance services, and the operation of soup kitchens. In ANZSCO it is '4231 Aged or Disabled Carer', which again combines aged and disability carers together. Neither of these are ideal for analysing the state of the disability care workforce.

Allied health professionals who work in the disability support sector are similarly hard to identify, as it is difficult to distinguish between those that may provide services occasionally or those that provide them full time to people with disability. The classification of allied health professionals is also contentious and subject to revision.

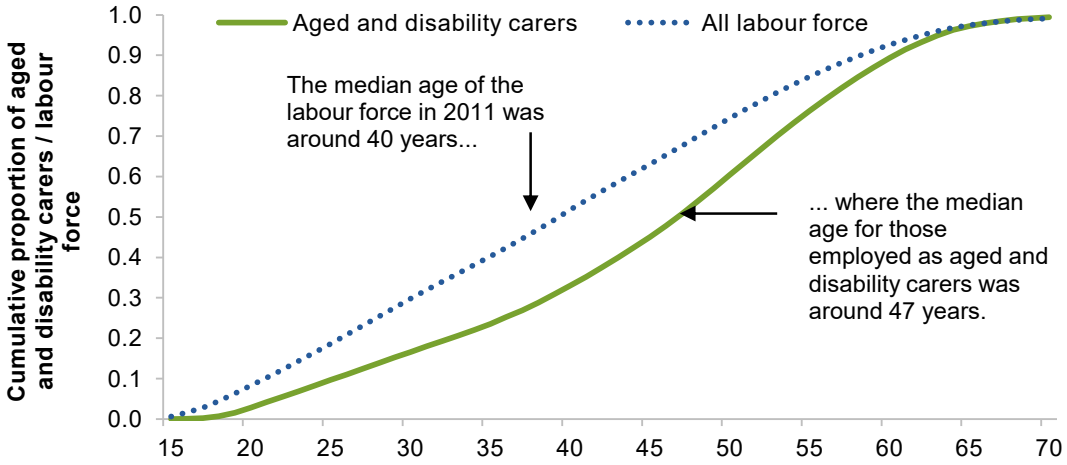
> There is no one definition which prescribes the disciplines considered as allied health. At the meeting of the Council of Australian Governments in July 2006, agreement was reached to establish NRAS [the National Registration and Accreditation Scheme] for health professionals, beginning with the ten professional groups registered in all jurisdictions, of which seven fall under the allied health banner: chiropractic care, optometry, osteopathy, pharmacy, physiotherapy, podiatry, and psychology. … A further four allied health professions joined NRAS on 1 July 2012: Aboriginal and Torres Strait Islander health practitioners, Chinese medicine practitioners, medical radiation practitioners and occupational therapists. … Other allied health professions that are not included under NRAS, but are considered in the Commonwealth's health workforce policy planning, include: Audiologists, Counsellors, Dieticians, Exercise physiologists, Music therapists, Nutritionists, Pathologists, Social workers, Sonographers, Speech pathologists. (Department of Health and Ageing 2013)

Other studies, including the Commission's inquiry into *Disability Care and Support* (PC 2011), relied on 'one-off' surveys and alternative data sources to better understand the disability care workforce. This included a detailed survey by Martin and Healy (2010). This survey remains the most specialised data source for the disability care sector workforce, though is now becoming dated. A more recent survey on the disability care workforce (Cortis 2017) provides an update to some of the matters examined by Martin and Healy.

[74] Commission estimates based on ABS (*TableBuilder*, Education and Work, May 2016).

Figure 9.1 **People working in the aged and disability care sector are older than the labour force in general[a]**

2011

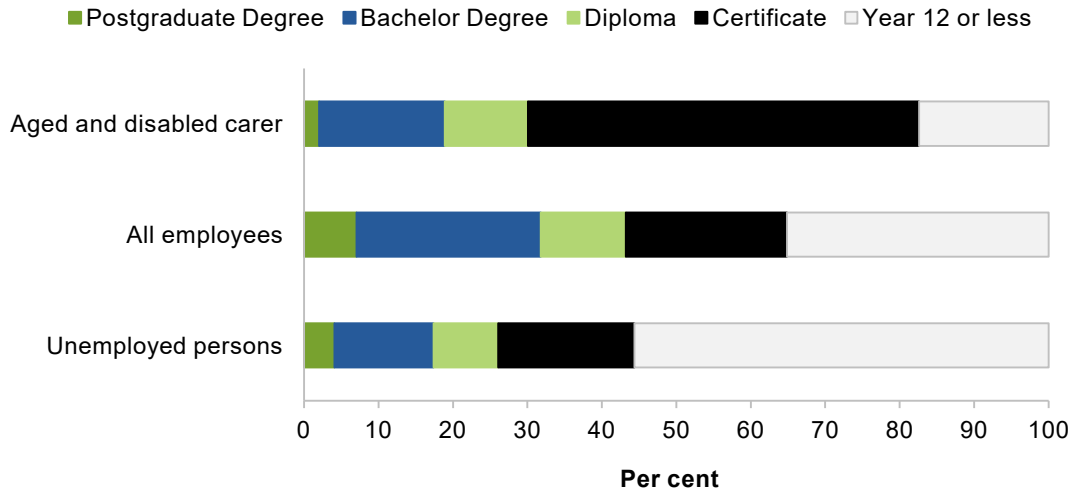


[a] Based on ANZSCO code 4231 'Aged or Disabled Carer'.

Source: Commission estimates based on ABS (*TableBuilder Basic,* 2011 Census).

Figure 9.2 **People employed in aged and disability care roles are more likely to hold certificate-level qualifications[a]**

Highest level of educational attainment, 2016



[a] Aged and disability care roles based on ANZSCO code 4231 'Aged or Disabled Carer'. The Bachelor Degree category includes postgraduate certificate and diploma qualifications.

Source: Commission estimates based on ABS (*TableBuilder,* Education and Work, May 2016).

9.2 What workforce will be needed?

While estimates of the number of workers required to deliver supports allocated through the NDIS vary, the consensus is that the workforce will need to increase by between 60 000-90 000 full-time equivalent employees (FTE) — or roughly double in size.

> The workforce will need to increase from approximately 73 600 full-time equivalent (FTE) workers, to an estimated 162 000 FTE workers. (DRC 2015a, p. 19).
>
> The workforce opportunities and challenges as a result of the introduction of the NDIS are very significant. It is expected that the NDIS will generate between 60 000 and 70 000 new jobs on a full-time equivalent basis over the next three years. This represents about 20 per cent of the total number of new jobs forecast to be created in Australia over this period. (Bonyhady 2016, p. 5)

The NDIA's market position statements suggest that about an additional 70 000 FTE workers will be needed from 2015-16 to 2019-20 (NDIA 2016c, 2016l, 2016s, 2016u, 2016w, 2016x, 2017v).

The evidence to date — at the early stage of transition — is that the workforce is growing quickly, but not fast enough to meet the overall growth target. About 18 per cent growth in FTE employees is required to meet the expected workforce needed for the scheme.[75] Data collected on the workforce by National Disability Services (NDS), a peak body for disability care providers, indicate that the number of FTE workers in the sector is growing at a rate of about 6 per cent each year (Alcorso 2017, p. 3). Data from the NDS's Financial Benchmarking Project (in partnership with the University of Western Australia) indicate annual growth of FTE workers of about 12 per cent (Gilchrist and Knight 2017b, p. 47). The ABS Labour Force data indicate growth of about 13 per cent for the most recent year.[76] Each of these indicate that workforce growth is less than what is needed.

Data on allied health professionals, albeit patchy and reported in a period early in the trial phase, also indicate that growth rates in FTE employees are slow (table 9.1). Clearly, there are considerable challenges emerging in scaling up the workforce to meet the needs of NDIS participants.

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75 Commission estimates based on NDIA (2016c, 2016l, 2016s, 2016u, 2016w, 2016x, 2017v).

76 Commission estimates based on ABS (*TableBuilder*, Education and Work, May 2015 and May 2016) indicate the number of people employed in aged and disability care occupations increased by about 27 per cent between 2015 and 2016 according to ABS Labour Force data. Based on the proportion of part-time to full-time positions, halving the rates of reported 'headcount' growth allows for a rough approximation of the FTE growth targets.

Table 9.1 **The number of registered allied health professionals[a]**
2014

Allied Health Category	*Number registered*	*Average hours FTE equivalent per worked per week 100 000 population*		*Average annual growth rate in FTE per 100 000 population (%)*
Psychologists	31 489	32.7	87.4	1.3[b]
Physiotherapists	27 011	34.7	83.3	2.1[b]
Occupational therapists	16 757	33.1	52.2	3.2[c]
Chiropractors	4 902	32.8	15.8	1.3[b]
Podiatrists	4 314	36.2	16.1	4.0[b]
Dental prosthetists	1 223	38.8	4.9	-2.6[b]
Aboriginal and Torres Strait Islander health practitioners	322	40.7	1.2[d]	4-5[e]

[a] Only selected allied health professions shown from National Registration and Accreditation Scheme data (box 9.1). No data are available for speech therapists and dieticians. The data for 2015 were recently released (Department of Health 2017c), but are not reported in a form that can be easily compared with the above. [b] 2011 to 2014. [c] 2013 to 2014. [d] 76.4 based on Aboriginal and Torres Strait Islander population.[e] 2012 to 2014. A range is presented given the low precision in which the data are reported.

Sources: Commission estimates based on ABS (*Estimates and Projections, Aboriginal and Torres Strait Islander Australians*, 2001 to 2026, Cat. no. 3238.0, series B); AIHW (2014a, 2014b, 2014c, 2014d, 2014e, 2014f, 2014g).

Challenges to reaching the workforce target

While estimates of FTE employees are helpful for providing an overview of the growth required, they mask a wider variation in supply and demand at a more disaggregated level. There are many different workforces that will provide services for NDIS participants, and the challenges and policy responses to each will vary. A better way is to consider the disability care workforce across 'role and region'.

- Role covers the types of workers needed to fulfil a NDIS participant's needs, which in turn will depend on individual choice, disability and other family circumstances. This translates to the skill mix of workers needed, and in turn, the mix of general carers, allied health professionals, and other workers required.
- Region covers the different number and growth in workers required in different locations.

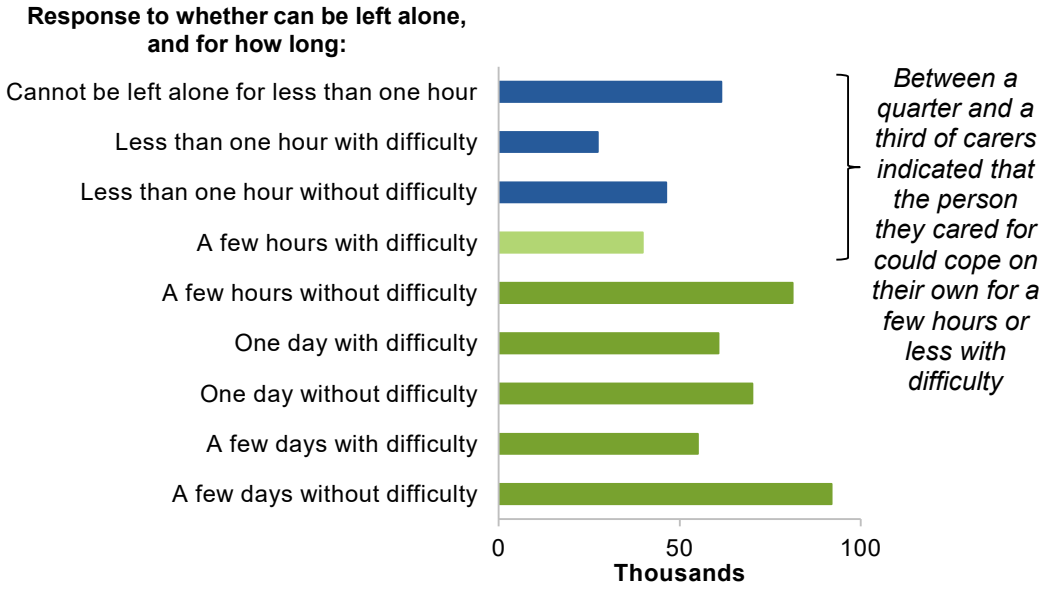
Role challenges

Peak hours

Disability carers are often required for only a few hours each day at 'peak times' — there is high demand for carers in early mornings and evenings to help people with disability get in

or out of bed, showered and fed (Physical Disability Australia, sub. 38, p. 11). This is reflected in the Survey of Disability, Ageing and Carers, which indicates that about three-quarters of people with severe or profound disability require attendant care for a few hours a day before encountering difficulties (figure 9.3).

Figure 9.3 **Amount of care required before recipient has difficulties[a]**
2015



[a] Based on the response by the carer for those with severe or profound disability aged 15 years or more.

Sources: Commission estimates based on ABS (*Disability, Ageing and Carers Australia: Summary of Findings, 2015,* Cat. no. 4430.0, table 42).

This means that there are times of the day when more carers are needed than the average would suggest, which would require a greater headcount than the FTE figures suggest. This has implications for how 'flexible' the workforce needs to be. As the NDIA said:

> Participant demand for care often occurs at 'peak times' or high demand periods which may include 7-9am (breakfast) and 4-8pm (bathing and mealtime) with less demand at late morning or mid-afternoon. This poses challenges for the sector to develop more mature rostering and staff management practices which are emerging in some areas. (sub. 161, p. 98)

Making greater use of a more casualised workforce could provide the labour needed in those hours of greatest demand. However, there are also some impediments, including:

- minimum shift requirements under the Social, Community, Home Care and Disability Services Industry Award, and the cost of casual loadings and penalty rates for working less desirable hours (such as those outside ordinary hours of work)
- quality concerns, such as whether NDIS participants want a different carer for each instance of care, and issues of reliability of casual labour (Cortis 2017, p. 6)

- whether there is the supply of casual labour to allow such an approach.
  - This includes the attractiveness to work on a casual basis for prospective workers, and the risk that more experienced and better qualified workers may seek permanent jobs elsewhere given the disincentives associated with less secure work (AAWA, sub. PP219, p. 8; Independent Inquiry into Insecure Work in Australia 2012, pp. 55-58).
  - Potential changes to casual employment in modern awards may also affect the supply of casual workers (box 9.2).

Box 9.2 Changes that may affect casual employment in the future

The Fair Work Commission (FWC) completed its four-yearly review of modern awards in July 2017. One of the matters it examined was the growing trend of casual employment, and the possibility that more casual workers were employed in patterns of work consistent with permanent employees. Some participants in the FWC review raised concerns that such employees were denied the benefits of being permanent employees, such as some entitlements under the National Employment Standards. The FWC noted:

> Although the casual loading for which modern awards provide notionally compensates for the financial benefits of those [National Employment Standards] entitlements which are not applicable to casuals, this does not take into account the detriments which the evidence has demonstrated may attach to the absence of such benefits, particularly for adult long-term casuals who are financially dependent on their casual employment. These include attending work while sick, not taking recreational leave because of concerns about whether any absence from work will endanger future employment, the incapacity to properly balance work and attending to personal and caring responsibilities and commitments, changes in working hours without notice, and potential for the sudden loss of what had been regular work without any proper notice or adjustment payment. Additionally there are other detriments associated with casual employment of this nature, including the lack of a career path, diminished access to training and workplace participation, poorer health and safety outcomes and the inability to obtain loans from financial institutions. (2017, para. 7)

In response, the FWC developed a draft model 'casual conversion' clause that provides a mechanism to allow those employed as casuals on a 'permanent' basis to achieve permanent employment. The draft clause allows:

- casual employees that have been working for a period of 12 months or longer in a pattern of hours on an ongoing basis consistent with the full-time or part-time provisions of the relevant award to request for conversion to a permanent position
- employers to only refuse the request for reasons including that:
  - to do so would require a significant adjustment to the casual employee's hours of work
  - it is reasonably foreseeable that the casual employee's position will cease to exist.

(continued next page)

Box 9.2 (continued)

The draft model clause is yet to be implemented, and subject to further consultation by the FWC.

A casual conversion clause as presently drafted by the FWC could have ramifications for the National Disability Insurance Scheme (NDIS) workforce and scheme sustainability. Much of the scheme's settings rely on a significant increase in casual employees who would work fairly consistent and predictable hours. If these workers took up the option to convert to permanency, then this could reduce the flexibility of employers to respond to demand from scheme participants (and could require adjustment to the assumptions used in the National Disability Insurance Agency's pricing approach). What is unclear is how many employees might opt to use a casual conversion clause. While some employees may be attracted to more secure employment, it would come at the cost of loading attached to casual employment.

One incentive such a clause could create is for employers to keep the number of hours worked by employees low to avoid the risk of a casual conversion occurring. This would, all else being equal, increase the number of workers required to provide NDIS supports, as the same number of hours would be spread across a larger number of shorter shifts. More data on the work patterns of those working in disability care and support roles in the NDIS is needed to understand how the introduction of the clause may affect providers, employees and the sustainability of the scheme.

Sources: FWC (2017) and Pallot et al. (2017).

Qualified staff in general

The quality of care provided to NDIS participants will depend in large part on the quality and skills of the workers providing disability supports. For many roles, formal qualifications are important, if not mandatory, to provide supports. For other roles, formal qualifications are less important. The available evidence suggests that the 'average' level of formal skills in the disability care workforce will decline over the transition period of the NDIS (box 9.3).

This raises the question — is a formal qualification the most important or necessary characteristic to secure employment as a disability support carer?

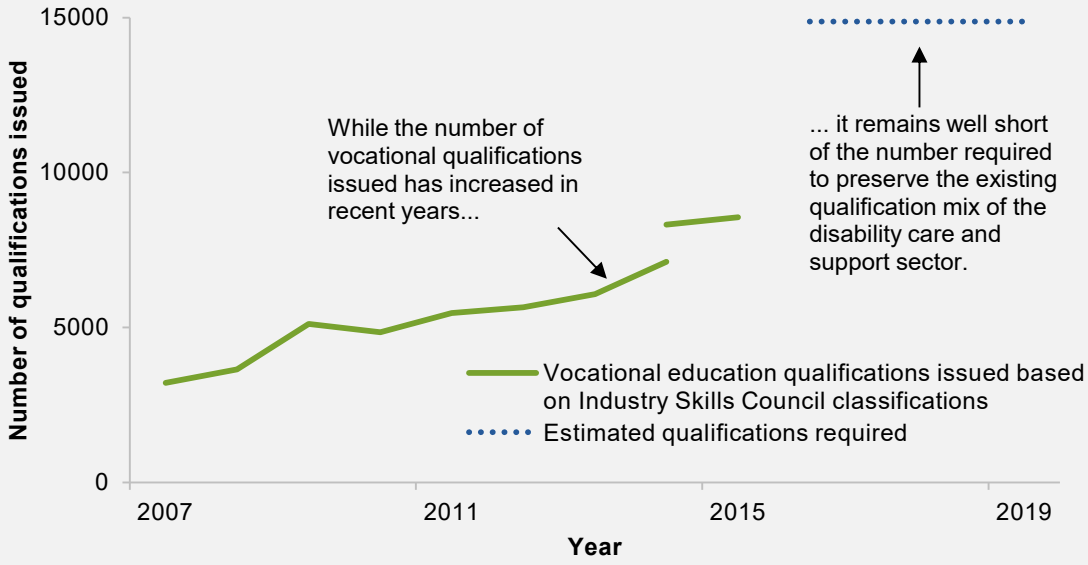
A survey of firms specialising in disability support by the Department of Employment (2014, pp. 2, 5) found the evidence to be mixed.

- 89 per cent of providers said that 'personal qualities' were 'important or very important' in terms of the characteristics sought, compared to 70 per cent for 'relevant experience' and 47 per cent for 'relevant qualifications'.
- 89 per cent of firms said that their minimum requirement for employment was a certificate-level qualification. However, 26 per cent of firms indicated that they regularly employed unqualified workers, suggesting this requirement was not a binding constraint for some firms.

Box 9.3 Not enough new trainees to maintain formal qualifications[a]

People employed in aged and disability care roles are more likely to hold a formal qualification than the workforce in general. The most common level of qualification for disability and aged care workers is a certificate III or IV. The number of people completing a qualification against expected workforce targets provides a measure of how the qualification mix of the workforce may look by the end of the National Disability Insurance Scheme transition.

The National Centre for Vocational Education Research dataset on vocational education outcomes (VOCSTATS) indicates that, if workforce targets are met, there will be a smaller proportion (than currently) of workers holding a certificate-level qualification. The figure below shows that about 50 000 certificate or diploma level qualifications were issued in the nine years between 2007 and 2015, while about another 60 000 qualifications would be necessary in the four years between 2016 and 2019 to preserve the same distribution of qualifications observed in the 2011 census.



This indicates that the proportion of workers holding certificate-level qualifications in disability care related studies will fall over the transition period. However, it is not clear what mix of qualifications will be necessary for all National Disability Insurance Scheme participants.

[a] Estimate is derived by subtracting the expected and current midpoint estimates of FTE disability care and support workers from the NDIA's market position statements and multiplying by a scaling factor of 0.85 to apply the proportion of full-time equivalent workers with a certificate or diploma qualification. This yields a result of 59 500 additional qualified workers, which when apportioned over 4 years requires 14 875 new qualified workers per year. Vocational qualifications are identified using Industry Skills Council classifications that include the term 'disability' in their title (specifically, codes CHC20599, CHC30302, CHC30408, CHC30799, CHC40202, CHC40302, CHC40308, CHC40312, CHC40799, CHC50102, CHC50108, CHC50799, CHC60102, CHC60108, CHC60112, CHC60799). The HSU (sub. PP316, p. 8) suggested that 'Certificate III in Individual Support' (CHC33015) be included — it is not included because the qualification can be aged care specific, and that there are concerns about the relevance of the qualification to disability care in general (ACT Government, sub. PP312, p. 13). Note that these data are presented in terms of qualifications awarded rather than qualifications used on a FTE basis. The break in series reflects changes in concordance between previously offered qualifications and current qualifications.

Sources: Commission estimates based on ABS (*TableBuilder,* Education and Work, May 2016) and NCVER (*VOCSTATS*, March 2017).

This inconsistent story was also reflected in evidence provided to the Commission's 2011 inquiry into *Disability Care and Support*. While some providers argued that a minimum standard or qualification should be mandated for disability support staff, others said that formal qualifications sometimes fell short of providing 'work ready' employees, and that on-the-job training was far more important (PC 2011, p. 740).

In practice, the benefits of a formal qualification depend on the role that a disability care worker is employed in, and the client's needs. The NDIS will also mean that many workers will need to learn additional skills in the market-based environment for disability supports.

> The NDIS differs considerably from previous reforms as it moves away from 'block funding' programs to a 'fee for service' model. Earlier reforms had little effect on frontline workers. But now workforce models are changing. Frontline workers need to have an understanding of sales, customer service and the ability to work within financial constraints as well [as] being able to adapt and customise service delivery in a person centred model.
>
> Conversations are being held in the sector regarding formal qualifications and whether they are necessary. Some organisations are recruiting workers with no experience and no formal qualifications, with new staff undergoing customised organisational training only. For other organisations, formal qualifications are a pre-requisite. This brings opportunities for a diverse workforce. (Queensland Alliance for Mental Health, in VICSERV & CMHA 2017, p. 46)

It seems reasonable to conclude that the lack of certificate-qualified workers will affect some firms and present a challenge to meeting the workforce target of the NDIS, but the evidence is too limited to say which areas will be most disadvantaged. Also, participants may prioritise attitude and aptitude, and choose to employ less qualified staff who better suit their needs.

Qualified allied health professionals

Allied health roles are very different to attendant care roles. Allied health professionals specialise in a range of different areas, and hold higher level qualifications relative to the disability support workforce in general.

> Allied health professionals are generally educated in the university sector with bachelor degrees, usually three to four years duration. However, in a development common to other health professions, there is an increasing move to postgraduate degrees, for example an initial generic undergraduate science degree followed by a Masters in an individual discipline. (Department of Health and Ageing 2013)

Formal qualifications are almost always a requirement for allied health professionals to practice, which means building up qualified staff can take much longer than for other roles. Constraints in this regard were recognised as part of the *Integrated Market, Sector and Workforce Strategy*.

> It is estimated that the highest rate of increase in the demand for disability workers will be for allied health professionals. The disability sector will need to work closely with related community service sectors, particularly health and aged care, to ensure the demand for allied health professionals is met.

> To support the sector and enhance the supply of allied health professionals to the disability sector, the Commonwealth and jurisdictions will work with the sector, education authorities, and professional bodies to ensure that professional education prepares graduates adequately to work in the NDIS. At the same time, to encourage allied health professionals to choose the disability sector, the Commonwealth will work with these same stakeholders to strengthen the sector's capacity to provide high-quality placements and support continuing professional development for allied health workers. (DRC 2015a, p. 20)

If the allied health professional workforce does not build quickly enough, this could lead to unmet demand for participants and a substitution away from using professional carers to using more general workers instead. There is some evidence that this is already occurring.

> A perception was expressed in the wave 1 interviews that the pricing structure of the NDIS would bring change to the role of allied health professionals through encouraging the increased use of non-professional staff. By wave 2 a de-professionalisation of the disability workforce was more commonly being reported, with increasing numbers of allied health assistants in the sector. Concerns were raised about the ability and skills of these workers to provide more complex supports and the impact this could have on the quality of care and outcomes for participants. (Mavromaras, Moskos and Mahuteau 2016, p. 48)

And one of the providers interviewed in the evaluation said:

> We have employed a number of inexperienced people, but I believe that's starting to backfire … Just the inexperience and the lack of knowledge on how to work with behaviours or understand confidentiality, or things like professional distance and all those types of things. And we're sending inexperienced people out to work individually with people with disabilities. (Mavromaras, Moskos and Mahuteau 2016, p. 48)

Evidence presented to the Commission provides another inconsistent story about supply and demand for allied health workers in the NDIS. On the one hand, the number of providers registered to deliver allied health services to NDIS participants has grown strongly (NDIA 2016r, p. 43), and in line with the expected number needed by the end of the transition period. However, many who have registered are not yet providing services to scheme participants. This makes it difficult to determine if they are registering in advance of the NDIS rollout or have changed their mind about delivering services.

Many disability service providers pointed to a number of allied health roles that are moderately or extremely difficult to fill. For example, more than half of the firms surveyed by National Disability Services said that they had experienced difficulties recruiting speech therapists and occupational therapists (NDS 2016, p. 38). The *Intermediate Review of the NDIS* also identified persistent shortages in the areas of speech pathology, occupational therapy and psychology supports (Mavromaras, Moskos and Mahuteau 2016, p. 32), although supply to those who needed such services had increased.

As one staff member of the NDIA in the Intermediate Review put it:

> The NDIS has worked twofold. It's increased the amount of service available so people can see other OTs [Occupational Therapists] outside of what they would have been able to. But there's

an increased demand. The increased demand is way above the increase of services. (Mavromaras, Moskos and Mahuteau 2016, p. 54)

Some service providers and peak bodies expressed concerns about whether there will be enough allied health providers for NDIS participants, and the consequences for sectors (box 9.4).

A lack of allied health professionals represents a risk that supports of appropriate (and necessary) quality may not be available to some NDIS participants. The time it takes to train an allied health worker — both in terms of formal qualifications and on-the-job training — means that it may be too late to prepare the necessary allied health workforce without either diverting them from other caring sectors, or to seek skilled migrants to fill the workforce gap in the short term. Both approaches involve costs.

Box 9.4 Finding allied health workers can be difficult

Matt Burrows:

> The workforce is a wicked problem. … To think that we, as service providers, can just advertise for and employ that many qualified staff (eg therapists) in such a short time is just misguided. Let alone the considerations of balancing a commercial and compassionate culture during this transition time.
>
> At entry to the NDIS in 2012-13 the employment market for therapists relied heavily on internationals supported to work domestically on 457 visas. By 2016-17 the training institutions had geared up and graduates now make up a steady portion of the new recruits. But there remains a gap and that gap is being filled from the full employment market being accessed elsewhere. Australia only has so many therapists and their entry into the NDIS employment field means they are exiting elsewhere. (sub. 7, pp. 3–4)

Disability Services Australia:

> Professional staff, in particular Psychologists and Speech Pathologists are generally difficult to attract (especially in Regional areas) in a very competitive marketplace. This has driven the need to implement creative sourcing strategies such as the hiring of interns for a short term solution. We have also seen significant wages growth in the allied health professions due to labour shortages. (sub. 9, p. 9)

Australian Physiotherapy Association:

> Our members have suggested that increasing the NDIS workforce to that which is projected as being required will not be possible in the current policy settings. They have advised us that demand for services has already stripped supply of providers. (sub. 93, p. 16)

Allied Health Professions Australia:

> Current demand for services is already exceeding the available supply of allied health providers and there is no evidence of short term changes to this workforce shortage. (sub. 37, p. 16)

An ageing workforce and population presents a greater challenge

Australia has an ageing population, and this is reflected in the increasing average age of:

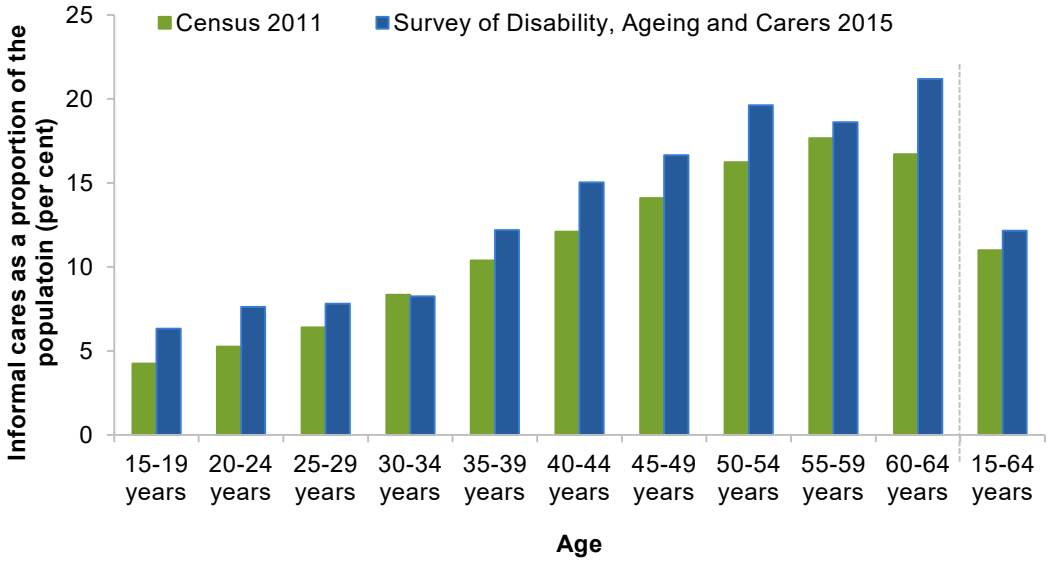
- formal carers employed to look after people with disability (figure 9.4)
- informal carers who look after friends and family with disability

- the general population, which will affect the on demand for carers more broadly.

As noted above, the average age of carers employed in the aged and disability care workforce is higher than for the general workforce. The average age of people employed in aged and disability care is about 47 years, and about a quarter are above the age of 55 years (figure 9.4).[77] An increasing proportion of the care workforce is likely to retire in the coming years, with the average retirement age of those employed in the personal care and assistance occupations about 55 years in 2014-15.[78] Only about half of those working in disability care intend to still be working in the sector in five years' time, with a further third unsure (Cortis 2017, p. 24).

Informal carers are also ageing. The trend since the 2011 Census is an increasing proportion of people aged 50-64 years providing care for others (figure 9.4). The ability of informal carers to continue providing this care as they age is likely to diminish. As the degree of informal care a NDIS participant receives affects the amount of formal care supports that they are allocated, this suggests that as informal carers age, there will be greater calls on the NDIS to provide more supports and this will require a larger formal workforce.

Figure 9.4 **Informal carers are growing older**



Sources: Commission estimates based on ABS (*TableBuilder Basic,* 2011 Census; *TableBuilder,* Survey of Disability, Ageing and Carers 2015, Cat. no. 4430.0).

The ageing population also means there will be more intensive demand for carers. While aged care workers are not perfect substitutes for disability care workers, there are some roles

[77] Commission estimates based on ABS (*TableBuilder Basic,* 2011 Census).

[78] Commission estimates based on ABS (*Retirement and Retirement Intentions, Australia, July 2014 to June 2015,* Cat. no. 6238.0, unpublished data).

that cross over, and about one-fifth of disability care providers are intending to enter the aged care sector (NDS 2016, p. 13). This means that even if new carers are trained, they may not be attracted to the disability care sector as the aged care sector expands. As Disability Services Australia said:

> There is no doubt that as Baby Boomers retire from full time work there will be an overall impact on a range of employment sectors. Whilst there may be some potential for retirees to take on casual disability support or mentoring roles, the ageing population will also create an increase in demand for aged care workers, in direct competition with the recruitment for workers in to disability roles. (sub. 9, p. 9)

And even if the disability sector can attract workers from the aged care sector, there could still be implications for scheme costs. For example, if the quality of aged care services falls because of workforce shortages, there could be a stronger incentive for NDIS participants to remain in the scheme past the age of 65 years.

The role of wages in growing the workforce

Most of the payments from the NDIS will be spent on wages, given the labour-intensive nature of disability care. While price caps will have an impact (chapter 8), this is likely to mean more money will be available for workers. From a policy perspective, the question is whether this money will be sufficient to induce more workers to provide disability supports. This depends on how competitive the disability care market is, how responsive care workers are to wages, and in turn, why people work in the disability care sector.

Analysis conducted prior to the introduction of the NDIS suggests that pay is one of many motivations to work in disability care. For example, a study of community service employees undertaken in 2009 found that only 16 per cent of employees were attracted to work in the disability services sector primarily for the pay (Martin and Healy 2010, p. 135). A desire to help others and a desire to do something worthwhile were far more important motivations (nominated by 76 and 68 per cent of workers, respectively) (Martin and Healy 2010, p. 135). As one disability support worker said:

> I love this industry. It's not about coming into work, doing an 8 hour shift and leaving. It's so much more than that. For some people we can be their eyes, their ears or their hands. (United Voice, sub. 118, p. 2)

However, there is also evidence that higher rates of pay can help retain workers in disability care roles and attract new workers to the sector. Just over half of employees who left a disability support provider surveyed by the Department of Employment (2014, p. 17) said that they left for a position that had 'better pay and conditions', and about 60 per cent of firms used increased remuneration as a means to improve retention. Given the ageing workforce, higher wages could be used to keep workers from retiring, to the extent that wages can increase under the NDIA's price caps.

Overcoming the perception that caring jobs do not lead to fulfilling careers may be necessary to have enough workers to provide NDIS supports. As noted in the Integrated Market, Sector and Workforce Strategy:

> To meet the increased demand for disability workers, including allied health professionals, it will be necessary to assist suppliers to promote the disability sector nationally as a career. (DRC 2015a, p. 20)

A number of study participants noted that caring roles are seen as unattractive due to the nature and remuneration of the work.

> The nature of the work of disability support staff may not in itself be attractive enough to appeal to many school leavers and those looking for a career change in later life. The work itself can be highly complex and carry significant risk, especially when supporting people with severe challenging behaviours or people with complex medical support needs. Greater provision for training support staff is vitally important at present, providers are limited in the amount of training that can be provided due to cost pressures. (Macarthur Disability Services, sub. 57, p. 8)

> The NDIA has observed over the course of trial and transition that caring jobs are often poorly valued. Common reasons cited for a lack of retention (Department of Employment survey of Personal Care Workers 2014, National Aged Care Workforce Census and Survey) include the low conditions of work and physical and emotional toll of the job. This is regrettable. (NDIA, sub. 161, p. 97)

> That caring roles are poorly [valued] is not perception, it is reality. Caring jobs are poorly valued. Pay rates are mostly minimal. Good or exceptional performance of the role is rarely valued financially. (Autism Aspergers Advocacy Australia, sub. 178, p. 26)

> Low prices also militate against the sector creating additional jobs that would be useful in alleviating professional shortages, such as allied health assistants and peer workers. (NDS, sub. 51, p. 9)

How labour will respond to conditions under the NDIS over the longer term is hard to assess. The data make it difficult to understand the number and hours worked by employees of disability care providers. The unprecedented scale of workforce growth required, combined with a new market-based approach, also mean that historical data on wages and work patterns are less useful to estimate the future. The interaction with other care sectors — especially aged care — will also be important. More data will need to be collected to make meaningful wage policy when it comes to NDIS workers.

Regional challenges

The disability care workforce needs to double in aggregate, but the scale of growth required in individual regions varies between as little as 5 to over 300 per cent (figure 9.5).[79] Most regions will need to grow their disability care workforce between 50 and 150 per cent. While some of the percentage increases are large, many are based on a very low number of workers

[79] Regions are groups of local government areas, which are the geographical basis for the NDIA's market position statements.

to start with. This is especially the case in rural or remote areas where a few workers can represent a doubling of the disability care workforce.

Some of the challenges with thin markets in remote areas are discussed in chapter 7, but it is worth noting that there are several regions within metropolitan areas where the required growth is about 200 per cent:

- South Western Sydney, where about an additional 5800 FTE workers are needed (growth of 215 per cent)
- Southern Melbourne, where about an additional 2500 FTE workers are needed (growth of 211 per cent)
- Beenleigh, where about an additional 2300 FTE workers are needed (growth of 190 per cent)
- Brimbank Melton, where about an additional 1700 FTE workers are needed (growth of 197 per cent).

Figure 9.5 **Variation in growth required in different regions[a]**

Each dot represents the growth in the amount of FTE employees needed relative to the current situation, both in terms of the number and proportion, between 2015-16 and 2019-20.

[a] The NDIA's market position statements provide a range of estimates for the number of FTE disability workers at present and what will be needed in the future. To derive these estimates for growth, the midpoints of each range are used. No data are available for Western Australia. Regions are groups of local government areas.

Sources: Commission estimates based on NDIA (2016c, 2016l, 2016s, 2016u, 2016w, 2016x, 2017v).

These data, as published, do not capture the mix of roles within the FTE positions. For example, they do not distinguish between the hours of care provided by an in-home carer as opposed to those provided by an allied health professional. All of this emphasises the need for policies that seek to mitigate workforce shortages to have a focus at a regional level, where different policy responses may be more appropriate across different regions and roles.

The bottom line?

The scale of workforce growth required, combined with challenges of worker roles and regional variation, means that the NDIS workforce targets are unlikely to be met by 2020. As both the Intermediate Review of the NDIS and the former Chair of the NDIA noted:

> While the NDIS had led to an increase in the supply of disability supports, the Scheme had also led to an increase in a demand for services (and particularly therapy services); NDIA staff concluded that overall, demand now exceeded supply. (Mavromaras, Moskos and Mahuteau 2016, p. 54)

> The Bilateral Agreements imply that in the current fiscal year of 2017-18 demand for disability services will increase by 40 per cent. The lack of progress on workforce readiness for the NDIS means that shortages and, potentially, significant shortages will appear in many areas within the next 12 months. This means that the transition to the full NDIS by mid-2019 is not achievable. (Bruce Bonyhady, sub. PP333, p. 17)

The trends to date show that providers are already responding to workforce shortages by using less skilled labour. In some cases, this may compromise the quality of care received by participants and could become more widespread as the NDIS is fully rolled out. This, in turn, will reduce the effectiveness of the NDIS, compromise its insurance principles (and increase long-term costs), and in some cases, be a risk to participants' wellbeing.

It is more difficult to make an assessment about how far the workforce will develop beyond the transition given the uncertainties about how yet-to-be implemented policies will affect the supply and demand for workers (such as the implementation of the NDIS Quality and Safeguarding Framework, outcomes of future price reviews, and the implications of the NDIA's Market Intervention Framework).

FINDING 9.1

The disability care workforce will not be sufficient to deliver the supports expected to be allocated by the National Disability Insurance Agency by 2020.

9.3 What can be done to improve workforce readiness?

The challenges confronting the readiness of the workforce, if left unaddressed, could create short-term and long-term risks to the sustainability of the scheme and the wellbeing of participants. In the short term, a lack of qualified workers may mean that less qualified staff are used to deliver supports, or there will be unmet demand. This, in turn, erodes the benefits of the insurance approach over the longer term, meaning that the costs to support participants will be higher than necessary. However, some of these challenges can be addressed relatively quickly, or alternative arrangements employed to mitigate their effects.

Getting the right balance between strategy and action

The responsibility for funding sector and workforce development was allocated to the Australian Government as part of the 2012 Intergovernmental Agreement for the National Disability Insurance Scheme Launch (ANAO 2016, p. 16). The Department of Social Services (DSS) is responsible for many of the roles developing the disability care workforce to meet the needs of the NDIS, including: coordinating and facilitating responses to workforce shortages; coordinating with other Australian Government agencies to build workforce supply; and developing a coordinated response in particularly challenging areas — such as the demand for allied health professionals (Kruk 2016).

Australian Government initiatives to foster disability care workforce readiness are focused primarily on frameworks and principles developed in consultation with the NDIA (table 9.2). These are designed to provide guidance on how the workforce is to develop.

Such a strategic approach to developing a market — especially one so ground-breaking as the NDIS — was appropriate for the trial period. However, as the scheme begins to build up over the transition period, practical implementation of the strategic objectives is required, particularly to develop the workforce. Relying on strategic policies alone is leading to uncertainty among providers.

> Several strategies have been published (Assistive Technology, Rural and Remote, Market and Workforce). They provide directions but are light on implementation detail. For these strategies to inform the planning and investment decisions of service providers, they need to be underpinned by clear publicly-available plans. (NDS in ANAO 2016, p. 32)

Table 9.2 **Many strategies affect workforce development**

Entity	*Strategy*
NDIA (2013, 2017e)	2013–16 Strategic Plan and 2017–21 Corporate Plan
NDIA (2015c)	Assistive Technology Strategy
NDIA (2016i)	NDIA Market Approach — Statement of Opportunity and Intent
NDIA (2016t)	Rural and Remote Strategy
NDIA (2017b)	Aboriginal and Torres Strait Islander Strategy
NDIA (forthcoming)	Provider of Last Resort Strategy
NDIA (forthcoming)	Market Intervention Framework
DRC (DSS 2016d)	Quality and Safeguards Framework
DRC (2015a)	Integrated Market, Sector and Workforce Strategy
DRC (DSS 2017d)	National Disability Strategy 2010-2020
DSS (2015c)	Sector Development Fund Strategy and Operational Guidelines
DSS (2017b)	Integrated Plan for Carer Support Services

The Australian National Audit Office (ANAO), looking at the market transition under the NDIS, found that the Integrated Market, Sector and Workforce Strategy lacked the details necessary for the transition.

> While establishing a national approach to the market transition, the Strategy does not provide a clear basis for coordinated actions, as it does not commit jurisdictions to specific deliverables, with agreed timeframes, accountabilities and milestones. DSS advised the ANAO that 'detailed timeframes and accountabilities will likely be captured in a bilateral context going forward, recognising the unique characteristics in each jurisdiction in terms of the market and workforce.'
> …
>
> Further detail about how the Strategy is to be operationalised, including specific actions and timeframes, would assist stakeholders, particularly service providers who need to make investment decisions. In July 2016, DSS advised the ANAO that it intends to develop a Strategy 'action plan' for 2016-17 and into the future. Publishing this action plan, including key priorities and initiatives, timeframes and milestones, may help to address stakeholder concerns. (ANAO 2016, p. 32)

The Sector Development Fund (SDF), which is funded by the Australian Government with $146 million to support the NDIS market transition between 2012-13 and 2017-18, includes workforce development as one of its objectives. The DSS administers the SDF by allocating grants to organisations and governments to address areas of identified need. However, in its evaluation of the SDF, the ANAO (2016, p. 34) found that there was limited evidence of the Commonwealth adopting a strategic approach to grant-making, and that a more strategic approach is warranted, informed by evaluation of funded projects.

More recently, most Australian Governments have taken action in response to concerns about workforce shortages (table 9.3), but have done so with different approaches and priorities. There is a risk that fragmented workforce policies will lead to duplication or

unnecessary programs at a time when the scheme can least afford it. As a union that represents many disability carers said:

> Unclear delineation of market development and stewardship responsibilities between the National Disability Insurance Agency (NDIA), the Commonwealth Department of Social Services (DSS) and the States and Territories has resulted in no substantive progress on a workforce development strategy focusing on attraction, retention, skills or quality. (Health Services Union, sub. 132, p. 4)

More recently, the DSS has made efforts to lead workforce developments among NDIS stakeholders, though this is still a work in progress.

> Significant workforce growth is needed to meet demand at full Scheme. DSS has been working with state governments, the NDIA, and the sector to support disability workforce development. This includes working directly with jurisdictions to leverage their expertise in the delivery of disability services to identify and address workforce gaps and to develop workforce plans. (DSS 2017h, p. 12)

While the COAG Disability Reform Council and the DSS have taken steps to clarify responsibilities, further refinement — and speed — is necessary. The 'big tent' approach to workforce development remains appropriate, but the responsibilities of different parties should be made public — a point agreed by the DSS (sub. PP318, p. 16).

- State and Territory Governments should have more responsibility for workforce development issues over the transition period. They know the history of unmet need and the best approaches for solving workforce issues in particular jurisdictions.
- The Australian Government should retain oversight of the scheme, and focus on areas that affect the supply and demand of care workers from an economy-wide perspective, including the interaction of the NDIS with other care sectors, including aged care and monitoring trends in the supply of skilled workers through tertiary and vocational education.
  - The Australian Government should use immigration to address workforce shortages (discussed below).
- The NDIA is best placed to provide more information to governments in the form of actuarial and scheme data collected to provide more granular detail on where supply gaps are emerging, or likely to emerge.
- Providers should also be regularly consulted by governments about emerging workforce policy issues, such as where the incentives of the scheme may be affected by other laws and regulations, like minimum standards, conditions of State, Territory and Australian Government awards, and training and development.

Table 9.3 **Some of the initiatives to build the NDIS workforce undertaken by Australian governments**

Jurisdiction	*Initiatives*
New South Wales	The New South Wales Government spent $5 million to supplement its 'industry development fund', which provides a range of resources for firms to transition to the NDIS and includes materials regarding workforce development (Nucleus Group 2015, pp. 2–3). The New South Wales Government is 'also investing in vocational education and training to create a workforce pipeline of specialist capabilities to meet the needs of the NDIS' (sub. PP230, p. 7).
Victoria	The Victorian Government (sub. 174, p. 18) spent about $26 million (supplemented in part by the Sector Development Fund (SDF)) on its Keeping Our Sector Strong policy, which has the goal of 'developing and growing the disability workforce over the transition to full scheme'.
Queensland	The Queensland Government has committed $2.8 million to establish the WorkAbility program, which is a consortium of four Queensland industry peak bodies aimed at driving 'expansion and diversification of the Queensland workforce over the transition years, engaging, attracting and connecting people to jobs in the sector' (sub. PP345, p. 16).
Western Australia	The Western Australian Government is considering a workforce development plan for the state to ensure that 'the 9 000 to 10 000 additional jobs over the next decade can be filled with properly qualified workers' (WA CCI 2017).
South Australia	The South Australian Government has sought independent advice about likely workforce needs at a more detailed level, and has provided grants as part of its Provider Readiness Program (SA DCSI 2017). It has also provided $4 million to fund 'Disability Workforce Hubs' that aim to 'connect job seekers with local employers, training providers and employment agencies to help fill local job opportunities in the growing disability sector' (SA DCSI 2016; South Australian Government 2017).
Tasmania	The Tasmanian Government 'is investing more than $8 million over six years in skills development to increase the disability workforce in Tasmania' (sub. PP247, p. 9), and has also funded a workforce development plan for the state (Petrusma 2016).
Australian Capital Territory	The ACT Government has invested in market development, and made a number of direct grants to provider organisations, including some using SDF monies (ACT Government 2016, pp. 33–35) .
Australian Government	In addition to the SDF, the Australian Government committed an additional $33 million over three years in the 2017-18 Budget to 'assist service providers in rural, regional and outer suburban areas to provide the workforce required to meet the expected growth in the disability and aged care sectors arising from the introduction of the National Disability Insurance Scheme and an ageing population' (Australian Treasury 2017b, p. 145).The Department of Education and Training has previously provided about $3.5 million in funding to help providers be NDIS ready by helping them plan workforce needs and identify the skills they will require (Department of Education and Training 2017a, p. 13).

The workforce development responsibilities of State and Territory Governments should reduce as the NDIS fully rolls out and replaces their existing disability support programs. However, State and Territory Governments should remain 'in the tent' when it comes to workforce policymaking given the interaction between the NDIS and other mainstream services.

RECOMMENDATION 9.1

The roles and responsibilities of different parties to develop the National Disability Insurance Scheme (NDIS) workforce should be clarified and made public by the beginning of 2018.

- State and Territory Governments should rely on their previous experience in administering disability care and support services to play a greater role in identifying workforce gaps and remedies tailored to their jurisdiction.
- The Australian Government should retain oversight of workforce development, including how tertiary education and aged care policy interact and affect the development of the workforce.
- The National Disability Insurance Agency should provide State and Territory Governments with data and analyses held by the Agency to enable those jurisdictions to make effective workforce development policy.
- Providers of disability supports should have access to a clear and consistent mechanism to alert the National Disability Insurance Agency, the NDIS Quality and Safeguards Commission, and the Australian, State and Territory Governments about emerging and persistent workforce gaps.

An evidence-based approach to workforce policy is needed

A lack of data makes it difficult for policymakers and market stewards to properly exercise direction and support to the sector for it to develop sustainably. The existing data do not allow for measurements of specialisation, or differentiation of caring roles (such as between aged and disability care). Nor is it straightforward to examine labour supply and wage outcomes. This means that tasks that are simple for other industries — like identifying the response in labour supply to an increase in wages — are impossible to undertake with any degree of certainty. As the DSS said:

> A significant limitation to assessing the NDIS market readiness is the availability of market and workforce data. DRC has agreed Market Key Performance Indicators to monitor NDIS market performance and identify emerging market risks and, as the Scheme matures, will assist the NDIA with identifying risk requiring intervention. (sub. 146, p. 34)

These key performance indicators will be drawn from scheme data, which will provide a richer dataset on providers and participants. However, the nature of the data means that it will be less suited for measuring workforce growth and gaps over the transition period and over the longer term. The evidence base on the NDIS workforce needs to be commensurate

with the importance of the scheme itself, and shared broadly among stakeholders. As the Victorian Government said:

> Victoria considers that greater sharing of data and information between the NDIA, the Commonwealth and providers is needed to ensure that workforce development strategies are aligned. (2017b, p. 19)

More data need to be collected on the supply and demand of disability care workers. On the demand side, the NDIA's market position statements provide the necessary information on when and where workers will be needed, and should be updated regularly. On the supply side, the Australian Bureau of Statistics should be funded to collect policy-relevant data on the disability care workforce.

RECOMMENDATION 9.2

The National Disability Insurance Agency should publish more detailed market position statements on an annual basis. These should include information on the number of participants, committed supports (disaggregated at a level of detail consistent with the guides used to set price caps), existing providers and previous actual expenditure by local government area.

The Australian Government should provide funding to the Australian Bureau of Statistics to regularly collect and publish information on the qualifications, age, hours of work and incomes of those working in disability care roles, including allied health professionals.

There is some scope to expand the supply of carers in the short term

One short-term policy to bolster the workforce is to make better use of existing disability carers. About 20 per cent of current aged and disability care workers express a desire to work more hours, and half of these want to work fulltime (figure 9.6). This confirms what Martin and Healy (2010, p. 146) observed — that frontline disability care workers 'generally wanted a substantial increase of 10 or more hours' on their weekly workload.

However, workers' desire to work more hours cannot be realised if policy settings and workers' preferences do not align. As the South Australian Government said:

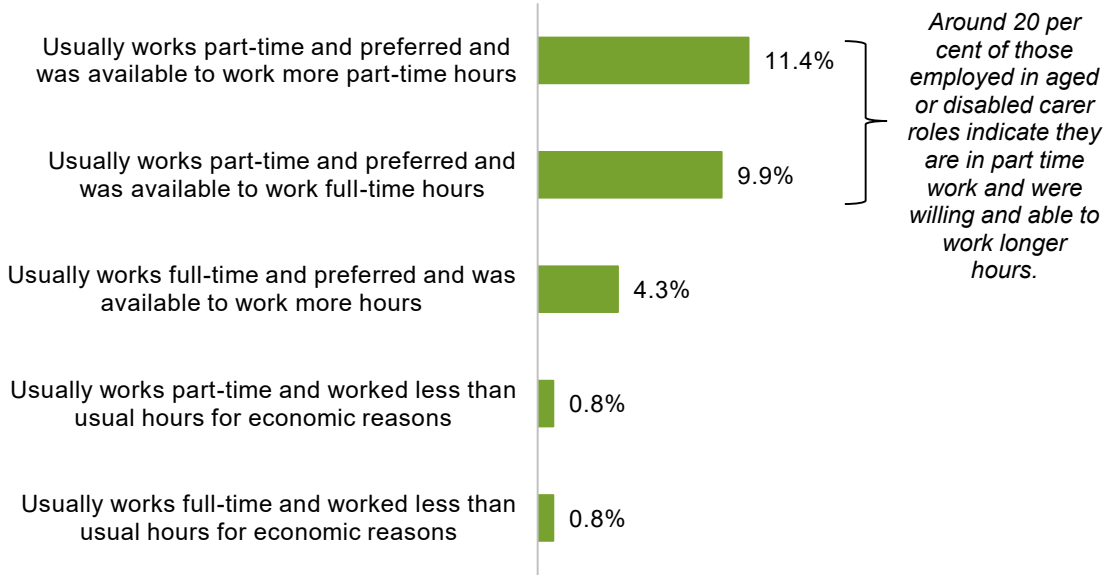
> Offering additional hours and more full time positions is an effective strategy to increase the size of the workforce, capitalising on the use of existing skilled workers and potentially offering greater security for some, particularly in the short term. However, this should also be balanced with being an employer of choice and offering flexible work arrangements to retain skilled workers in the sector. SA would therefore be interested in analysis being conducted on what level of inducement is provided by the flexibility of work arrangements that part time employment provides. (sub. 203, p. 14)

The Commission agrees, and considers that building the evidence base is key to identifying and addressing further impediments to making the most of the existing workforce. There

may also be impediments to working additional hours arising from the price caps set by the NDIA. This is an issue that the independent pricing monitor and pricing regulator should assess and respond to, if necessary (chapter 8).

Figure 9.6 **Aged and disability carers express a desire to work longer hours[a]**

Per cent of aged and disability carers, based on ANZSCO definitions, 2016



[a] Residual are those who are not underemployed (about 72 per cent of aged and disabled carers). 'Economic reasons' include being stood down or there not being enough work available.

Source: Commission estimates based on ABS (*TableBuilder,* Education and Work, May 2016).

Greater use of skilled migration should be used to address shortages

While reducing underemployment for general care workers may bolster supply of some workers, there is almost no underemployment in allied health professions.[80] The long lead time to train these workers also means that shortages could persist over the shorter term, and potentially beyond the end of the NDIS transition period.

An option to meet a shortfall in the short term is to make greater use of skilled migrants. This was proposed by the Commission in its 2011 *Disability Care and Support* inquiry (2011, pp. 720–721). The Commission considers that the existing policies and regulations for using skilled migrants are appropriate to meet the needs of the NDIS over the transition

[80] Commission estimates based on ABS (*TableBuilder*, Education and Work, May 2016).

period, if required.[81] The flexibility of using staff employed on visas over a few years is also of value to the scheme, as participants may have changing preferences over a similar time period.

That said, using skilled migrants is not an immediate solution. Like any new worker, there is a period of on-the-job training required to become proficient in providing services, and in the case of allied health, it will still be necessary for sufficient mentoring to occur. These issues touch directly on setting the appropriate prices for supports over the transition period to enable a sufficient margin for such training to occur — an issue for the independent price regulator discussed in chapter 8.

Some participants to this study disagreed that greater reliance on skilled migration is an appropriate approach to workforce shortages. For example, Allied Health Professions Australia, while agreeing that skilled migration is one way to increase the number of qualified allied health professionals, said that the time spent to acclimatise skilled migrants to Australian conditions was as intensive as training someone locally.

> … skilled migrants are unlikely to be familiar with local health and social systems and services and may not have specialised skills as required to provide appropriate support to many participants. As a result these skilled migrants are likely to have skills and knowledge at a level that is closer to entry level allied health professionals and requiring mentoring and support. Experience suggests that significant time is required for overseas-trained graduates to learn to navigate the complex interaction of systems and understand the various parties involved in providing support. These factors mean that there will need to be significant investment to ensure that skill[ed] migrants can provide services of equivalent quality and AHPA [Allied Health Professions Australia] submits that it may be more effective to pursue alternatives such as incentivisation of Australian graduates and other workers. (sub. 37, p. 18)

However, the time to train someone to understand Australian conditions should be shorter than the time to achieve the formal qualifications to practice.

The precarious nature of skilled migration visas was also raised by study participants, with some stating that 457 visas should not be viewed as a substitute for training local workers.

As the Australian Services Union and the Disabled People's Organisations Australia said:

> Any migrant worker scheme for the NDIS should provide permanent migration and only be considered after there has been local labour market testing. The NDIS provides a significant opportunity to address high levels of unemployment for many people, including people with

[81] Commission estimates based on ABS Census data from 2011 indicate that about 10 per cent of those working in a group of allied health professional occupations (based on the ANZSCO classes relating to dieticians, optometrists and orthoptists, health therapy professionals (not further defined), occupational therapists, physiotherapists, podiatrists, speech professionals and audiologists) were born overseas and arrived in Australia after 2000, suggesting that avenues for skilled migration are possible. Analysis by the ABS found that the second most commonly reported industries of Skilled Program migrants' employment was in the Health Care and Social Assistance industry division, which includes carers and some allied health professionals (ABS 2010). It is too early to tell if recently announced changes to skilled migration visas (Dutton and Turnbull 2017) will impact on this flexibility.

> disability. While we do not support a precarious, exploitative 457-style visa scheme for NDIS workers, we do support the development of a comprehensive workforce plan to retain and attract new workers locally. (sub. 198, p. 2)

Skilled migration is a policy response that should focus on meeting the shortfall in specific roles (rather than as a general measure to address all shortages), and more clearly delineating workforce development responsibilities among governments will provide a better platform to train and develop local workers. However, given the risk of shortages in the transition period, greater use of skilled migration is likely to have more benefits than costs in this period. As previously put by the Commission:

> Overall, the role of immigration as a source of labour must balance the impacts on wages and other strategies for eliciting domestic supply of workers, and the reality that significant labour shortages are still likely, especially during the rapid growth in disability supports during the establishment phase of the NDIS. In that vein, immigration should mainly address acute and persistent shortages. (2011, p. 720)

And by the DSS:

> Migration programs, such as labour agreements, have been used in the aged care sector to meet workforce demand. A similar program could be considered for the disability sector if actions to grow the domestic workforce do not meet demand. (sub. PP318, pp. 17–18)

What remains to be seen is whether the shortfalls persist over the longer term, which is when further review and consideration should be given to changes to workforce development and immigration policies. This could be facilitated as part of the expected future reviews of the NDIS, including the regular reviews by the Joint Standing Committee on the NDIS.

RECOMMENDATION 9.3

The Australian Government should adjust immigration policies where necessary to address National Disability Insurance Scheme workforce shortages.

New technology may reduce demand for workers

Greater use of technology could reduce the need for some disability care workers, and mitigate a potential workforce shortfall. Understanding the extent that technology could be 'labour-saving' is difficult: the market for disability supports is undergoing major change, and what NDIS participants will demand is still unclear. That said, there is a range of emerging technologies that could reduce the need for workers. Some examples highlighted by the NDIA (sub. 161, pp. 98–99) as promising include:

- 'smart' alert and monitoring systems that reduce reliance on person-to-person supports in specialist disability accommodation and for participants with at-risk behaviours
- innovative transport services, such as accessible car-sharing

- telepresence technologies that allow informal carers to maintain and develop their care, and to seek readier access to assistance when needed. Telepresence can also allow for some therapy services to be provided over a distance, which can alleviate the need for providers in rural and remote areas. Such an approach was also endorsed by Allied Health Professions Australia (sub. 37, p. 17), The Shepherd Centre (sub. 107, pp. 14–15) and Speech Pathology Australia (sub. 136, pp. 47–48).

Given the scheme is in the early period of transition, it is difficult to tell what technologies will emerge, what effects they will have on the need for workers, and what the implications for scheme costs may be. The impact of technological advances are not taken into account in the NDIA's long-run costs modelling. Given the uncertainties involved, this is appropriate, and removes any risk of overstating cost savings.

Using volunteers

The number of volunteers, and the amount of volunteering they undertake, affects the workforce needed for the NDIS. Inclusion Melbourne (sub. PP207) and Volunteering Australia (sub. PP274) highlighted the cost savings and beneficial impact on workforce pressures, as well as other benefits of volunteers. These benefits stem from the strength and inclusion of genuine relationships that form between people with disability and volunteers that want to spend time with them (as opposed to being there as part of a paid relationship). As the NDIA said:

> Using services designed to match volunteers with participants can help to build informal networks and facilitate greater independence and social inclusion. Over time, this can reduce the reliance on or preference for paid supports among some participants. These programs involve rigorous on-boarding and carefully match participants and volunteers to increase the likelihood of a relationship forming. There are a number of existing services that connect volunteers with participants, such as Volunteering and Contact ACT, and Inclusion Melbourne. (sub. PP327, p. 47)

While volunteers supply their time for free, the use of volunteer-staffed supports is not costless. There are 'fixed' or up-front costs (including legally required checks and screening) and ongoing costs incurred by volunteers in meeting their volunteer role. Organisations that match volunteers with people with disability also have ongoing costs such as insurance, overheads and the administrative costs of managing volunteers.

The sources of funding for volunteer organisations are changing under the NDIS. Volunteer organisations use private fundraising and philanthropy, as well as government grants to meet the costs of providing volunteers. But as governments shift disability funding into the NDIS (chapter 12), direct grants to volunteer organisations are diminishing. Other sources of funding are available for volunteer organisations to use, such as Information, Linkage and Capacity Building (ILC) grants, but these grants target activities more broadly compared with the previous grants (chapter 6). There is also a capacity–building support that

participants could have included in their plans to initiate a connection with volunteer organisations (NDIA 2017q, p. 57).

The cost of providing volunteer supports under the NDIS have changed too, with the person-centred approach meaning that volunteer organisations need to better match volunteers with the characteristics, goals and other supports of participants. Greater coordination between volunteer and participant is necessary to ensure that the supports provided by volunteers align with others from the NDIS and mainstream services.

Within this context, some volunteer organisations are struggling to adapt to the scheme. This is putting the benefits they provide at risk. As Inclusion Melbourne said:

> It is unclear how and if volunteer based services […] are to be funded under the NDIS. The lack of inclusion of volunteering in the foundational philosophy of the NDIS and the exclusion of line items for volunteer management in the NDIS Price Guide are very concerning and represent a real danger for loss of social capital. … There is a danger of losing thousands of volunteers and hundreds of thousands of hours of support to people with disabilities unless this situation is resolved. (sub. PP207, p. 8)

A recent analysis by Extended Families Australia, Interchange Incorporated, People Outdoors and Inclusion Melbourne found that many volunteer organisations want to provide services to NDIS participants, but are not preparing to do so. Some consider this a risk to participants, their families and the broader community.

> This statistic is very concerning and represents a real danger for loss of social capital. It undoubtedly reflects the lack of information and government policy regarding how volunteering programs will fit and be funded under the NDIS. With no clear pathways for transition, this leaves organisations floundering and without clear messages to give people with a disability and their families currently supported by volunteers. There is a widespread concern from organisations about the impact of failure or delayed transition of programs into the NDIS where volunteers directly support people with a disability into the NDIS. (Inclusion Melbourne 2016, p. 14)

How should funding of volunteer organisations be considered?

Funding for volunteer organisations needs to strike a balance between several objectives. For volunteering to provide the greatest benefit, government funding of volunteer organisations should not crowd out the fundraising or support that people would provide anyway. Nor should funding be structured in a way that means volunteers are, or are perceived to be, 'paid supports' rather than people who want to offer their time to make a genuine connection and difference to people with disability. At the same time, funding and support to volunteer groups should reflect the broader social benefits they enable, and the cost and labour savings that they may allow.

The Commission's 2011 *Disability Care and Support* inquiry suggested that as formal supports were rolled out to participants in the NDIS, volunteers would focus on providing supports outside the scheme, and to all people with disability — largely funded through ILC (PC 2011, pp. 218–224). However, as the ILC program becomes more clearly defined, it

does not seem to be a good fit for all volunteer activity. As a result, the Commission considers it may be worth the NDIA trialling some new funding arrangements for volunteer organisations, particularly in this period where the workforce is not developing quickly enough.

RECOMMENDATION 9.4

Some volunteer organisations are finding it difficult to provide supports to eligible scheme participants. There is merit in the National Disability Insurance Agency:

- considering whether volunteer organisations should be funded to cover both the initial costs of connecting participants with volunteers and ongoing costs of volunteer management. The Agency should consider whether this is best done through line items for scheme participants or through a more direct funding arrangement with volunteer organisations
- trialling different funding arrangements to cover ongoing costs of volunteer management and collecting data on the outcomes of participants that use such services to better evaluate the costs and benefits of volunteer organisations providing scheme supports over the longer term.

9.4 How does informal care affect the workforce?

Unpaid informal care by family members, friends and community groups remains a critical part of the NDIS. Under the current payment system, the funding a participant receives takes into account the level of reasonable and sustainable informal support received, but as noted by the NDIA, 'the maintenance of ordinary family relationships, and the increased independence this entails for the participant, is central to the purpose of the Scheme' (NDIA, sub. PP327, p. 49).

To the extent that participants have natural and informal supports in their lives, this reduces the amount of formal care considered necessary. However, a lack of informal care could increase the need for formal carers, and require an even faster build-up of the disability care workforce.

Workforce shortages will mean that some people with disability will have to continue for some time yet to rely on their informal carers. But there are two constraints on informal carers providing additional hours of care. One is the declining ability to care (especially in the case of ageing informal carers) and other commitments (such as paid employment, or the need to engage in paid work). The other is a lack of respite services.

The ageing of informal carers means that many carers will be unable to provide additional care in the future. The most striking example are ageing parents of adult children with disabilities. Many ageing parents contributed to this study (box 9.5) and it is clear that their capacity to offer additional care is extremely limited, and should not be relied upon.

Box 9.5 **Many parents are currently the 'provider of last resort'**

Rosa Miot:

> The NDIS is crucial to my future. I have a 40 year old daughter with an intellectual disability. I have been her full time carer all of her life. … However, I am now 70 years old and I will need the NDIS to provide her with the ongoing supports she will need to be able to remain living in the community as she has done all her life. I would like to be able to concentrate on my own life and health needs and not be overburdened with the caring role. (brief sub. 134)

Evelyn Ware:

> My husband and I are 89 and 82 years old respectively and have a daughter aged 55 with autism and intellectual disability. Although living in the community she requires a considerable amount of support with budgeting, health matters, cooking and general management of her life. … once we are unable to provide the assistance we are now providing she will need to have more support from NDIS, or go into supported accommodation as her disability prevents her from living independently in the community. (brief sub. 137)

Pat van der Beek:

> Our intellectually disabled son is 41 years old this year and my husband and I are 73 and 72 respectively. When the NDIS rolls out in our area in July, we are hopeful that we will have additional resources to enhance his life. His siblings are busy with their own families, careers and lives in general and there is no certainty that they will be able (or willing) to provide the necessary support for their brother when we no longer can. … While we are currently both in reasonable health, there is obviously no guarantee this will continue; inevitably, our son will be without our support in the later years of his life. … We have genuinely done our utmost to give him the best possible life to this point and welcome the introduction of the NDIS which we hope will enhance his future while also lifting some of the responsibility from our shoulders. (brief sub. 70)

However, for others, the constraint is less to do with ability and more to do with the forgone wages that caring entails. Alleviating these constraints may allow informal carers to support family members with disability for longer and more intensively. One way to do this is to pay informal carers.

Is paying informal carers appropriate to reduce calls on the workforce?

Paying informal carers to provide attendant care judged to be reasonable and necessary under the NDIS has potential benefits, definite costs, and considerable risks. In the position paper, the Commission included a draft recommendation suggesting that the guidelines on paying informal carers should be relaxed for the period of transition, as a way to reduce workforce shortages.

The benefits of paying informal carers are that such payments can enable informal carers to provide a greater quantum of care, which reduces the calls on the formal carer workforce. Depending on a participant's circumstances — such as those in thin markets — payments to informal carers may be the only way that some will receive funded attendant care under the NDIS. If this care is not judged as reasonable and necessary, there could be greater calls on

other mainstream services, or on the scheme itself, over the longer term.[82] But while this could be beneficial to participants and reduce long-term costs, it is difficult to know what the scale or scope of these benefits might be.

Much clearer are the additional costs to the NDIS of paying informal carers, which would depend on the eligibility for such payments and the rate of payment. Currently, the NDIA's (ndd) operational guidelines 'will not fund a family member to provide personal care or community access supports unless all other options to identify a suitable provider of supports have been exhausted'. (In practice, this has sometimes been interpreted to mean that family members who are paid to provide supports do not reside at the same location as the participant (NDIA 2014b, p. 5), or that this is a rule disallowing the employment of a participant's relative to provide supports (QAI, sub. 115, p. 15)). While the NDIA does not currently collect data on how often these exceptional circumstances occur, the Commission understands that NDIS payments to family carers are very rare. Accordingly, increasing the scope of paying informal carers means that there will be greater costs to the scheme.

There are also risks to paying informal carers, which have their own potential costs and benefits that need to be considered. Participants in this study highlighted several of these risks, which fall into three broad groups: the risks to participants, risks to informal carers, and risks to the sustainability of the scheme (table 9.4).

It is difficult to quantify the likelihood and costs associated with these risks, but each points to higher potential costs or poorer potential outcomes for scheme participants. Participants have experienced safer outcomes, less unmet need and greater satisfaction under some schemes that provide paid family care (PC 2011, appendix G). But in other schemes, experience suggests that the risks and costs of paying family carers can be substantial.

One example is the experience of the NSW Lifetime Care and Support scheme (now part of icare) in paying family carers. The scheme only allows payment to family members in exceptional circumstances, including instances of geographical isolation and culturally-sensitive situations. Where such payments have been made, the dependence on the income has sometimes disrupted family relationships, including the payments for care becoming a key source of income for the extended family. It has also led to some difficulties where the needs and aspirations of the participant and their family carers change, such as when family carers become too old and frail to provide the proper attendant care they are paid to supply (icare, pers. comm., 19 September 2017).

[82] The benefits from paying informal carers are reflected in the policy decisions of many OECD countries Most OECD countries have some paid benefits program designed to support the providers of informal care. Typically, these fall into two sorts of programs: a paid allowance to the informal care giver and a payment to a person with disability that can be used to pay family carers. Austria, Belgium, the Czech Republic, France, Italy, Luxembourg, the Netherlands, New Zealand, Norway, Poland, the Slovak Republic, Spain, Sweden, the United Kingdom, and the United States all have some variant of the latter that allows for payments to pay for family members to provide disability care, though the rate and eligibility criteria vary considerably (OECD 2011, p. 139). However international comparisons are difficult to make, especially as different jurisdictions often use a range of eligibility and means test criteria in relation to such payments.

Table 9.4 **The risks from paying informal carers could be considerable**

Risk faced by	*Potential outcome*
Scheme participants	• Informal carers may provide a lower quality of care than professional carers. This could undermine participant wellbeing, and in some cases, recovery. • Participants may suffer harm or exploitation without appropriate institutional safeguards. • Payments can undermine family relationships by introducing a payment for care that was previously being provided out of love. When such payment arrangements are put in place, they can be very difficult to unwind, especially where a degree of dependence on the funding occurs.
Paid family carers	• Payments to family carers would not be costless to the economy more broadly, as they may reduce the incentives of carers to find other paid employment. • While payments may be provided to carers, these could be offset by an increased administrative burden and other costs. For example, paid family carers may need to register as a provider. • The value of the payments may be offset through the withdrawal of other (means-tested) government programs.
The scheme overall	• Additional administrative costs to the scheme. This includes the difficulty of determining that paid time to informal carers is used for the reasonable and necessary supports provided under the scheme, rather than for hours of informal care that were expected to be provided anyway. • Payments to family members to provide care may inhibit a market-driven solution that would otherwise respond to the shortfall. • Such payments could affect the interpretation of what amount of informal care may be expected of participants without payment. If payments to family members were to become the norm, then this could affect the amount of paid supports expected as part of reasonable and necessary criteria of the NDIS. This could substantially increase scheme costs.

Sources: Based on Carers Australia (sub. PP224, pp. 11–13); icare (pers. comm., 19 September 2017); NDIA (sub. PP327, pp. 49–50); Prader-Willi Syndrome Association of Australia (sub. PP228, p. 6).

Another example is the difficulties faced by the New Zealand Ministry of Health in keeping payments to family members financially sustainable. Legal challenges that broadened the extent of family carer payments increased their cost substantially in 2012, requiring a legislative change to constrain the cost (NZ HRC nd). These experiences show that paying informal carers can, in some cases, lead to undesirable outcomes from a financial, legal and scheme sustainability perspective.

The key policy question is whether taking such risks by paying informal carers is worthwhile to address the potential shortage of formal carers being faced by the NDIS. For such an approach to be effective, participants would have to *want* to use paid informal care, and informal carers would have to be prepared to supply paid care.

Study participants' views were mixed on the effectiveness and desirability of paying family members to provide care (box 9.6), with the strongest support coming from participants who see thin markets as presenting the greatest risk of a lack of supply of paid, formal carers.

Box 9.6 Some of the views on paying family members to provide care

National Disability Insurance Agency:

> The NDIA considers that the unintended side effects of such a change will cause social and financial problems that outweigh the workforce supply benefits. … Paid informal care by family members has the potential to negatively affect the social bonds between participants and families … Paid Informal care is likely to compromise the sustainability of the NDIS. (sub. PP327, pp. 49–50)

Physical Disability Australia:

> If participants are able to utilise some of their support packages to supplement the income of parents, partners, siblings and other extended family members then they will be less of a burden to them, they will be actively contributing to the economic well-being of the family and they will have the benefit of privacy at those times when they don't want workers in their homes but still need support with particular tasks. (sub. PP306, p. 4)

Australian Federation of Disability Organisations:

> Half the membership supported the relaxation of the operational guidelines to allow for the payment of informal carers citing it as an expression of the principle of choice and control. Member organisations from this group stated that in rural and regional areas informal carers may already be providing disability support in the absence of available disability support providers. This option would acknowledge that relationship, resource it and may allow for the person with a disability to continue to live at home with family rather than having to move away from all that they know and trust in order to receive disability support. (sub. PP325, p. 19)

Carers Australia:

> Many family and friend carers would regard being paid to care for a loved one as anathema and possibly an extra source of relationship strain within the family. Among those who are anxious about the consequences of family carer employment, the possibility that carers will become even more entrenched in their caring role is often raised. Further, paying informal carers can create extra burdens, particularly if it assumes that it will be in addition to the care already provided, or carers feel that receiving payment means they should be doing more than they are already.
>
> However, we know from consultations around the NDIS, that other carers and those they care for regard the option to choose to pay family or friend carers, in preference to a worker who they believe would not provide the same standard and quality of highly personal holistic care, is a key element of choice and control. Having noted the lack of consensus around the merits of paying family and friend carers, we are of the view that [payments to informal carers] bear consideration, especially in cases where replacement care is not readily available and where, as a consequence, carers are not benefiting from NDIS supports in the way intended. (sub. PP224, p. 10)

Northern Territory Government:

> The Position Paper's Draft recommendation … suggesting the relaxation of paying informal carers living in the same residence as the participant is supported, particularly for Aboriginal and remote communities. However, the NDIA will need to ensure access to such payments is simple and clearly understood by Aboriginal Australians, and that appropriate protections are in place for participants. (sub. PP359, p. 5)

The lack of data collected on where participants have been allowed to use paid family carers under the scheme, and the lack of clarity on when such circumstances occur, means that it is difficult to assess the level of workforce savings they could enable from past practice. Nor is it clear how such arrangements would interact with other NDIA policies, such as the Market Intervention Framework and Provider of Last Resort Policy (chapter 7).

Given the uncertainties about costs and risks, it would be premature to recommend any changes to paying family carers before a better evidence base is collected. At any rate, given the risks highlighted by the NDIA on payments to informal carers, it seems necessary for the good governance of the scheme that the Agency collect better data on its current arrangements in this area.

RECOMMENDATION 9.5

The National Disability Insurance Agency should collect data on the number of participants who make use of paid informal carers to deliver scheme supports, including the costs associated with such payments and their length of use.

Respite

Respite[83] services can help informal carers care for longer. A lack of respite may mean that informal carers are unable to support family members and friends who are NDIS participants. This will require more formal and costly supports in their place. It was for this reason that the Commission in its 2011 *Disability Care and Support* inquiry recommended that the needs of carers be considered as part of a participant's individualised supports (PC 2011, p. 340).

A number of respite options (such as the *Mental Health Respite Carer Support Program*) have been wound up, with the funding provided to the NDIS (Mental Health Australia, sub. PP321, p. 13). Replacement support for carers outside the scheme, including information and linkage about respite, is to be provided under the DSS' *Integrated Plan for Carer Support Services*, but this service is still to be fully implemented. A gap is emerging for respite services both within and outside the NDIS as the scheme transition occurs.

In this context, a number of study participants argued that respite services are not well catered for under the NDIS. Concerns raised included that there is a lack of respite supports in plans, or insufficient quantities of respite options for family members (Carers Australia Victoria, sub. 131, pp. 37–38; Carers ACT 2015, pp. 1–3).

It can also be difficult for some participants and their families to identify available respite options under the NDIS support list, as it is not clearly labelled as 'respite' (Anglicare Australia, sub. PP339, p. 11).

[83] Some participants in this study said the term 'respite' is pejorative and prefer the term 'family care'. The Commission is sensitive to this issue, but has used the term 'respite' for clarity — both because it is included in the NDIA's Price Guide (NDIA 2017q, p. 28) and most study participants, including people with disability, used the term in their submissions.

As the Intermediate Review into the NDIS said:

> … both the quantitative and qualitative data indicate that many family members and/or carers of NDIS participants are unable to take adequate breaks from providing support and they cannot access carer support in a consistent manner. (Mavromaras, Moskos and Mahuteau 2016, p. xiv)

Respite can be accessed under the NDIS in two ways:

- A line item in participants' plans that provides for short-term accommodation (often there is a cap on the number of days provided each year).
- A core support can be used to fund additional in-home care or support in shared facilities (NDIA, sub. PP327, p. 51).

While placing the options for respite in plans maximises choice and control for the participant, it can lead to inappropriate levels of support for informal carers (Inclusion Australia, sub. PP357, p. 23; National Mental Health Commission, sub. 153, p. 4) — especially as some block-funded supports for carers are withdrawn. As Anglicare Sydney said:

> … carer needs and supports are not formally recognised as part of NDIS packages. There is no formal assessment of the needs of the carer, no funding package for the carer and no guarantee of involvement in the assessment of the care recipient's needs. … With the closure of carer-specific support services, Anglicare is concerned that carers will no longer receive the same amount of support, let alone improved levels of support, under the new system. (Kemp et al. 2016, p. 10)

Such an approach is at odds with practices in other jurisdictions.

> Although carers' goals and aspirations are recognised in the guidelines for carer support under the NDIS, there is no formal assessment process for their needs. In the UK, carers' needs are assessed independently of the needs of service users. In the US, needs of all members of the family are assessed at once. (Hamilton et al. 2016, p. 1)

The NDIA noted that alternatives to respite, including 'community-based activities such as camps and innovative daytime opportunities that connect a person to their community' were becoming apparent under the scheme. Also, the choice not to call respite 'respite' was a deliberate choice made by the Agency in the interests of participants and families.

> On the advice of the NDIS Independent Advisory Council (IAC), 'respite' is not a distinct service listed on participant plans. The IAC notes that the 'respite' paradigm sets up an unhelpful dynamic portraying people with disability as 'burdens of care'. Parents and other carers do not need 'respite', but may need 'rest, recovery, re-energising and inspiration'. The IAC favours reframing the question to 'What would it take to enable the family and the person with disability to get a life?' Participant plans under the NDIS list specific services instead (such as short-stay supported accommodation). (sub. PP327, p. 51)

The Commission considers that the use of alternative arrangements that better connect people with disability to the community and provide respite to informal carers is an excellent example of the benefits of the scheme. However, it should also be noted that day programs

and occasional camps may not be sufficient respite in some circumstances, especially where the supply of such alternatives does not keep pace with demand. Also, not labelling short-term accommodation as respite is inadvertently causing confusion and leading to poorer outcomes for some informal carers.

This is concerning from both a wellbeing and a financial sustainability point of view, as the benefits of respite usually exceed the cost of providing them. For example, research and analysis conducted by the Victorian Ombudsman and Victorian Equal Opportunity and Human Rights Commission found that it costs far less to provide 'intensive' respite for children with disability compared with placement in out of home residential care (VEOHRC 2012, p. 54). Respite services provided to young carers have contributed to improved emotional and physical wellbeing, as well as better opportunities to complete schooling (ARTD Consultants 2008, p. vi). Internationally, respite services are recognised as both improving the wellbeing of carers, improving the quality of care to people with disability, and reducing costs to governments (OECD 2011, pp. 127–129).

Informal care, and the ability to call upon informal carers, is a vital part of the supports provided by the NDIS. Without respite services, the sustainability and success of the scheme are imperilled. It is the Commission's view that it is appropriate for respite supports to be allocated to participants on the basis of the amount of informal supports expected of informal carers, that respite should be more clearly labelled, and that the options available to participants to use their core supports for respite are clearly set out.

RECOMMENDATION 9.6

The National Disability Insurance Agency should:

- ensure planners take into account the amount of respite care that is reasonable and necessary under an individualised support package, based on the amount of informal care that is expected to be provided by informal carers
- label short-term accommodation supports provided in participants' plans in a way that makes it clear that these supports can be used for respite
- better inform participants and their informal carers that core supports provided in individualised support packages can be used to fund additional in-home care or support in shared facilities to provide respite
- include specific measures to ensure a supply of respite services in its provider of last resort policies.

Another issue raised repeatedly to this study was that price caps offered for short-term accommodation under the NDIS (which is used for respite), are too low to be sustainable, especially for participants with complex needs or challenging behaviours (Cerebral Palsy Alliance, sub. 163, att. 1, p. 4; HSU, sub. PP316, p. 8; Nardy House, sub. PP216).

In turn, the NDIA (sub. PP327, p. 50) noted that '[i]t is too early in the Transition to provide a view on whether the NDIS has affected supply and demand for respite services', and that:

> … as part of the independent pricing review, the NDIA has asked for advice on improving pricing effectiveness for the pricing of short-stay support, and for emergency and crisis supports. This will inform the NDIA's position on whether respite services can be more effectively provided. (sub. PP327, p. 51)

The Commission's recommendations on price monitoring and regulation are aimed at addressing concerns about the adequacy of pricing (chapter 8). Concerns that existing providers may be struggling to transition across to the NDIS, and that a lack of respite services may result, mean it is prudent for the NDIA to explicitly consider respite supports in its provider of last resort policies (chapter 7).

10 Participant readiness and market stewardship

Key points

- The National Disability Insurance Scheme (NDIS) relies heavily on well-informed participants making decisions in their best interests. Participant readiness depends on a number of factors, including: an individual's capacity; their network, carers and peers; assistance provided by the NDIS; assistance available in the community; how ready the market is to provide supports; and the complexity of the scheme.
- Some participants (and their families) are finding it difficult to understand and interact with the NDIS. This is in part because the scheme is a new way to allocate and supply disability supports. Some transitional issues are also contributing to these difficulties.
  - If participants are unable to interact well with the NDIS, the benefits of the scheme will not be fully realised. This has consequences for participants and their families, the financial sustainability of the scheme, and the broader community.
- Some participants receive NDIS supports to help them implement their plans, including support coordination, which makes up about 4 per cent of committed supports. The National Disability Insurance Agency (NDIA) needs to clarify the role of support coordination and allocate it based on need (rather than for a fixed time period).
- The NDIA is currently responding to participants' concerns about the online portal (which is used to manage plans) and developing the eMarketPlace. Providing timely and useful information to help participants find providers should be a matter of priority.
- Intermediary services, which can help participants manage their plans, can also reduce transaction costs and the complexity of the scheme for participants. More should be done to encourage the use of intermediaries, particularly to unlock the benefits of self-management. In a mature scheme, intermediaries could also help streamline administration and compliance costs, as well as protect participants by helping them to understand their consumer rights and protections under the scheme. However, the safeguards that apply to intermediaries to protect providers and participants need to be monitored closely so they can be adjusted to changing need as the scheme evolves.
- Disability advocacy is critical to helping participants engage with the NDIS, and for all people with disability. These services need to be appropriately funded by governments, with data collected to evaluate future funding arrangements at full scheme.
- Market stewardship would be improved by increased clarity of roles and responsibilities, data collection and greater collaboration between governments.

The new model of disability support envisioned by the National Disability Insurance Scheme (NDIS) relies heavily on well-informed participants making decisions in their own best interests. As a result, participant readiness is central to the success of the scheme. The

outcomes of the scheme are directly linked to how ready participants are to enter the NDIS; to get the plans that they need; to find their supports; and to self-manage their own affairs (if they want to).

Participant readiness also affects scheme costs. If people with disability are unable to navigate the scheme, this will lead to lower participation in the scheme, underutilisation of supports, and mean that the intended benefits of the scheme are not fully realised. While this will reduce scheme costs in the short term, it may lead to higher costs (both inside and outside of the NDIS) in the long term.

This chapter looks at participant readiness and the supports available to assist participants use the scheme (section 10.1). It then discusses options for improving participant readiness (section 10.2). (Participant engagement in the planning process is discussed in chapter 5.) The chapter concludes (section 10.3) with a wider perspective on market readiness issues, focussing on what governments need to consider to help participants, providers and workers deliver NDIS supports efficiently and effectively.

10.1 What is participant readiness?

Participant readiness should be considered in the context of the changes that the NDIS is driving for people with disability. Participants are moving from a scheme where they had little choice and control over their supports to a new system, where they have more opportunities to exercise choice and control. This change brings with it new challenges, including:

- thinking about the best way to achieve their goals
- shopping around for providers
- managing administrative and financial tasks.

And participants are tackling these new challenges while the scheme is still rolling out and as the disability support market is changing. As one study participant said:

> Telling people they have choice and control, does not give them the skills to find appropriate service providers, which are much harder to find when they are full and simply tell people to go somewhere else if they are not happy with something. There is no information anywhere on how people can choose providers, what to look for in them, the sorts of questions to ask and what sorts of things you might want to consider. Equally when providers are all full, then what options are there. (Belinda Jane, sub. 80, p. 10)

There will be some degree of 'learning-by-doing' as participants spend more time in the NDIS and become more familiar with the scheme. But the experience to date is that participants need help to become well-informed consumers who are able to make decisions that result in cost-effective outcomes.

This was recognised by the COAG Disability Reform Council.

> … many people with disability will not have had the opportunity to exercise choice. Some people with disability may require additional support to effectively exercise informed choice, especially those with high and complex needs. (2015a, pp. 14–15)

Similarly, the Victorian Ombudsman noted that:

> The NDIS is a market driven model, rooted in the belief that people with disability are best placed to decide how their money should be spent on services to support them. For many people with disability, this is a long awaited improvement, however for people with severe cognitive impairment and/or limited communication, it can present new barriers. For the most vulnerable, capacity will never improve; it is not a developmental challenge that will be rectified as people 'become more confident and skilled consumers in the market'. This fact must be acknowledged and provided for within the NDIS. (2015, p. 90)

There are two main aspects to participant readiness to exercise choice and control:

- the capacity of participants (and their families) to navigate the NDIS — including their ability, willingness, disability type, experience, skills and resources
- the complexity of the NDIS — including interactions with the National Disability Insurance Agency (NDIA), Local Area Coordinators (LACs) and providers to access and purchase supports. Participants also need to navigate the interfaces with mainstream services like health, education and transport (chapter 6). The more complex the scheme, the more skills participants will need to engage with it.

The two levers available to improve participant readiness are therefore: developing the skills (and capacity) of participants, and reducing the complexity of the scheme. While both levers have costs and benefits, they are not mutually exclusive, but interdependent and complementary.

What help is there for participants?

Scheme participants have access to resources to help them navigate the scheme, and to exercise choice and control over their supports. They range from general assistance available to all participants to more specialised services to address particular needs.

Participants also have options around how they manage their plans (box 10.1).

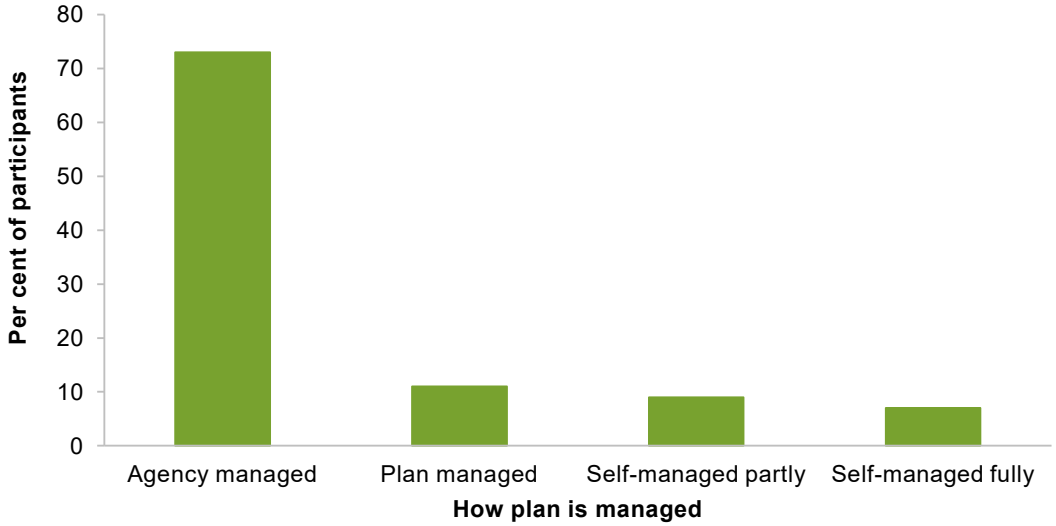
- Participants can use a NDIA-managed ('Agency-managed') plan. Under this option, participants are required to find supports from providers that are registered with the Agency. The NDIA then directly reimburses providers after they deliver supports to the participant.
- Participants can self-manage part or all of their supports. Under this option, the participant finds supports from, and manages payment to, providers. Participants can pay providers and then seek reimbursement from the NDIA, or pay providers once the participant receives funds from the NDIA (NDIA 2017x).

- Participants can use a 'plan manager'. The plan manager can either manage the payments, or provide assistance in terms of finding, hiring and firing providers on behalf of the participant. Plan managers are often referred to as financial and service intermediaries (these are the line items in approved NDIS plans to fund such supports) (NDIA 2016j, p. 48, 2016k, p. 48).
  - Financial intermediaries hold funds and manage risk on behalf of participants.
  - Service intermediaries provide broader technical assistance, including: assisting participants develop skills with plan management; negotiating and coordinating supports; sourcing providers; negotiating the method and timing of the delivery of supports; negotiating individual requirements as part of support management; recruitment, training, support and employment of staff (NDIS IAC nd). (However, the distinction between financial and service intermediaries is somewhat blurred in practice, as the service intermediary role can only be undertaken in conjunction with the financial intermediary role (NDIS IAC nd).)
- Participants can also use a combination of the above three options to meet their needs (NDIA 2017x).

Most participants to date have chosen an Agency-managed plan, rather than using a plan manager or managing their plans themselves (figure 10.1).

Figure 10.1 **How NDIS participants are managing their plans**

For participants who entered the scheme between 1 July 2016 and 30 June 2017



Source: NDIA (2017y, p. 21).

Box 10.1 Managing the funding for supports under a participant's plan

The *National Disability Insurance Scheme Act 2013* (Cwlth) (NDIS Act) allows a participant to choose how to manage their funding for supports. Management of funds is defined as:

- purchasing the supports identified in the plan (including paying any applicable indirect costs, such as taxes, associated with the supports)
- receiving and managing any funding provided by the National Disability Insurance Agency (NDIA)
- acquitting any funding provided by the NDIA (s. 42(1)).

A participant with an approved plan (or one that is being prepared) may make a request that funding be managed wholly, or to a specific extent, by one of the following:

- the participant — this is known as 'self-management'
- a registered plan management provider nominated by the participant
- the NDIA
- the plan nominee nominated by the participant or the CEO of the NDIA (ss. 42(2), 43).

The NDIS Act does not permit self-management of funds in some circumstances, including when:

- the participant or the plan nominee is an insolvent under administration (ss. 44(1), 44(1A))
- self-management would present an 'unreasonable risk to the participant' (s. 44(2)(a)). This is prescribed by the *National Disability Insurance Scheme (Plan Management) Rules 2013* (Cwlth), which includes a range of factors relating to the participant's legal capacity and decision-making ability that the CEO of the NDIA must consider in making this determination (NDIS Act s. 44(3)(a), *National Disability Insurance Scheme (Plan Management) Rules 2013* (Cwlth) rr. 3.7 and 3.8)
- the NDIS Rules have prescribed matters that must not be managed by a participant (s. 44(2)(b)).

If a participant does not make a plan management request, the plan is to be managed by the registered plan management provider specified by the NDIA, or by the NDIA itself (s. 43(4)). If this occurs, the CEO of the NDIA 'must, so far as reasonably practicable, have regard to the wishes of the participant in specifying who is to manage the funding for supports under the plan' (s. 43(5)).

General assistance is available for all participants

Assistance to implement and manage a plan is available for all scheme participants, including via LACs, Early Childhood Partners, Information, Linkages and Capacity Building (ILC), and plan managers (sometimes referred to as intermediaries).

LACs link participants to the NDIS, and to information and support in the community. They work with the local community to make it more inclusive for people with disability. LACs can also help participants understand the NDIS and implement their plan. Participants can receive help to:

- find and start receiving the supports that they need

- self-direct or self-manage their plan
- find mainstream and community services (NDIA 2017n).

However, LACs are still being rolled out. The nature of their services also means that they assist participants with less complex needs (NDIA, sub. 161, p. 107).

ILC-funded projects focus on community inclusion, and making sure that the community becomes more accessible and inclusive for people with disability. This includes:

- personal capacity building — making sure that people with disability and their families have the skills, resources and confidence that they need to participate in the community, or access the same kind of opportunities or services as others
- community capacity building — making sure that mainstream services or community organisations become more inclusive of people with disability (NDIA 2017k).

ILC was not part of the NDIS trial period, but is being progressively rolled out during transition (chapter 6). The NDIA has provided grants to organisations to carry out activities in the community, with further funding rounds open in the second half of 2017 (NDIA 2017k; Prentice 2017).

Participants can also use a plan manager (registered with the Agency) for some or all of their supports. A plan manager can take on a range of different tasks for the participant, allowing the participant to effectively 'outsource' the tasks that they feel least comfortable with managing, and in turn, reduce their administrative burden. For example, plan managers can coordinate payments between the participant, provider and the NDIA, but participants retain choice and control over their supports. Plan managers can also take a larger role, such as searching and securing providers to meet a participant's needs — effectively acting as an agent for the participant.

Support coordination is available for some participants

Some participants who may have less capacity to actively manage their affairs, including those with complex or high support needs, can have 'support coordination' items as part of their plan. These items include: support connection; coordination of supports; participant training in planning and plan management; and specialist support coordination (NDIA 2017q, p. 55, 2017r, p. 56, 2017s, p. 56, 2017t, p. 56).

Whether support coordination is allocated to a participant is determined in the same way as other supports — based on what is reasonable and necessary for the NDIS to provide in meeting a participant's needs or goals. About 54 per cent of scheme participants had funding for support coordination included in their plans between July 2016 and March 2017, although only 37 per cent of participants had support coordination allocated in the June 2017 quarter (NDIA 2017y, p. 21). About 4 per cent of committed supports in participant plans after 30 June 2016 were allocated to support coordination (figure 2.9).

The NDIA said the participants most likely to benefit from support coordination include people:

- with severe and multifaceted disability requiring multiple supports
- who are young and in nursing care
- with conditions of a degenerative nature, and supports requiring regular active management and ongoing adjustment due to the participant's changing needs
- with episodic mental or ill health support needs
- requiring regular crisis management
- with poorly resourced families or limited or no informal support networks
- requiring child protection or criminal justice involvement
- with a history of changing and challenging support provision (sub. PP327, pp. 53–54).

The NSW Government also nominated other groups.

> There is likely benefit in specialist support co-ordinators identified for particular groups of participants, such as children and young people, people with psychosocial disability, and Aboriginal participants. (sub. PP230, p. 9)

Support coordinators provide more intensive assistance to help a participant understand their plan, and to choose and connect with providers — effectively a more personalised and in-depth service than what LACs would provide (NDIA ndc, nde). Support coordination also aims to build and strengthen the participant's capacity to connect to and coordinate informal, mainstream and funded supports to reduce the reliance on support coordinators and others in the future. This includes resolving points of crisis, developing capacity and resilience in a participant's network, and coordinating supports from a range of sources (NDIA, sub. PP327, p. 53).

Other groups can also provide assistance to participants

While LACs, ILC, plan management and support coordination are all provided under the NDIS, there are other groups and representatives — including Disability Support Organisations (DSOs), peer support groups, advocacy organisations and trustees — who also play an important role assisting participants and their families to engage with the NDIS.

Peer support groups allow scheme participants and their families to share their experience, information and knowledge with others about issues associated with disability and the scheme (including helping people think about their goals, supports they might need and support options). Peer support groups can also provide information on how best to find and arrange supports, and connect with community activities. Some peer support groups are forming as the NDIS rolls out (for example, the Mental Health and NDIS Facebook Support Group (sub. 8), and the NDIS Grassroots Discussion Facebook Group).

Trustees can also help participants manage their affairs. For example, public trustees, established by State and Territory Governments, aim to ensure that all members of the community (including people with disability) have access to financial management services in the event that their capacity to make decisions is affected. Public trustees can make decisions on behalf of a person with disability in the best interests of that person (known as 'substitute decision making'), taking into account their needs and views. The *National Disability Insurance Scheme Act 2013* (Cwlth) (NDIS Act) also allows the CEO of the NDIA to appoint a public trustee as a participant's nominee in order to make decisions on planning and actioning supports.[84] These arrangements are still to be tested, and need to be carefully monitored to ensure that they are fit-for-purpose.

Navigating the NDIS is proving difficult for some participants

While there is assistance to navigate the scheme, some scheme participants are finding it difficult to understand and interact with the scheme, and to exercise choice and control over their supports. Some participants said they are finding it difficult to understand their plans (chapter 5); to find, negotiate, purchase and coordinate supports with providers in a timely manner (for example, ADACAS, sub. PP260, p. 6); and to seek assistance from the NDIA when problems occur (JSCNDIS 2017a, pp. 62–63).

A number of study participants mentioned problems with clear communication of the participant pathway. This partly reflects the changing nature of the disability support landscape. Under the previous system, scheme participants who had access to support programs (typically block-funded) often relied on advocates and providers to be the 'first port of call' to seek remedies, information or changes to services. Under the NDIS, participants now have a range of options when seeking information or clarity — including approaching a LAC or the NDIA itself. A lack of fit-for-purpose information means participants can be confused, and providers are continuing to help them navigate the system. As one study participant said:

> There needs to be much more focus on communicating clearly and simply with clients. For instance, at the moment, plans are vague and written in 'government speak'. If the government is concerned about clients overspending, the NDIS needs to give clients clear information on what their funding is for and clear conditions under which it can be spent. (Angela Blakston, brief sub. 168)

[84] To the best of the NDIA's knowledge, there have been no instances of the CEO (or their delegate) appointing a nominee for a participant under Chapter 4, Part 5, Division 2 of the NDIS Act (NDIA, pers. comm., 7 September 2017). However, there are some concerns that nominees may have a narrower ability and responsibility compared with what a public trustee would ordinarily be able to do in the interests of the beneficiary. The Australian Law Reform Commission and participants in this study also noted that there may be a conflict in the duties required of a nominee as defined in the NDIS Act, and relevant State and Territory legislation (ALRC 2014, pp. 151–152; Financial Services Council, sub. 98, pp. 4–5), but this is yet to be tested in court.

Carers Australia also said that:

> If anything has characterised the NDIS to date it is poor communications performance. It has failed to communicate changes in the Scheme as it has been rolled out to potential participants. Its communications have frequently been heavily jargonised and pitched at a very high level. Even people whose job it is to understand NDIS developments and operations often struggle with exactly what is being communicated. In some cases the NDIA has been successful in making elements of the Scheme intelligible to consumers; for example, in a number of their plain English guidelines to supports available under the NDIS. This approach needs to be incorporated into all communications with participants, their carers and providers. (sub. 195, p. 22)

Providing information about the scheme in plain English is one relatively low cost way the NDIA can make the scheme less complicated for participants and their families.

The time spent by providers assisting participants and their carers to navigate the complex system can be significant, and often are 'unbillable hours' of support (JSCNDIS 2017a, p. 64). Participants and their carers said that often they are unable to obtain helpful advice from the Agency or LACs (JSCNDIS 2017a, pp. 61–63; Macarthur Disability Services, sub. 57, p. 9). The NDIA acknowledged that:

> People with disability and their families and carers have reported that there is continued difficulty in understanding the NDIS and the process of moving through the [participant] pathway. (sub. 161, p. 107)

Vision Australia said that some information provided by the NDIA (particularly for the purpose of pre-planning) was not in a format that was accessible by participants, especially for those who are blind or have low vision.

> … much information produced by the NDIA is inaccessible — either not electronically accessible, or the print versions are not produced in either braille or large print, or information is provided in image or tables that cannot be read by text to speech software or is difficult to navigate with magnification. Informed choice and decision making requires information: the current situation forces many people who are blind or have low vision to rely on supports of others, despite preferences for independence. (sub. PP252, p. 2)

Reflecting the complexity and variation of needs and circumstances among participants, some participants will be more ready than others. This, in turn, partly reflects the extent of help that they received under previous disability support arrangements. For example, one study participant said that:

> I don't think I will have trouble utilising my plan, because I am overdue some support and will fully appreciate the value of NDIS funding. I've done my research and I know what's available in my area; however, I appreciate that I live in a city area where there is choice of providers and my needs will not be difficult for me to articulate and negotiate around. (Name Withheld, sub. 5, p. 1)

However, another study participant commented that:

> As a now plan-managed NDIS participant I find it even harder, if anything, to manage that additional layer of administrative burden and all I really want to do is to go back to the good old

> days when the MS [Multiple Sclerosis] Society told me what I want and needed and provided it at a reasonable cost. … there are many benefits to it, including being able to shrug off the burden of managing your costs and choices with a reasonably low level of bureaucratic rigidity. In the meantime … I am an 'under-utilisation' risk to the NDIS, with the immediate threat of having my unused funding cut back — not because I don't want and need the features these choices provide, but because I can't get organised to utilise the promised benefits and it's easier to blow my budget RIGHT OUT than navigate the NDIS' portal … (Kirsty Magarey, sub. 150, p. 4)

Others are also unclear about who is ultimately responsible for helping participants navigate the system, including when supports are being replaced by the NDIS.

As one study participant said:

> In a recent conversation with my mother where we discussed the upcoming pre-planning meeting, my mother was under the impression that Minda Inc. would be acting as an agent for N in the actual planning meeting with the NDIA. From her perspective, she had assumed that as Minda Inc. would be acting as an agent that that would mean that neither she nor N would not need to have to go through meeting. But I'm not sure that's the correct assumption. Nonetheless, the pre-planning meeting with Minda Inc. still requires my mother to complete some paper work on behalf of my brother and to spend time continuing to cajole N to attend that meeting. (Name Withheld, sub. PP365, pp. 1–2)

10.2 How can participant readiness be improved?

Making clearer the role of support coordination and other assistance

It was recognised before the NDIS was implemented that it would be necessary to build the capacity of participants to interact with the scheme. The NDIA's 'participant pathway' reflects this, and includes funding for participants with limited capacity to navigate the scheme.

> The NDIA has designed the participant pathway to include support for participants during the planning and implementation phases … In the implementation phase, the NDIA provides LACs for those with less complex needs and funding for support coordination for the intensive participant groups. … The NDIA has also identified that there is a need for work in the support coordination sector, particularly in some cohorts such as where participants have challenging behaviours, rural and remote areas and where there are gaps in mainstream services that the NDIS cannot fill. Work continues to educate support coordinators on the capacity building role expected of their function which is designed to build the skills of individuals over time to make support decisions themselves. (NDIA, sub. 161, p. 107)

Support coordination is the key means to bolster the readiness of participants with complex needs. For example, Mental Illness Fellowship of WA said that support coordination is particularly important for participants with multiple levels of disadvantage and/or psychosocial disability.

> Where people live in quite complex situations, are impacted by poor physical health, poverty and social isolation support coordination is a critical component keeping people well and managing

their day to day living. At times support coordination is also a critical link between people's physical and mental health providers. (sub. PP221, p. 4)

However, there is some confusion about the role of support coordinators. It is also not clear whether support coordinators are effective in helping scheme participants find providers, or whether participants who most need these supports have access to them (box 10.2).

Box 10.2 Confusion about the role of support coordinators

Cheryl McDonnell:

> We need a step by step guide. A clear list of who is who and who does what. What the heck is a support coordinator and what exactly can they achieve in an hour a week? … Especially at the start of a plan, [a] support coordinator needs to be much more active. (sub. 79, p. 3)

Early Childhood Intervention Australia Victoria/Tasmania:

> There has been a lack of clarity and guidance around the function, allocation and use of support coordination funding … Providers also report a wide variation in the quality of the support provided. (sub. 129, p. 11)

Summer Foundation:

> In addition to the set up administration, many Support Coordinators are reporting significant time being spent in rectifying poor plans that do not represent the Participants' requirements. The NDIA states that Support Coordinators 'do not make a judgment about the adequacy of the plan and do not make requests for an unscheduled plan review on behalf of Participants'. Nevertheless Support Co-ordinators report on the amount of time overall that is being spent on rectifying inadequate planning at the Agency level, and this impacts on their work in reaching Participant outcomes. (sub. PP293, p. 4)

National Disability Insurance Agency:

> The NDIA agrees … that more clarity is needed around the role of support coordination, the effectiveness of support coordination, and the allocation of support coordination to the participants who most need it. (sub. PP327, p. 52)

The limited availability of quality and skilled support coordinators in some areas was noted by study participants, as well as delays in participants receiving support, and waiting lists for support coordination (NSWCID, sub. PP234, p. 6; Victorian OPA, sub. PP241, p. 3; Royal Institute for Deaf and Blind Children, sub. PP259, p. 7; Summer Foundation, sub. 113, p. 13).

The Victorian Government (sub. PP298, pp. 28–29) observed that some support coordinators were not equipped to assist participants with complex needs, particularly in crisis management and care coordination — resulting in State (and Territory) Government departments being re-engaged to cover the capability gap, potentially poorer participant outcomes and higher costs for governments.

These concerns reflect, in part, the current problems around developing the supply of supports and the workforce to meet the needs of participants (discussed in chapters 7 and 9 respectively). The MJD Foundation (sub. PP233, pp. 8–9) said that the NDIA did not have a clear picture about the actual support coordination options available in communities, and that support coordinators who wished to make service bookings were hampered by their

inability to view participant plans in the portal. The New South Wales Government argued that:

> … better targeting and development of the support co-ordination market is required prior to the conclusion of transition. The NDIA should implement mechanisms to communicate the purpose of the function. It should engage with the sector to co-design and commission a sustainable and well-networked support co-ordination market. (sub. PP230, p. 9)

Study participants (including the MJD Foundation, sub. PP233, p. 8; MHCSA, sub. 308, p. 6) also said that support coordination that is time-limited and focused on capacity-building is not always appropriate for people with permanent and significant disability. In the ACT — the jurisdiction that is already at full scheme — there is some suggestion that the NDIA intends to withdraw support coordination altogether and that LACs will take over this role.

> Support coordination in the ACT has been through various stages. Initial plans did not include it and many plans were not implemented as a result. Now that the LACs have commenced in the ACT the NDIA has made it clear that support coordination will be withdrawn for the majority of participants as the LACs should be doing this role in addition to their many other functions. The NDIA's understanding of support coordination is that over time all participants will develop skills so that it is no longer required. This is a simplistic understanding that does not take into account that many people will want and need support coordination on an ongoing basis … The NDIA needs to take a more realistic approach to support coordination recognising that it can play a role in ensuring sustainability of supports and outcomes for the person with disabilities. (ADACAS, sub. PP260, p. 6)

However, it is not clear whether the shift from support coordination to LAC services is because initially LAC services were not in some regions, and support coordination was funded until LAC services were in place (NDIA 2017x).

Support coordination may be required on an ongoing basis in some cases, including in cases where a participant has elderly informal carers with declining capacity to undertake support coordination (ADACAS, sub. PP260, p. 6; David Parkin, sub. PP362, p. 19).

Summer Foundation, a major provider of support coordination, echoed concerns about the subsequent withdrawal of support coordination based on time rather than participant outcomes, as well as the inconsistent allocation of support coordination in the first place.

> The allocation of Support Coordination in a participant's plan is reported as both incredibly varied with a lack of transparency about how allocation principles are applied. This generates a feeling that there is inequity. Some report also seeing huge reductions in allocation in subsequent plans despite a continuing and genuine need for support. (sub. PP293, pp. 3–4)

Although it is too early to properly evaluate the efficacy and efficiency of support coordination, it is clear that participants, their families and carers, and governments value support coordination, and that it helps many people who receive and use it. Participants who are allocated and use support coordination have higher rates of utilisation (the ratio of used to committed supports in a plan) on average than those who are allocated, but do not use, support coordination. At face value, this suggests that support coordination can help build a participant's capacity.

Because effective support coordination is important for both participant outcomes and containing scheme costs, the NDIA should clarify the roles and responsibilities of support coordinators, and how they interact with the other groups who assist participants and their families navigate the NDIS (including LACs). The NDIA (sub. PP327, p. 55) said that it is seeking to make clearer the roles of intermediaries, but whether this includes support coordinators is unclear.

The allocation of support coordination in plans should also be made transparent, and be more explicitly linked to participants' needs, circumstances and outcomes (informed by supporting data where possible), rather than be time-limited. This approach is consistent with the legislative requirement that NDIS fund reasonable and necessary supports (NDIS Act, s. 34).

RECOMMENDATION 10.1

The National Disability Insurance Agency should:

- clarify to scheme participants and the community the role of support coordinators in relation to Local Area Coordinators, plan managers, mainstream services and advocates
- allocate support coordination to participants in their plans on the basis of need (and not for a fixed time period) in determining whether it is a reasonable and necessary support, pursuant to section 34 of the *National Disability Insurance Scheme Act 2013* (Cwlth).

How can scheme complexity be reduced?

The objectives of the NDIS mean that some parts of the scheme will be complex by design. Putting in place a framework to identify, assess, plan and provide supports for people with disability is no simple task. Guidelines and processes can introduce complexity in the pathway that participants need to navigate to meet their goals. However, unnecessary complexity can lead to miscommunication or a breakdown in continuity of care (Warr et al. 2017, p. 33), and ultimately reduced participant wellbeing. Complexity can also add to scheme costs and reduce efficiency. The challenge is to simplify the scheme as much as possible, while maintaining the integrity of the scheme.

The Commission heard that the NDIS is complex. The two main areas of concern were:

- participants finding providers
- participants (and providers) understanding and using the online portal where plans and payments are managed (box 10.3).

The rapid rollout of the NDIS has led to a number of transitional issues, including with the online portal. A review of the portal found many shortcomings in its implementation, mainly

stemming from the speed of the rollout (PwC 2016). The NDIA said it accepted the recommendations of the review and is addressing the portal issues.

> Significant difficulties with the implementation of the new ICT system in July 2016 adversely impacted on both participants and providers and caused a loss of community confidence in the NDIA's administration. An assessment of the failures from July 2016 have been documented in the PricewaterhouseCoopers *NDIS MyPlace Portal Implementation Review*. The NDIA accepts the broad thrust of those findings and has now implemented, or is the process of implementing, all of the recommendations from that report. (sub. 161, p. 15)

Box 10.3 The NDIS online portal is not easy to use

Syndromes Without A Name Australia:

> The portal has a number of plans on it if the plan has been reviewed, causing confusions for clients. The headings are not the same as what is written in the plan, leading to interpretation errors. The portal crashes a number of times and the dates need to be entered a certain way. Some days the portal works better than others. There is no form on the MyGov tab or NDIS website to ask for a correction if you accidently upload a payment request to the wrong category. One family is still waiting 6 weeks later to hear from NDIS re: this issue, after submitting an enquiry regarding this. As there is no way to upload receipts, the portal uploads are open to exploitation. (sub. 86, p. 2)

Mental Health Community Coalition of the ACT:

> Service Providers are often placed in the unenviable position of having to help participants use the My Gov website in order to use their NDIS plans, including by entering passwords – technically this is breaking the guidelines of use, possibly the law. (sub. 135, p. 28)

Summer Foundation:

> The current administration of the NDIS creates a high barrier for participation by individuals with complex needs. Young people in RAC [residential aged care] typically have few informal supports and many have cognitive impairment. Most don't have ready access to a computer and/or are not able to navigate the Internet, both of which are required to activate plans and to find and negotiate supports with providers … More accessible and flexible approaches to delivering information and building the capacity of people with disabilities and their families are desperately needed. (sub. 113, p. 25)

Vision Australia:

> … the Participant Portal is completely inaccessible for a participant who is blind or has low vision and relies on JAWS [Job Access With Speech, the screen reading software]. (sub. PP252, p. 12)

More recently, the NDIA (sub. PP327, pp. 26, 52) said that, as part of its current participant and provider pathway reviews, it is committed to providing an improved online portal.

On the basis of the NDIA's commitment to address portal issues, the Commission has not made any finding or recommendation on the online portal. However, as participants (and providers) rely heavily on the portal to manage supports and payments, any issues with the portal should be closely monitored to improve accessibility for scheme participants. The online portal should also be revisited in future reviews of the NDIS.

Timely and useful information can minimise transaction costs for participants

Participants need information about providers. As the Prader-Willi Syndrome Association of Australia said:

> NDIS participants must have access to information about the performance of providers (e.g. number of complaints against them, participant's budgets running out too early, etc.). (sub. 112, p. 6)

The Minister for Social Services said that information for participants (and providers) is critical to support an effective NDIS market.

> The NDIS market is the arrangements through which participants use NDIS funding to obtain goods and services from providers. Mechanisms to provide information to people with disability about providers and to develop participants' skills as consumers are part of the NDIS market. NDIS market risks include anything that might reduce choice and control by people with disability to access goods or services that support them to live an ordinary life. An effective NDIS market is dependent upon people with disability being empowered to make informed decisions about high quality and safe supports and providers being informed about and able to meet the needs of people with disability. (Commonwealth of Australia 2017, p. 53, [310])

Information can emerge naturally from private sources, such as peer-to-peer online comparison sites (Better Caring, sub. PP296), connecting services (Ubercare, sub. PP227) and peer support groups for disability supports (Mental Health and NDIS Facebook Support Group, sub. 8). And while this is already occurring, the extent of it is unclear. The NDIA said that it:

> … is already aware of a range of small e-markets emerging around the country. For example, app-based plan management and financial management platforms are emerging to enable payments to be made to providers from participant plans, alleviating the burden on participants and providers. Another emerging e-market provides the ability to match available housing with people who are looking for specialist disability housing. (sub. PP327, p. 55)

Some providers said they are providing information to participants to help them make choices (AOPA, sub. 123, p. 8). However, as the Tasmanian Government (sub. PP247, pp. 9–10) pointed out, private sources of consumer information can lack transparency, increase the fragmentation of information, and be driven by service providers rather than consumers. And information provided by peers may not necessarily be accurate either. The effectiveness of private platforms will be limited if the NDIA holds all the relevant information necessary for participants to make decisions (such as the availability of registered providers in a particular area) and if they cannot be easily integrated with the Agency's payment system. And private payment platforms, while increasing the ease of making payments and facilitating transactions, do not by themselves help participants find providers.

The NDIA, as a market steward (section 10.3), is responsible for providing information about providers to reduce participant search costs, to increase competition, to monitor the market, and to reduce information asymmetry (NDIA 2016i, pp. 24–25). This role will

become increasingly important as the number of participants and the disability support market expands during transition. This role also reflects a key area for action under the Integrated Market Sector and Workforce Strategy (DRC 2015a, p. 15) to enhance the amount of information available to consumers. It also embodies the NDIA's (2016i, p. 24) desire for participants to have easy access to information 'about all possible service providers from which they can choose'.

According to the NDIA (sub. 161, p. 65), the NDIS 'eMarketPlace' will support information discovery, encourage industry innovation, build local community capacity, and provide timely data and analytics to assist with the scheme's sustainability (box 10.4). The eMarketPlace is broadly consistent with the Commission's 2011 recommendation that the NDIA should provide a centralised internet database of service providers with information on the range of products and services, price, availability and links to measures of performance and quality (PC 2011, pp. 486–7).

Box 10.4 The eMarketPlace aims to help participants and providers

The eMarketPlace is a project of the National Disability Insurance Agency (NDIA) to 'support information discovery, encourage industry innovation, and build local community capacity' and to 'provide timely data and analytics to assist with Scheme sustainability' (NDIA, sub. 161, p. 65). This includes the introduction of 'cognitive intelligence capabilities' — a form of artificial intelligence that will allow for easier interaction between participants, providers and the NDIA. For example, participants will be able to ask general and personalised questions about the eMarketPlace and the National Disability Insurance Scheme, rather than contacting the scheme's call centre or shopfronts. The eMarketPlace is to be co-designed by the NDIA and people with disability.

The aim of the eMarketPlace is to maximise the benefits of the scheme by making it easier and more efficient for participants to find and access the supports that they need. It will also allow providers, businesses and community organisations to market their products and services. In turn, it should improve the responsiveness of providers to participant demand, encourage the supply of supports and innovation.

The eMarketPlace is expected to reduce transaction costs for participants, providers and the NDIA. According to the NDIA:

> By introducing an eMarketPlace and eventually automating much of the payments and processing function, the NDIA will reduce the time spent on these activities and consequently the potential costs.
>
> In general contexts, eMarket platforms may be able to reduce unit costs by between 15-30%. In the NDIA context, these cost savings may flow through to participants in some scenarios. Where the NDIS is incentivising participants to shop around, the eMarketPlace will likely result in the best price for support services, in particular homogenous supports, being achieved more often. As well as open price comparison and price competition, the eMarketPlace also adds an additional commissioning channel for the participant. Cost savings realised from eMarketPlace price competition will serve to promote the effectiveness of the eMarketPlace, incentivising eMarketPlace participation, improving the scale of use and the sustainability of the NDIS. (sub. 161, p. 66)

Sources: Adapted from NDIA (sub. 161, pp. 65–66, sub. PP327, pp. 54–55).

The NDIA (2016i, pp. 29–31) initially planned to introduce the eMarketPlace by the end of June 2018, but it is unclear how long this will take in practice (there are a number of market stewardship activities and projects that are to take place during this period, including end-to-end improvements from the participant and provider pathway reviews (NDIA, sub. PP327, p. 54)). The Agency recently indicated that the eMarketPlace will not be delivered by June 2018, but rather it will be launched 'at the appropriate time once developed', while also stating that there were 'no known blockages or barriers' (apart from technological requirements) (NDIA 2017c, 2017d).

Some progress has been made on the eMarketPlace. In 2016-17, the NDIA spent about $640 000 on the eMarketPlace, and has undertaken work, in collaboration with the Department of Human Services, on the architectural models and high level requirements of the capabilities that are needed for the eMarketPlace (NDIA 2017d). The NDIA (sub. PP327, p. 54) is in the process of confirming the requirements of an effective eMarketPlace with the DSS, with functional requirements likely to include the ability to find providers and connect them to participants, trade, make payments, rate services and collect data.

The next stage of development is to determine what infrastructure changes may be required (NDIA, sub. PP327, pp. 54–5). The NDIA (sub. PP327, pp. 54–5) intends to conduct a Request for Information to gather advice from industry stakeholders about innovative solutions and commercial models that could deliver the eMarketPlace. The Agency is working with the Department of Human Services (the NDIA's shared services partner) to confirm the utility and timing of a Request for Information.

The eMarketPlace, if implemented as described, will go a long way to ensure that participants have the information they need about providers. The NDIA (whether through the eMarketPlace or directly providing information) must address existing information gaps — such as the slow updates to existing provider lists (every three months), inaccessible provider lists, and lack of consumer satisfaction indicators about providers (particularly on service quality and performance) — and make the information publicly available as soon as possible.

The eMarketPlace will supplement other work by the NDIA to develop consumer guides on best practice in areas such as therapeutic supports and equipment (DRC 2015a, p. 15), which are currently being refined. Metrics are being developed to better understand purchasing patterns and timing of participants' decision-making (NDIA, sub. 161, p. 107).

Participants must have access to information about options for supports and providers that is timely, accurate, relevant, clear and accessible, if they are to exercise choice and control. For example, ADACAS said that:

> An e-market place, appropriately set up and run would be welcome however as it is very difficult currently for people to find supports and to make informed choices about service providers. (sub. PP260, p. 6)

The New South Wales Government (sub. 60, p. 4) pointed out that 'participants are particularly vulnerable to information asymmetries and/or a differential in bargaining power

between themselves and providers'. This is particularly the case for people with disability where quality of service is highly valued (as poor service can have significant negative consequences for participants' lives) and switching costs can be high.

Accessible information to participants about providers must be made available as soon as possible. The Agency should consider outsourcing delivery of the eMarketPlace to private providers if necessary.

RECOMMENDATION 10.2

The National Disability Insurance Agency should provide accessible information to participants and the public about the providers available in the market and indicators of participant satisfaction with those providers. This information should be updated in as close to real-time as possible, and be consistent with the stated objectives of the eMarketPlace discussed in the *Integrated Market, Sector and Workforce Strategy*. It should be provided no later than 1 July 2018.

Intermediaries could play a bigger role

For some participants, the most cost-effective (and preferable) option will be to delegate some or all of the administration of their plans to an intermediary.

Intermediaries can assist participants who struggle to self-manage their affairs. They can also reduce scheme costs by aggregating participants' purchasing power for common supports. But there is some evidence that the administrative burden of self-managing a plan is a disincentive for some participants to take full control of their supports. The Intermediate Evaluation of the NDIS observed that:

> At wave 1 the option of self-managed funding was not always fully understood by NDIS participants; nor was it always discussed in the planning meetings. By wave 2 it was evident that while NDIS participants had a greater understanding of what self-management was there remained very few self-managers. The main reason for this appeared to be a reluctance to take on additional administrative activities. (Mavromaras, Moskos and Mahuteau 2016, p. 72)

Similarly, a report by the Melbourne Social Equity Institute noted that some participants are deterred by self-management because it is perceived to be too complicated and burdensome.

> … some participants had not developed an integrated package of services to meet their individual objectives and needs. Rather, they had opted for a care package which served to reduce the burdens of self-management. … One participant, caring for two children with disabilities, brought two large folders of letters, forms, reports and notes to the interview to show us the enormous amount of paperwork involved in self-managing her children's plans. (Warr et al. 2017, pp. 32–34)

Because participants who want to and can self-manage their NDIS funds are more likely to have positive outcomes (box 10.5) it is important that there are incentives to self-manage. As the NDIS Independent Advisory Council said:

> … the IAC [Independent Advisory Council] has drawn on the many evaluations of approaches to service provision to argue that when participants self-direct their support and self-manage their funds they are more likely to be able to achieve positive outcomes because they have control over the 'what, when, where and by whom' of support, making it more likely that the paid support facilitates the desired lifestyle and compliments rather than drive out freely given support by family and friends (informal support). (sub. 149, p. 6)

Increased use of self-management (where appropriate and over the long term), could benefit participants and carers. If intermediaries can build the capacity of participants to self-manage, then they should be encouraged. Intermediaries can undertake a range of tasks that participants may need for them to better self-manage. For example, intermediaries can:

- develop a participant's capacity in understanding their plan, budget and the choices available to them (increase capacity / reduce complexity)
- collaboratively develop a plan for initial plan activation / implementation
- collaborate and coordinate with the NDIA, support coordinators and LACs
- [support] the participant in sourcing services and items (as needed)
- work with the participant and providers on establishing service agreements and supporting a participant in negotiating rates and schedules as needed
- work with providers on service bookings / agreements / invoicing / payment processes
- [provide] the participant tools and personal support to effectively manage their NDIS budget
- conduct invoice processing (participant approvals required), NDIS billing and provider payment processes
- [continue] plan and budget monitoring and capacity building and planning. (Integra, sub. PP268, p. 2)

By coordinating these activities, intermediaries can act as a 'one-stop shop' for scheme participants, reducing the complexity faced by participants. In short, they mitigate the complexity of the NDIS that may be unavoidable, and which can have real costs for participants. Mind Australia said that:

> … when processes are overwhelming or negotiations are difficult, the impact on an individual's mental health can be devastating. One participant in the choice project said that when she was accepted into the NDIS, she thought that getting good support would mean fewer stays in hospital. In fact, she was admitted to hospital eight times in her first year in the scheme, which she put down [to] the stress of dealing with the NDIS and NDIS processes. Ongoing navigational support is one means to address this situation. (sub. 144, pp. 11–12)

Box 10.5 The benefits of self-directed funding

Self-management is a means through which participants can exercise self-direction over their supports and their lives. As the NDIS Independent Advisory Council explained:

> The term 'self-direction' is a generic term for an approach that gives people with disability greater control over their support and their lives. The concept is often broken into component parts of self-directed planning, self-directed funding and self-directed support. Self-directed support can be managed through a service provider, a financial intermediary or via a direct payment (self-management). (sub. 149, p. 7)

There is a strong body of evidence to suggest that self-management — including the self-direction of funding and disability supports — results in better outcomes for people with disability and their families. For example:

- The UK Individual Budget pilot found that participants who were given the opportunity to self-direct their funding were more satisfied with the scheme, had greater aspirations, and more likely to report that they felt in control of their daily lives for a given level of expenditure (Glendinning et al. 2008).
- An assessment of the US Cash and Counselling program found that those who self-managed their funds were more likely to have their needs met and be more satisfied with their care. Further, there was no evidence that self-management led to greater care-related health problems, and a significant proportion of those who self-managed had a lower incidence rate of adverse events (Carlson et al. 2007).
- A study of the Victorian scheme that examined the use of individual support packages found that those who used them reported improved choice, control, independence and self-determination in their lives — positive outcomes that they attributed to the better control they had over the way they could organise their disability supports (Fisher et al. 2010, p. viii).
- Where self-management has been used in Australia and overseas, the risks of improper use of funds (such as fraud) appear to be limited. Auditing and close observation of payments have been found to effectively mitigate the risks of abuse of self-managed funding (Fisher et al. 2010, p. 47). The incentives faced by those who self-direct also play a role in reducing fraud: to misuse support funds does not result in a net gain to participants as it is their own budget as part of an individualised support package.

Ultimately, the broader benefits of self-management are reflected in the goal of better participant outcomes and more efficient use of disability supports.

> They move from dependent clients toward active citizens who have increased independence, self-management and inclusion and as a result require less support over their lifetime. (NDIS Independent Advisory Council, sub. 149, p. 9)

Intermediaries can also have broader, scheme-wide benefits. For example, intermediaries can:

- provide systemic feedback to the NDIA on any common and recurring issues, which in turn can reinforce the scheme's insurance approach
- enable participants to exercise choice and control by providing a wider selection of providers to choose from, and empowering them to make decisions
- help enforce quality and safeguards regulations, as they may have greater visibility and knowledge of the provider landscape that allows them to detect, monitor and screen poor quality or unsafe providers, and warn against 'sharp practices'

- reduce costs to participants and to the scheme, by purchasing services on behalf of participants in bulk that can reduce unit costs ('economies of scale'). This may also provide greater certainty to providers about longer-term demand and better spread the risk of providing disability supports
- minimise the burden on the NDIA and LACs — especially given the heavy workloads to bring people with disability into the scheme — by providing an alternative avenue for troubleshooting (Integra, sub. PP268; Plan Management Partners, sub. PP324).

Reducing barriers to participants using intermediaries

Many scheme participants are unaware that intermediaries are an option to help manage their plans. The Commission heard that LACs and the NDIA provide little information about intermediaries and the option of using them (Integra, sub. PP268, pp. 3–4; Plan Management Partners, sub. PP324, pp. 3, 6). For example, Family Advocacy said that:

> LACs do not seem to fully understand what self-management means. There appears to be superficial knowledge of what options are available to the participant. One family member reported that in their 'first plan' meeting, the LAC simply said they could agency plan or self manage but did not explain what this really means or provide any options of how that could work. Another LAC told a family that she could either have support coordination or plan management but not both. This is completely incorrect and makes no sense. The first refers to support in coordinating the Plan and the second relates to how the Plan will be managed by the participant. One does not depend on the other. (sub. PP346, p. 22)

The NDIA (sub. PP327, pp. 55–6) recognised that there are barriers to participants using intermediaries that are not in the interests of the participants and the scheme, and is currently addressing these issues as part of its participant and provider pathway reviews.

The Agency also proposed that the use of intermediaries could be encouraged by:

- providing greater clarity on the roles of intermediaries — to improve consistency in planning decisions (in providing funding to intermediaries), and reduce confusion in the sector and the NDIA
- reducing barriers to entry — including administrative barriers (for example, tight definitions of intermediary supports, fungibility in rules and price controls); improvements to the NDIA's processes and policies as part of the provider pathway; and harmonisation of processes across jurisdictions (for example, regulatory, registration and compliance requirements that are proportionate and risk-based) (NDIA, sub, PP327, pp. 55–6; Neville 2017, p. 10).

The administrative rules and prices that apply to intermediaries are best left to the NDIA and the body responsible for NDIS pricing, respectively. The NDIA's pathway reviews are intended to lead to better engagement and encouragement of intermediaries. For example, the NDIA said that it wants to improve data sharing with intermediaries to enable scalability and better participant supports (Neville 2017, p. 10). However, the first step is for the Agency to provide more information to participants and planners about the roles and use of

intermediary services as an option, particularly when participants are considering self-management.

Some safeguarding issues still need addressing

While intermediaries can unlock the broader benefits of self-management to scheme participants, there are some outstanding safeguarding and consumer protection issues.

Participants should not be 'hurried' or unduly pressured into self-management. Some participants will need to build capacity first in a number of areas before being ready to self-manage (even with the assistance of intermediaries, support coordinators and other capacity-building supports). This will take time. Self-management should therefore be considered a long-term goal for many participants, and should be assessed on a case-by-case basis.

It is not clear whether the NDIS Quality and Safeguarding Framework is appropriate for intermediaries. While the Framework and proposed Code of Conduct for workers and providers (which also applies to intermediaries) give participants protections (chapter 11), the role that intermediaries play is different to direct support providers. There is a risk that participants may come to depend on intermediaries to an extent where they may find themselves unable to switch between them, to determine if they are getting a good deal (such as whether participants are given sufficient choice over their provider), or whether intermediaries are acting in their best interests more generally.

Intermediaries (like any other registered provider) will need to be closely monitored over transition, particularly in the first few years of scheme rollout, in order to implement and adjust any specific safeguarding measures as necessary. General consumer protections and guarantees under the Australian Consumer Law, or other regulations (such as Australian Securities and Investments Commission licensing and professional requirements for financial service businesses) are not necessarily fit-for-purpose for NDIS participants (who may be less likely than other consumers to complain).

While there are protections for participants, there is relatively little in the way of protections for providers who must deal with intermediaries when problems arise. For example, beyond costly litigation pursuant to service agreements, there appears to be little recourse for providers who are paid late, in part or not at all, by intermediaries. This needs to be remedied immediately by adjusting the conditions of registration for intermediaries with the NDIA (and subsequently with the NDIS Quality and Safeguards Commission) to require the timely payment to providers. Intermediaries should be held to the same account as the NDIA when they manage a participant's plan.

There is also a question about whether intermediaries should also be allowed to be service providers. The Commission's view is that plan management services should be separate from service provision. This was noted as a positive way to avoid conflict of interest by some intermediary providers and to ensure that participants' needs are met (Integra, sub. PP268,

p. 4; Plan Management Partners, sub. PP324, p. 7). The NDIA has also proposed an ongoing review of independence and conflict of interest requirements, and how best to manage this for intermediary functions (Neville 2017, p. 10).

That said, it is important to note that the intermediary market remains underdeveloped, underused and uncertain. This makes it difficult to put in place safeguards at present, except to ensure that any regulations are risk-based. The Victorian Government said that:

> It is too early to say how well equipped and how well supported NDIS participants will be to exercise informed choice in this new marketplace. As the disability service market matures, it can be anticipated that intermediaries will emerge to facilitate mutually satisfactory transactions between providers and consumers, often aided by new information and communication technologies and tools.
>
> Appropriate regulatory responses for intermediaries will also need to be determined. In the interim, the readiness of participants to exercise choice is likely to rely heavily on NDIA funded initiatives and programs designed to assist participants navigate the disability support sector. Much of this support infrastructure is yet to be fully rolled out. (sub. 174, p. 19)

Intermediaries should be closely monitored over the next few years to ensure that there are no unnecessary barriers to their operation, but also as a means to better identify areas of complexity that participants are seeking paid assistance to overcome, which may be useful for ongoing scheme reform. The activities of intermediaries should also be monitored with an eye to developing any necessary safeguards that may be needed beyond the NDIS Quality and Safeguarding Framework (which will come into effect as each state and territory reaches full scheme (DSS 2017f)).

RECOMMENDATION 10.3

The National Disability Insurance Scheme Quality and Safeguards Commission, upon commencement, should closely monitor the operation of intermediary services under the National Disability Insurance Scheme, and make changes to safeguarding rules and codes of conduct as necessary to ensure that intermediaries act in the best interests of participants.

The National Disability Insurance Agency should provide clear and timely information about the option for participants to self-manage their plans, and the role that intermediaries can play to assist them to undertake different tasks on their behalf. The Agency should continue to assess the capacity of participants to self-manage on a case-by-case basis, consistent with the provisions of the *National Disability Insurance Scheme Act 2013* (Cwlth).

Advocates provide vital assistance to people with disability

Advocates for people with disability (including scheme participants) are independent people or organisations (without a conflict of interest) who directly speak, act or write on behalf of

the interests of an individual or group. This may extend to helping people with disability find and secure supports.

There are a number of different models of disability advocacy, including:

- systemic advocacy — aimed at bringing about systematic improvement in policy and practice, and removing discriminatory barriers for people with disability
- individual advocacy (also known as 'independent advocacy') — upholding the rights of individuals with disability by working on discrimination, abuse and neglect
- self-advocacy — supporting people with disability to advocate for themselves, or as a group (DSS 2017c, p. 2).

Advocacy has always been, and continues to be, important to people with disability, and particularly so for some groups.[85] COAG's (2011, pp. 17, 41) *National Disability Strategy* noted the role of advocacy in protecting and advancing the human rights of people with disability, their wellbeing and interests, as it enables them to participate in making decisions that affect their lives. As the Victorian Government said:

> The role of advocacy and self-advocacy will continue to be important in building participants' capacity to meaningfully exercise choice. Particularly during transition, some participants may need additional assistance to navigate the planning and plan implementation processes. (sub. 174, p. 19)

While many of the arguments for intermediaries are also applicable to advocates, advocates have a broader role supporting people with disability. Indeed, this is expressly reflected in the general principles of the NDIS Act in section 4(13).

> The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:
>
> (a) promoting their independence and social and economic participation; and
>
> (b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and
>
> (c) maximising independent lifestyles of people with disability and their full inclusion in the community.

Advocates help participants in a way that NDIS supports cannot

The NDIS affects the need for advocacy services by participants and their families. The need for advocacy may diminish as the support and assistance provided by the NDIS increases — for example, ILC, LACs, the NDIS Quality and Safeguarding Framework, intermediary and support coordination services may fulfil some of the roles previously undertaken by

85 For example, the DSS identified that people who are Aboriginal and Torres Strait Islander Australians; who are from culturally and linguistically diverse backgrounds; who live in rural, regional and remote locations; and who are very socially isolated (including those with communication difficulties and those in institutional care) are most likely to benefit from advocacy (DSS 2017g, p. 18).

advocates. That said, many of these supports are in transition, and still to be fully clarified or established. These NDIS supports reflect the DRC's agreement that the NDIS would fund decision supports, safeguard supports and capacity-building for participants, including support to approach and interact with disability supports and access mainstream services (DSS 2015b, p. 3). The DRC also agreed that systemic advocacy, legal review and representation would be funded outside the NDIS — in line with the Commission's 2011 recommendations (DSS 2015b, p. 3).

However, some study participants argued that there is an ongoing need for advocacy *because* of the NDIS, and that the need for advocacy by participants cannot — and in many cases, should not — be met by NDIS supports.

- There are limits to what information and peer support organisations can do for participants via ILC, particularly those with high support or complex needs, or who are unable to navigate the NDIS more generally.
- LACs, to date, have focused more on developing participant plans and less on linking participants to services and building participant capacity (as part of their ILC functions, chapter 6).
  - Advocates can help fill the gap *before* a plan is made and provide valuable pre-planning assistance — this is important because participants may not have access to support coordination, plan managers, intermediaries or other assistance.
  - Advocates can help ensure better quality plans for participants *during* the planning process (chapter 5) and in any *subsequent* plan reviews (including NDIS appeals).
- Despite the introduction of the NDIS Quality and Safeguarding Framework, some participants may have a lower propensity or ability to make complaints, and to seek redress on quality and safeguarding issues (ADACAS, sub. 87, pp. 22–23). Advocates can help participants prevent, identify, raise and resolve such issues — they are an important safeguard for participants. For example, Children and Young People with Disability Australia (sub. 188, p. 25) said that people are often unaware of the rights of children and young people with disability, the relevant legislation and protections, and require support to resolve specific issues. Survey data also indicate that people with disability are more likely than the population on average to experience multiple legal problems and unmet legal need (Coumarelos et al. 2012; PC 2014, p. 95).
- How effective support coordination and intermediary services are at helping participants and building their capacity is still unclear. This is partly due to a lack of clarity on their allocation to participant plans, expected roles and safeguarding issues. Even if these issues are resolved, advocates may continue to have an ongoing role in monitoring the *quality* of these services, and intervening in any safeguarding issues, particularly with respect to identifying and reporting violence, abuse and neglect against people with disability in institutional and residential settings (SCARC 2015, p. 213).

In its review of the National Disability Advocacy Program (NDAP), the DSS acknowledged the role of advocates compared with other supports (including the Commonwealth

Ombudsman for Disability), particularly their independence and the broad scope of matters within their purview.

> It is important to recognise the unique role of advocacy and understand the limitations and restrictions of other roles. For example, NDAP advocates are independent and can act solely on the side of the person with disability. This differs from NDIS LACs (who have conflicts of interest due to their direct or indirect employment by the NDIA) and NDIS Support Coordinators (who have an interest in maintaining the funding relationship). (2017g, p. 12)

Advocates assist with broader issues and access to mainstream services or the community more broadly (which NDIS supports are not designed for), particularly when there are failures and gaps in mainstream service systems (DPOA, sub. 165, pp. 12-13), and when people with disability have complex needs and multiple levels of disadvantage (Australians for Disability Justice, sub. PP342). For example, Leadership Plus, a Victorian advocacy organisation, reported that the top three issues in recent years related to:

- Services — service delivery and quality including disability specific agencies and others,
- Finances — including financial management issues with appointed Administrators, capacity to manage personal income, loss (or risk of loss) of funds due to theft or mismanagement by friends or family, and
- Accommodation — for example, having appropriate housing, maintaining tenancy in public and community housing, risk of homelessness, addressing safety concerns. (sub. 128, p. 1)

In short, advocates help participants navigate NDIS processes, manage interactions with other disability services, and ultimately exercise choice and control over their supports and lives.

> The role of independent advocacy should not be underestimated in assisting people through the pre-planning process, understanding what supports and service options that are available to them, what supports are considered reasonable and necessary, feeling confident to ask for a review of their plan if they are not happy and ensuring their plans do not simply replicate their current inadequate supports. Rather than reducing the need for independent advocacy, the processes used in delivering the NDIS have highlighted the need for strong independent relationships and support through advocacy that will ensure that people with disability do exercise choice and control and have their needs met. (SUFU, sub. PP242, p. 5)

> The evidence of this investigation [of the effectiveness of statutory oversight mechanisms in the reporting and investigating of allegations of abuse in the disability sector in Victoria] strongly suggests that the role of advocacy will need to be strengthened further with the introduction of the NDIS … Without a strategy to embed the role of advocacy, a market-based model appears inaccessible for a large sector of people with diminished capacity to make informed decisions. It is not viable for advocacy to take a secondary position in the safeguards framework. I consider advocacy to be key in a framework for Victorian people with disability who have no prospect of becoming empowered consumers and have no family or friends to voice their best interests. (Victorian Ombudsman 2015, pp. 89–90)

> Advocacy is one of the most important safeguards in protecting and upholding the rights of people with a disability … For the NDIS to deliver on the promise we made to people with a

disability — greater choice and control, we need to make sure they have the tools to enforce their rights. (Foley 2017)

All governments should continue funding disability advocacy …

Funding for most advocacy activities is shared between the Australian[86] and State and Territory Governments (except for South Australia) (DSS 2016e, p. 2). While the Commission recommended that State and Territory Governments should continue funding disability advocacy groups (PC 2011, pp. 523–5), most State and Territory Governments will reduce or cease funding advocacy services in accordance with Bilateral Agreements on the transition of the scheme (as it is considered to be a State specialist disability service (NSWFACS 2016)). The exception is the Victorian Government (2017a, pp. 263–4), which has committed funding for disability advocacy for 2017-18, and stated that it is 'committed to strengthening the disability advocacy sector' (Foley 2016, p. 2).

Although some jurisdictions intend to withdraw funding, there is still some uncertainty about what advocacy funding should be, and who should pay for it. This is reflected in recent amendments to the DRC's terms of reference to include a review of advocacy arrangements, including roles and responsibilities, by 31 October 2017 (DRC 2017c, p. 3).

In August 2017, the DSS completed its review of the NDAP (DSS 2017g), which considered what an updated NDAP should look like, and how it should work (including funding) in a NDIS environment (DSS 2016e, p. 2). The Australian Government announced that it will provide disability advocacy funding of $60 million over the three years to 30 June 2020 for:

- disability advocacy services under the NDAP
- NDIS Appeals providers
- disability representative organisations (disability peak bodies) (Porter and Prentice 2017).

As disability advocacy funding will be reduced by most States and Territories, disability advocacy organisations will need to rely more heavily on other sources of funding to continue their operations. These include public contributions (such as volunteering and donations), Australian Government funding, ILC funding or a combination of these sources.

For people with disability inside the NDIS, this outcome is at odds with the DRC's agreement and the Commission's 2011 recommendation. For people with disability outside the scheme — including those seeking to enter the NDIS as new participants — an unintended consequence will be service gaps and potentially poorer user outcomes. While there are intangible benefits from disability advocacy, the reduction or absence of advocacy

[86] NDAP agencies based in the NDIS sites may have additional roles, such as assisting people through the planning and internal review processes with the NDIA. Australian Government funding has been provided via the NDIS Appeals program to support people with disability who seek an external review of the NDIA's decisions through the Administrative Appeals Tribunal (DSS 2017c).

can impose real costs on the wellbeing of people with disability, their families and the broader community.

Although it is appropriate for disability advocacy funding to be withdrawn for *some* participants (to avoid overlap with NDIS supports), it remains the case that many participants and people with disability who are ineligible for the scheme need and would benefit from advocacy services (Daly, Barrett and Williams 2017, pp. 11–2; DARU 2017b, pp. 14–5; Porter and Prentice 2017). Funding for advocacy services for people with disability should continue both during and after the transition to the NDIS, just like funding for most other mainstream services (chapter 6). As noted by the Disability Advocacy Resource Unit (2017b, p. 7), while there is likely to be an increase in demand for advocacy in the short term, there will be continued demand for advocacy in the long term.

… but disability advocacy should still be funded outside of the NDIS

Just as NDIS funding arrangements reflect the different incentives faced by the Australian, State and Territory Governments (chapter 12), care must also be exercised in deciding how disability advocacy should be funded to avoid cost-shifting. If advocacy is funded solely by the Australian Government, then there may be pressure to help participants access services that are funded by the States and Territories. But if advocacy is funded solely by the States and Territories, there may be pressure to help participants to enter the NDIS and use services funded by the Australian Government.

The previous practice — where the Australian, State and Territory Governments all contributed to disability advocacy funding — is appropriate to address this concern. It also reflects the fact that advocates help people with disability to prevent and resolve issues in all government services, and the interface between these services. This approach is also consistent with the joint commitment made by all governments to the National Disability Strategy, and by extension, to all people with disability.

It is appropriate that disability advocacy funding remains separate from the NDIS for a number of reasons.

- All scheme participants initially come from outside of the scheme, and some participants will need advocates after they enter or exit the scheme.
- People with disability outside the scheme need and are major users of advocacy services.
- All people with disability benefit from advocates who advance systematic issues on their behalf and seek to improve the system.
- There is a conflict of interest if the NDIS funds the same organisations whose role it is to challenge the system. Separating funding from the NDIS would ensure the independence of advocates, which is central to their effectiveness in helping people with disability.

What should funding for disability advocacy be?

Limited evidence on the benefits and costs of disability advocacy makes it difficult to determine the appropriate level of funding for advocacy (box 10.6). The benefits of disability advocacy are difficult to quantify — although there are many examples and anecdotes that it leads to better outcomes for people with disability. The costs of disability advocacy funding by governments are also often reported in an aggregated manner that makes it difficult to separate specific funding from other services.

Without good cost-benefit analysis, but recognising that disability advocacy funding needs to continue in the short term, the Commission examined the advocacy funding arrangements in two different jurisdictions, and applied them nationally on a per capita basis (table 10.1). The approaches considered were:

- the Victorian Government's funding of disability advocacy under the Victorian Disability Advocacy Program. This program receives about $3 million each year for 24 disability advocacy organisations and has an annual target of 1700 users (Victorian Government 2017a, pp. 263–264; sub. PP298, p. 7). In 2016-17, the program was supplemented with the $1.5 million Victorian Disability Advocacy Innovation Fund, which was allocated to 15 disability advocacy organisations and designed to help people with disability access an advocate when they need it (Foley 2017; VDHS 2017)
- the Australian Government's commitment to fund disability advocacy by about $20 million per year on average until 2020. In 2016-17, about $17.7 million was provided under the NDAP to 58 advocacy agencies across Australia, with about 12 000 people with disability receiving individual support (DSS 2017g, p. 3).

Based on funding in these jurisdictions, total disability advocacy funding would be between $31.7 million and $40.0 million per year between 2017-18 to 2019-20.

The Commission considers that, at this stage, State and Territory Government funding should at least match the per capita contribution of the Australian Government. This would mean total funding of about $40 million each year between 2017-18 and 2019-20, and ensure continuity of advocacy services for people with disability, including scheme participants.

Over the next few years, policy-relevant data on disability advocacy will need to be collected to inform how future funding arrangements should be determined. The Commission recommends that in particular, services provided by advocates funded under the NDAP or by State and Territory Governments to people with disability should be recorded, and where possible, linked with other NDIA data to build an appropriate evidence base. The DSS should then use this evidence for future reviews of disability advocacy funding to ensure that funding levels reflect the costs and benefits of such services. Governments also need to clarify future funding arrangements in a timely manner to reduce uncertainty for both users and advocacy organisations.

Box 10.6 Quantifying the costs and benefits of disability advocacy

While many study participants provided useful anecdotes about the benefits of disability advocacy, more rigorous and systematic analysis of the costs *and* benefits of disability advocacy is needed to better determine the appropriate amount of advocacy funding by governments, and how funding should be used to maximise its efficiency and effectiveness. Cost-benefit analysis may also help to identify potential areas for improvement and reform in the disability system.

However, there is a lack of cost-benefit analysis on disability advocacy. A 2009 report prepared for the Department of Families, Housing, Community Services and Indigenous Affairs on the models of advocacy funded under the NDAP lamented about the lack of accurate and comparable cost and outcome data (particularly for individual advocacy), and in turn, the lack of evaluation of advocacy programs (Jenny Pearson and Associates 2009, p. vii). This is still true today.

- The DSS, in their review of the NDAP, noted that systemic advocacy is funded inconsistently across jurisdictions by NDAP because of a lack of data and reporting. Many stakeholders to that review recommended greater data collection and reporting to improve the advocacy evidence base and coordination on systemic issues (DSS 2017g, p. 22).
- The Victorian Government Office for Disability Advocacy Program also collects quarterly data on disability advocacy (DARU 2017a, 2017b, p. 4). However, the Disability Advocacy Resource Unit (2017a) noted that this data may have some measurement issues (including under-reporting, misreporting, data gaps and difficulties in interpretation), and made a number of recommendations to improve the integrity of the data.
- There are a lack of publicly available, disaggregated data on expenditure on disability advocacy. For example, expenditure data on advocacy is in the same category as information and print disability services, even though they are different to advocacy services (SCRGSP 2016b, tables 15A.7 and 15A.8)).

A recent cost-benefit analysis on advocacy has helped to shed some light on its value to the community. In a study commissioned by the Disability Advocacy Network of Australia, Daly, Barrett and Williams (2017) estimated that disability advocacy funding of $232 million would provide net benefits of about $600 million to Australia (in net present value) for the ten years from 2017 to 2026 (or about $60 million per year). (While the analysis made some generous assumptions, including large cost reductions in the justice system and creation of employment due to advocacy, the overall conclusion that disability advocacy provides a net benefit to the community is still valid.)

Table 10.1 **Benchmark estimates of proposed disability advocacy funding ($ million)[a]**

Annual funding for the period 2017-18 to 2019-20

	NSW	*Vic*	*Qld*	*SA*	*WA*	*Tas*	*NT*	*ACT*	*Aus Gov*[b]	***Total***
Benchmarked to the Victorian Government's funding of $3m per year	3.7	3.0	2.4	0.8	1.3	0.2	0.1	0.2	20.0	**31.7**
Benchmarked to the Australian Government's funding of $20m per year	6.4	5.1	4.0	1.4	2.2	0.4	0.2	0.3	20.0	**40.0**

[a] These estimates are based on taking the contribution made by a particular jurisdiction to disability advocacy funding and applying it on a per capita basis to all other jurisdictions. It assumes an equal split of disability advocacy funding between the Australian and State and Territory Governments — a proportion that is consistent with the split of historical advocacy, information and print disability funding under the National Disability Agreement (SCRGSP 2016b, table 15A.8). [b] This assumes that the Australian Government's contribution is fixed at $20m per year, reflecting the recent funding announcement.

Sources: Commission estimates based on ABS (*Demographic Statistics*, Australia, December 2016, Cat. No. 3101; *Population Projections*, Australia, November 2013, Cat. No. 3222); DSS (2017g, p. 3); Victorian Government (sub. PP298, p. 7); and Porter and Prentice (2017).

RECOMMENDATION 10.4

The Australian, State and Territory Governments should continue to fund disability advocacy organisations. State and Territory Governments should fund disability advocacy to 2019-20 by an amount that at least matches the per capita contribution of disability advocacy funding announced by the Australian Government.

The Australian, State and Territory Governments should also collect data from funded disability advocacy organisations about people with disability who use their services, and their outcomes. This data should be in a format that can be linked with data held by the National Disability Insurance Agency, and be made publicly available. The Department of Social Services should undertake an independent evaluation of advocacy funding at the beginning of 2020 to inform future funding arrangements, and thereafter periodically evaluate disability advocacy. These reports should be made public.

Supporting the outcomes from disability support organisations

Other organisations, which identify themselves as disability support organisations (DSOs), assist scheme participants to engage with the scheme and the community. In 2011, the Commission used the term to describe the support that these organisations provided to people using NDIS services — including brokering, managing administration, mentoring and planning — and to distinguish their role from that of traditional specialist service providers (PC 2011, pp. 101, 414–22).

As the scheme has evolved, so too has the definition of DSOs. It is now used in a range of different contexts, including:

- peer connection — in 2014, the Australian Government's Sector Development Fund funded 18 DSOs to facilitate up to 20 peer support groups over the life of the project (NDIA 2015b, p. 80)
- advocacy and helping prospective participants
- information sharing and community connection
- intermediary roles (for example, Plan Management Partners, sub. PP324)
- participant capacity building roles.

The term DSO is less relevant than the *supports* they provide to people with disability and the outcomes they achieve. The Commission's recommendations in this report — if implemented — should provide adequate resources for the roles of DSOs and reduce the burden on them.

- Improvements to the planning process (including LACs engaging in pre-planning) (recommendations 5.2 and 5.3) will enable participants to receive their reasonable and necessary supports.
- Properly resourced ILC is an avenue for DSOs to connect people with disability to the community (recommendation 6.1).
- Properly funded disability advocacy will provide additional support for participants to navigate the NDIS (recommendation 10.4).
- Allocating support coordination in plans based on need will help participants to build the skills they need to exercise choice and control, and ensure that they get the NDIS-funded supports they are entitled to (recommendation 10.1).
- Making available accessible information to participants about providers, reflecting the objectives of the eMarketPlace, will help participants access the supports that they need (recommendation 10.2).
- Trialling volunteer organisations to provide supports creates a means to preserve social capital and allow greater choice for participants (recommendation 9.4).
- Clarifying the role of intermediaries (and therefore making them easier to access) will help reduce the administrative and search costs faced by participants (recommendation 10.3).

These recommendations are, in the Commission's view, sufficient to enable DSOs to do their important work supporting people with disability, including scheme participants. Should the Commission's recommendations not be implemented, then Governments and the NDIA will need to consider increasing funding via other channels to ensure that participants — both actual and potential — are appropriately supported.

10.3 Market stewardship

Market readiness issues reflect poor market stewardship

As discussed in chapters 7–9, and in this chapter, there are substantial challenges developing the market supply of disability supports. While some progress is being made, there are still difficulties growing the significant number of providers and the disability care workforce required, as well as helping participants to become informed and effective consumers (figure 10.2). This is occurring at a time when the rapid pace of the rollout — and growth in demand for supports — is at its greatest. Based on experience to date, there will be a shortage of disability supports under the scheme in the short to medium term.

Many of these challenges could have been — and should have been — anticipated and acted upon earlier. This highlights the need for more effective market stewardship by governments (including the NDIA). As the Agency said:

> Market stewardship recognises that when governments implement policies to increase consumer choice and adopt market-based delivery, they must also oversee how the marketplace develops. (2017e, p. 8)

And just as providers, workers and participants need to change their approach to disability supports, so too must governments.

FINDING 10.1

The supply of disability supports in the short to medium term will not be able to meet participant demand resulting from the National Disability Insurance Scheme. This is due to a combination of factors, including rapid intake of the scheme, difficulties faced by participants to navigate the new markets for disability supports, difficulties by providers to adjust quickly to a new market-based model of service delivery, and underdeveloped market stewardship.

Figure 10.2 **The challenges confronting NDIS markets are symptoms of a greater need for better market stewardship**

Key issue	Provider readiness: Price Signals	Provider readiness: Non-Price Signals	Workforce readiness	Participant readiness
Responsible stakeholders	Price regulator (currently NDIA)	Provision of market information (NDIA)	Coordination of workforce development activities by Governments, DSS and NDIA	Assistance in plans (NDIA)
Main current actions	McKinsey & Company price review initiated by the NDIA	Changes arising from the NDIA provider pathway review	Sector Development Fund Workforce action plan developed by DSS	Changes arising from the NDIA participant pathway review
Commission recommends	Principles-based pricing Independent price monitor and regulator (NDIS Quality and Safeguards Commission)	NDIA to release more frequent and granular data on participant demand NDIA to make public its Provider of Last Resort policy and Market Intervention Framework	Better coordination between governments, providers and the NDIA to develop the workforce Appropriate data collection Trialling use of volunteers	Implement objectives of the eMarketPlace Clarifying the supports that help participants Encouraging use of intermediaries Continue funding disability advocacy

All of the market readiness issues suggest that market stewardship needs improvement

Clarify and make public the roles and responsibilities for each party
Require transparent and regular reporting against outcomes
Collect and make public disaggregated, tailored and forward-looking market data
Coordinate market stewardship actions across all sectors

What is market stewardship and the role of governments?

To facilitate the significant market growth required, governments need to change their approach to the design, oversight, management and regulation of the market for disability supports. More effective government stewardship of the market is required than previously to create and manage the NDIS market.

Government stewardship involves governments taking steps in the design, delivery and improvement of services to ensure that services meet objectives (PC 2017b). The aim of stewardship is usually to protect equity — to ensure the individual wellbeing of users and to maximise community welfare. In the NDIS, the objective of government stewardship is to ensure that participants can access reasonable and necessary supports from the market, and ultimately have greater choice and control over their lives.

To date, many of the challenges of government stewardship are in the design of the scheme — such as planning (chapter 5), funding arrangements (chapter 12), and the interface between the NDIS and mainstream services (chapter 6) — which often need coordination and cooperation by multiple governments. As a result, the Australian, State and Territory Governments are NDIS government stewards.

An additional and unique challenge for the NDIS is the need for market stewardship — a specific form of government stewardship. Aimed at facilitating the creation and development of a market, it is often required as part of structural reforms, particularly when governments have previously been large service providers (such as in the disability support sector). Market stewardship can require active intervention to not only protect participants, but also to support the functioning and sustainability of markets so that it benefits all participants (Carey et al. 2017, p. 3). This includes promoting innovation, the diffusion of best practice and higher standards of services to people with disability.

In the NDIS, market stewardship means facilitating the timely creation and development of the disability support market, and ensuring that it develops in a way that meets the objectives of the scheme. As discussed in chapters 7–10, the challenge is to facilitate a substantial increase in the number of disability support providers and workers to meet participant demand, and to ensure that participants have the skills and supports they need to navigate the market. The NDIA has the designated role of market steward. The Agency described its goals as being:

> … to create an efficient and sustainable marketplace through a diverse and competitive range of suppliers who are able to meet the structural changes created by a consumer driven market. More specifically this involves:
>
> - enabling existing and emerging suppliers to mature at an appropriate and sustainable rate;
> - providing an environment for innovation in planning and delivery of supports; and,
> - building strong business integrity systems and processes and capability. (2016i, p. 4)

To achieve these goals over the transition period, the NDIA's market stewardship activities have focused on the delivery of disability services, which include:

- regulation — such as price setting and provider registration (chapter 8)
- models of service provision — including government commissioning or provision of services in thin markets, and under provider of last resort arrangements (chapter 7)
- information provision to the market — particularly to participants and providers
- managing transitions and implementation — including the withdrawal of government service provision (chapter 7).

This reflects the continuum of NDIS market intervention options available to the NDIA to develop and correct the NDIS marketplace, which range from 'light touch' to highly interventionist actions (NDIA 2016i, p. 23).

Market oversight is also needed to protect participants

Market stewardship also requires complementary market oversight. Market oversight is a forward-looking task which involves prudential supervision of the system (including the practices and financial performance of providers), identifying systemic risks and, where possible, taking mitigating action. This may require mandatory performance reporting from providers, the acceptance of complaints, and investigation powers. Doing so would enable monitoring and evaluation of any trends in the quality or cost of services, although this may be difficult given the decentralisation of services in the NDIS. It would also ensure that market stewardship responses are proportionate to the risks.

In the NDIS, market oversight is particularly important to regulate the quality of services and to safeguard the rights of people with disability. The Senate Community Affairs References Committee (2015) found that violence, abuse and neglect of people with disability is widespread, and recommended stronger independent oversight mechanisms. Currently, the DSS (sub. 146, p. 34) is responsible for market oversight, and reports on the effectiveness of the NDIS market, including market trends and outcome quality. Under proposed legislation, the core functions of the NDIS Quality and Safeguards Commissioner will include NDIS market oversight and consumer protection. This will include monitoring changes in the NDIS market which may indicate emerging risk, as well as monitoring and mitigating the risks of provider failure and unplanned service withdrawal (s. 181E(i), National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017 (Cwlth)).

Under the NDIS, particularly during the transition phase, governments need to help participants exercise choice and control over their supports and lives, and to improve their wellbeing. This is an ongoing responsibility. They can do this by not only directly helping participants navigate the NDIS and the market, but also by actively facilitating the market supply of disability supports — to ensure that there are diverse and competitive markets for participants. Regardless of the approach taken, the ultimate focus of market stewardship

should be consistent with the person-centred approach of the scheme — to enable people with disability to achieve their goals and live better lives.

How can market stewardship be improved?

The market readiness issues to date highlight the need for more effective and holistic market stewardship than at present. As noted by the UK Institute for Government, effective market stewardship requires governments to:

- clarify roles, responsibilities and accountability arrangements
- be more considered, open and flexible in design
- focus on competition, market structure and market dynamics
- increase transparency (Gash et al. 2013, p. 6).

Clarify responsibilities and coordinate responses

Clearly defined market stewardship roles and responsibilities promote transparency and accountability of market development responsibilities.

Although the NDIA is designated as the market steward, *all* governments take actions that affect market outcomes, and so have some responsibility for market stewardship. All governments have a duty to participants to actively facilitate the supply of disability supports, particularly as there are multiple and diverse local markets that differ by jurisdiction. Without the cooperation of other market stewards, the NDIA's efforts to develop the market are unlikely to be effective or efficient.

To date, responses from jurisdictions have varied and their effectiveness is unclear. Some are spending additional money to support participants (and providers), while others are relying more heavily on the market to provide services. While some of the variation in responses reflect specific jurisdictional differences (including the rollout timetable), some of this variation also highlights the uncertainties around the roles and responsibilities of governments under the NDIS. In practice, this has led to gaps, duplication and shifting of responsibilities, and lack of accountability. This poses a risk to the scheme and to the wellbeing of participants and their families.

It is possible for governments to work together in the interests of participants. Host jurisdictions are likely to provide services in monitoring the overall integrity and effectiveness of the national NDIS Quality and Safeguarding Framework. For example, worker screening and approval of restrictive practices[87] by providers will continue to be managed through current State and Territory government processes (DSS 2016d, p. 17).

87 Restrictive practices are any intervention that has the effect of restricting the rights or freedom of movement of a person with disability, with the primary purpose of protecting the person or others from harm. They include the use of seclusion and consequence driven practices, as well as chemical, mechanical, physical, psycho-social and environmental restraints (DSS 2016d, pp. 66–67).

The DRC should set a clearer, more specific and practical delineation of market stewardship roles, individual and joint responsibilities, as well as accountability arrangements of the Australian, State and Territory Governments ('accountability maps'). Where Governments, their agencies and/or the NDIA are responsible for a market stewardship task, there should be clear and transparent reporting about specific actions and outcomes (including the costs, benefits and risks of any actions), timeframes and progress towards goals.

While clarifying responsibilities is important, there should also be more effective cooperation and coordination between the Australian and State and Territory Governments, particularly with other care sectors (such as aged care and health) and mainstream services (such as employment, education and transport). This is important as participants need to access both NDIS and mainstream services. Collaboration may also allow NDIS market stewards to draw on the lessons from other sectors with similar market development issues and/or consumer-directed reforms (such as aged care).

Evidence and risk-based market intervention

A strong risk-based focus on the market supply of disability supports is essential (balanced against the costs and benefits of any proposed market intervention). Under the previous arrangements, governments that provided or commissioned services faced the risk of non-delivery of services by providers — with little or no risks borne by providers and people with disability. The NDIS market-based approach to services means that there are now new and emerging risks to participants and providers, not just governments. Risk-based market stewardship is needed to maximise the net benefits of the NDIS market-based approach, while minimising the associated risks to participants, providers and the broader community. For example, risk-based regulation requires the identification, analysis and treatment of risks; development of contingency plans; and monitoring and evaluation of outcomes (VCEC 2015).

However, to date, market stewards have not given market supply issues sufficient and timely attention. This may be partly due to ambiguity about who is responsible for market development, what market stewardship entails, why it is needed, and lack of capacity or impartiality of governments to undertake market stewardship functions. As such, 'the system for identifying and addressing emerging issues is currently informal and unfixed in the NDIS implementation' (Carey et al. 2017, p. 14).

Effective market stewardship needs to be forward-looking, transparent and evidence-based. In practice, market stewardship efforts in the NDIS are hampered by limited and fragmented information and data on the disability support market. Interventions should be subject to rigorous evaluation and be sufficiently flexible to help stewards to adapt to unpredictable market developments. The Tasmanian Government remarked that:

> … better NDIA market data would assist providers to respond on likely participant demand. The Tasmanian Government has been calling for greater market analysis for some time …

> Performance indicators for the NDIS market will be critical tools for monitoring readiness and anticipating supply shortages and provider failure. (sub. PP247, p. 8)

At the same time, market stewards need to engage in open and iterative engagement with providers, workers, participants and the broader community. For example, provider engagement could inform:

- system, program and service design (effectiveness and efficiency)
- market intelligence (current and emerging activity, trends, forecasts etc)
- market sustainability (organisational trends etc)
- participant needs (assessment and planning, person centred practices)
- innovation (new ideas, new ways of doing things) (Community Services Industry Alliance, sub. PP251, p. 4).

This information would also inform research, benchmarking, monitoring, evaluation and quality assurance. A more bottom-up approach (as opposed to the current top-down approach) would facilitate local responsiveness and flexibility.

The Commission recommends the collection and publication of more timely, disaggregated, tailored and forward-looking market data by the Australian, State and Territory Governments, in conjunction with the NDIA and the NDIS Quality and Safeguards Commission, to support market oversight and stewardship. This includes qualitative information and feedback from liaison with market participants. Better information would enable greater flexibility, evaluation and refinement of risk-based market stewardship responses.

The way forward

In the transition period, market stewardship is critical to the wellbeing of participants and their families. Now, more than ever, there must be more investment in market stewardship. The Commission has made a range of recommendations (relating to pricing, providers, workers and participants) in this regard. However, these specific recommendations are a symptom of, and do not exhaustively define, the structural problems in current market stewardship arrangements. Market stewardship more generally could be improved by clarifying responsibilities for market stewardship, collection of more specific market data, and more effective government collaboration.

Market stewardship is a dynamic role that will evolve over time as the scheme is rolled out. While it is difficult to be certain about the future pathway of market stewardship, what *is* certain is that *ongoing* market stewardship will be needed. Market stewardship must receive ongoing and consistent priority by governments and their agencies, be forward-looking, flexible and adaptive to changing circumstances. This is essential to support an effective NDIS market, the scheme's sustainability, and the lives of participants and their families.

RECOMMENDATION 10.5

The COAG Disability Reform Council should immediately clarify and make public the roles and responsibilities of the Australian, State and Territory Governments with respect to market stewardship (those actions required to define and support the effective functioning of sustainable and enduring markets for participants and providers). This should include clear and transparent reporting of the specific actions and outcomes they are to achieve (including costs, benefits and risks), timeframes and progress towards goals.

The Australian, State and Territory Governments should:

- with the National Disability Insurance Agency and the National Disability Insurance Scheme Quality and Safeguards Commission, collect and make publicly available disaggregated, tailored and forward-looking market data, including provider and workforce data on supply gaps
- coordinate their market stewardship actions across all sectors, particularly with other care sectors and mainstream services.

11 Governance

Key points

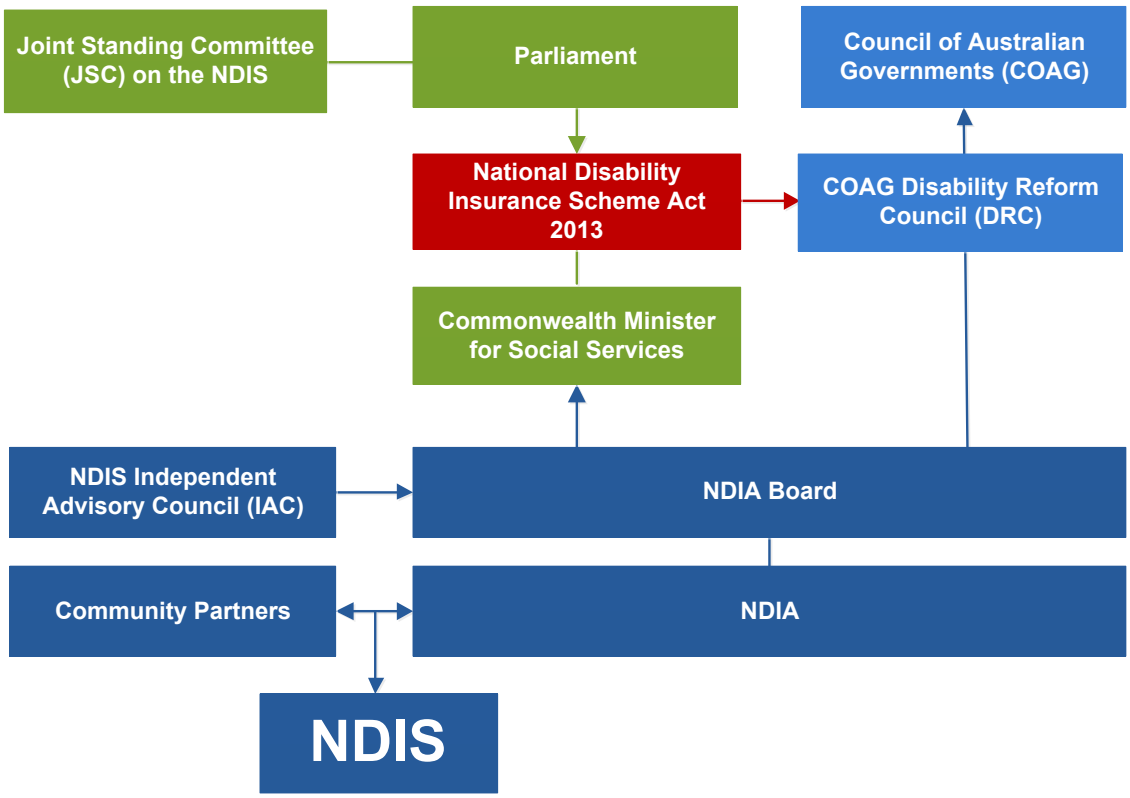
- The governance arrangements for the National Disability Insurance Scheme (NDIS) provide a good foundation for delivering the scheme. However, improvements can be made.
- More clarity should be provided around some roles and responsibilities, including Local Area Coordinators, mainstream services and market stewardship.
- The process for agreeing to Category A NDIS Rules should continue to require unanimous agreement from all jurisdictions, but changes are needed to allow for faster response times where emerging issues threaten the scheme's financial sustainability.
- The National Disability Insurance Agency (NDIA) should be given autonomy to independently manage the NDIS as an insurance scheme. The NDIA's operating cost target should be changed and the Australian Government should remove the cap on staff directly employed by the NDIA.
- Internal review processes have the potential to increase scheme costs and poor planning processes can increase the number of reviews. External review outcomes could also significantly affect scheme costs. The NDIA should publicly report on internal and external review processes.
- The timeframe to implement the NDIS Quality and Safeguarding Framework is ambitious. However, it needs to be met to ensure quality and safety for scheme participants, and to provide clarity and reduce the regulatory burden on providers. Regulation and quality assurance arrangements should be continually monitored and refined as needed.
- While the Western Australian NDIS is meant to mirror the national scheme in many respects, there is a risk that the governance arrangements could lead to a divergence in participant outcomes. There are also costs associated with setting up parallel schemes. Western Australia should be part of the national scheme.
- Current NDIS performance reporting does not have a sufficient focus on plan quality. Reporting on quality needs to be developed as a priority. Reporting on scheme participants' outcomes and attainment of participants' goals also requires further development.
- The focus of governments and the NDIA on participant intake, at the expense of quality and participant outcomes, has compromised the success of the scheme. The NDIA should better balance participant intake, the quality of plans and participant outcomes.
- The Australian, State and Territory Governments should immediately start planning for a changed participant intake timetable for the rollout of the NDIS. In doing so, they need to ensure that continuity of support arrangements are in place and assess whether additional resources are required for the scheme to meet its objectives.

This chapter examines the National Disability Insurance Scheme (NDIS) governance arrangements in the context of scheme costs and financial sustainability. Section 11.1 provides an overview of the governance arrangements. Sections 11.2 to 11.8 discuss issues with the current governance arrangements including: clarity and transparency around roles, responsibilities and processes; the NDIS Rules; the National Disability Insurance Agency's (NDIA's) structure and governance; the Western Australian NDIS; review processes; regulation; and performance reporting arrangements. Section 11.9 discusses the timetable for the scheme rollout.

11.1 Overview of governance arrangements

The NDIS is established under the *National Disability Insurance Scheme Act 2013* (Cwlth) (NDIS Act) (figure 11.1). The NDIS Act sets out (among other things) the objectives of the NDIS, eligibility, how plans are prepared and reviewed, the governance arrangements for the NDIA, and internal and external review processes. The Act is supported by the NDIS Rules, which are legislative instruments that provide more detail on the operation of the NDIS.

Figure 11.1 **Summary of the NDIS governance arrangements**



Source: Adapted from NDIA (2016b, p. 127).

The Australian, State and Territory Governments share governance responsibility for the NDIS. The COAG Disability Reform Council (DRC) is responsible for NDIS policy and broader disability policy. Its members include the Ministers responsible for disability policy, the Treasury portfolio from each Australian, State and Territory Government, and a representative from the Australian Local Government Association (DSS 2017a).

The Australian Government Minister for Social Services is responsible for administering the NDIS Act. However, many of the Minister's responsibilities require agreement from, or consultation with, State and Territory Governments prior to being undertaken. The Minister's functions include making NDIS Rules and appointing Board and Independent Advisory Council members. The Minister can also issue directions to the NDIA about the performance of its functions (NDIA 2016b, 2017i; NDIS Act).

In addition to their governance role through the DRC, State and Territory Governments are responsible for regulating providers until the *NDIS Quality and Safeguarding Framework* is implemented (DSS 2016d, p. 17).

The NDIA is responsible for managing and delivering the NDIS. It is an Australian Government agency established under the NDIS Act and the *Public Governance, Performance and Accountability Act 2013* (Cwlth) (PGPA Act) (NDIA 2017i; NDIS Act, s. 117). Its main functions include:

- delivering the NDIS to support the independence and social and economic participation of people with disability, and enabling them to exercise choice and control in the pursuit of their goals
- managing, advising and reporting on the financial sustainability of the NDIS
- facilitating innovation, research and best practice in the disability sector
- building community awareness of disabilities
- collecting, analysing and exchanging data on people with disability, and the supports provided to them
- undertaking research relating to disabilities (NDIA 2017ab; NDIS Act, s. 118).

The NDIA is governed by a Board, which is responsible for setting the strategic direction of the NDIA, managing risks and monitoring and reporting on the Agency's performance (NDIA 2017w). The Board is advised by the Independent Advisory Council (IAC). The IAC is a panel of experts including people with disability, carers of people with disability, at least one person with expertise on disability in rural or remote areas, and at least one person with expertise in the supply of equipment or provision of disability services. The IAC can provide advice to the Board about the way in which the Agency administers the NDIS and helps to meet the objectives of the NDIS Act. The IAC can provide advice either on its own initiative or at the written request of the Board (NDIA 2017j).

A Parliamentary Joint Standing Committee on the National Disability Insurance Scheme was established in 2013 to review the implementation, administration, performance, governance

and expenditure of the NDIS, and other NDIS-related matters referred to it by parliament (JSCNDIS 2017b; NDIA 2016b, p. 131). To date, the Committee has provided two progress reports on the implementation and administration of the NDIS, a progress report on general issues around implementation and performance, an interim report on the provision of hearing services under the NDIS and completed an inquiry into services for people with psychosocial disabilities related to a mental health condition.

Different arrangements for Western Australia

Western Australia has different governance arrangements for the NDIS to the rest of Australia. While it is intended to provide similar supports to the national scheme, the Western Australian NDIS (WA NDIS) is:

- administered by the Western Australian Government, not the NDIA
- funded differently (chapter 12)
- being rolled out one year later than the national scheme (2017-18) (box 11.1).

Box 11.1 The NDIS in Western Australia

In January 2017, the Western Australian and Australian Governments signed a Bilateral Agreement for the implementation of the WA NDIS. Under this agreement, Western Australia will have a locally administered scheme, but the scheme is to be consistent with the national NDIS. The WA NDIS began rollout on 1 July 2017 (one year later than the national scheme).

Unlike the national scheme, the WA NDIS will be managed by the State Government under State legislation. A WA NDIS authority will be established to manage the scheme which, similar to the NDIA, will have a Board and Independent Advisory Committee.

The intention is that the WA NDIS will be consistent with the national scheme in a number of areas, including:

- eligibility requirements
- the core principles, including access to reasonable and necessary supports, choice and control and guaranteed portability
- the application of the National Quality and Safeguarding Framework
- the complaints and appeals process, which will mirror the national process including access to the Administrative Appeals Tribunal
- reporting requirements, including the requirement to report quarterly to the DRC
- other governance arrangements, including relevant Rules under the NDIS Act
- contributions to policy at the national level by the Western Australian Government.

Sources: Australian Government and Western Australian Government (2017); WADSC (2017).

Are the current governance arrangements effective?

The high-level governance arrangements for the NDIS mostly reflect those recommended by the Commission in its 2011 inquiry on *Disability Care and Support*, and provide a solid foundation for delivering the scheme and managing financial sustainability.

One difference is the Australian Government minister responsible for the NDIS. In 2011, the Commission recommended that the Australian Government Treasurer be the responsible Minister for the NDIS because of the proposed commercial focus of the NDIA, and the need to ensure strong cost controls, insurance characteristics, long-run sustainability and appropriate management of funds (PC 2011, p. 432). The Commission envisaged other ministers, such as the Minister for Social Services, playing a prominent role in disability policy.

However, instead, the Australian Government Minister for Social Services has primary responsibility for the NDIS. There is a risk that the intention that the scheme be firmly based on insurance principles will be less evident by placing it in a department that deals with welfare programs.

The following sections discuss areas of concern about the governance arrangements.

11.2 Lack of clarity around roles and responsibilities

While the high-level governance arrangements for the scheme are clearly set out in the NDIS Act, the Heads of Agreements, the Bilateral Agreements and other policy documents, there is a lack of clarity in practice around roles and responsibilities. For example, there is a lot of confusion about the role of Local Area Coordinators (LACs). DARE Disability Support said:

> DARE's understanding of the role initially envisaged for the LACs, namely frontline problem solving and assistance with plan implementation, appeared to change shortly before transition to planning and the Coordination of Supports for non-complex participants, surely a foreseeable gap in NDIS planning resources. (sub. 182, p. 7)

The confusion is probably, in part, because the NDIA experimented with different delivery models for LACs before settling on the current outsourced model (NDIA, sub. 161, p. 4), and because LACs were diverted away from their intended activities towards planning-related tasks. As the NDIA said:

> The need to meet bilateral estimates has also meant that for the first period of transition the NDIA has asked LAC partners to divert their resources into information gathering to facilitate the approval of plans and implementation of plans. (sub. 161, p. 56)

There is also a lack of clarity around the responsibilities of the NDIS and mainstream services, and how governments are approaching continuity of support (chapter 6). As noted by the Department of Social Services (DSS):

> The Council of Australian Governments (COAG) agreed principles to determine the responsibilities of the NDIS and mainstream service systems, which are generally sound, but need clarifying at an operational level. (sub. 146, p. 4)

The Commission is recommending that the Australian, State and Territory Governments make their approach to continuity of care, and the services they intend to provide, public and that a standing agenda item be added to the agenda of the relevant COAG Councils to address how mainstream services interface with the NDIS (chapter 6).

Other areas in need of greater clarity include supply side arrangements, including the roles and responsibilities of Australian, State and Territory Governments around market stewardship (recommendation 10.5).

Given the scale and complexity of the scheme, and the focus on insurance principles — which involves ongoing monitoring and refining of the scheme — some uncertainty and changes to roles, responsibilities and processes is inevitable, especially while the scheme is in transition. However, it is crucial that governments and the NDIA continue to work to ensure clarity and transparency in the governance arrangements so they do not undermine accountability and put the success of the scheme at risk.

11.3 NDIS Rules

The NDIS Rules are legislative instruments that provide more detail than the NDIS Act on the operation of the NDIS (NDIA 2017m). The Australian, State and Territory Governments are jointly responsible for the NDIS Rules. There are four categories of NDIS Rules (box 11.2). The Minister for Social Services has overarching responsibility for making Rules, and each Category requires a different level of involvement or agreement from State and Territory Governments. The Minister can also delegate the power to make Rules to the CEO of the NDIA, with the agreement of State and Territory Governments (NDIS Act, s. 201). NDIS Rules are disallowable instruments which means they are tabled in Parliament and open to Parliamentary veto or disallowance for fifteen sitting days. If a motion is brought to disallow an instrument, Parliament has an additional fifteen sitting days to vote on or withdraw the motion (Parliament of Australia 2017).

Most of the Rules currently in force are either Category A or Category B Rules. Category A Rules cover most of the sections of the NDIS Act, including (but not limited to) extra guidelines and information on disability and early intervention requirements, what must be included in plans, and the statement of participants' supports. Category A Rules require unanimous agreement from the Australian Government and each State and Territory Government (NDIS Act, s. 209).

Box 11.2 Categories of NDIS Rules

There are four main categories of NDIS Rules.

- Category A — The Australian Government and each host jurisdiction must agree to the Rule.
- Category B — The Australian Government and the specific host jurisdiction that the Rule relates to must agree to the Rule.
- Category C — The Australian Government and a majority of host jurisdictions must agree to the Rule.
- Category D — Each host jurisdiction must be consulted on the Rule (NDIS Act, s. 209).

In addition, under sections 125B and 180C of the NDIS Act, the Minister responsible for the *Insurance Act 1973* (Cwlth) can make Rules related to the management of risk and the Scheme Actuary's duties.

Most of the current NDIS Rules are either Category A Rules (requiring unanimous agreement) or Category B Rules (requiring agreement between the Australian Government and the relevant host jurisdiction).

Category A Rules

The current Category A Rules cover areas such as:

- rules to assist in determining who can become a participant, including extra details about age, residence and early intervention requirements (*National Disability Insurance Scheme (Becoming a Participant) Rules 2016* (Cwlth))
- requirements in determining representatives for children, and what that child's representative must comply with (*National Disability Insurance Scheme (Children) Rules 2013* (Cwlth))
- nominees, including their appointment, duties and cancellation and suspension (*National Disability Insurance Scheme (Nominees) Rules 2013* (Cwlth))
- how supports in a participant's plan should be specified and how to assess whether it would pose an unreasonable risk for a participant to manage their own plan (*National Disability Insurance Scheme (Plan Management) Rules 2013* (Cwlth))
- criteria for approving registered providers of supports and requirements registered providers of supports must comply with (*National Disability Insurance Scheme (Registered Providers of Supports) Rules 2013* (Cwlth))
- funding of Specialist Disability Accommodation (*National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2016* (Cwlth)).

Category B Rules

Category B Rules are jurisdiction-specific Rules. They generally relate to the schedules for phasing participants into the scheme (such as the Rules regarding the preparation of participant plans), or the specific State and Territory laws that prevent a person providing certain information to the NDIA (*National Disability Insurance Scheme (Protection and Disclosure of Information) Rules 2013* (Cwlth)).

Are the arrangements for NDIS Rules affecting scheme costs?

Some concerns were raised by study participants about the governance arrangements for Rule changes. Both the NDIA and the DSS pointed to the length of time it can take to introduce or amend NDIS Rules.

> The process for amendment of the NDIS Rules requires agreement from a majority or all (depending on the rules) of the States and Territories. Recent experience of seeking amendments to rules is that the process takes considerable time. (NDIA, sub. 161, pp. 48–49)

> This has proved cumbersome and complicated for most rules and other actions, such as making appointments and issuing directions, requiring unanimous agreement by the Commonwealth and the States. This can delay the timely sign-off of amendments, and can potentially impact timely direction being provided to the NDIA. (DSS, sub. 146, p. 32)

The NDIA and the DSS both raised the example of the *National Disability Insurance Scheme (Specialist Disability Accommodation) Rules 2016* (Cwlth) (Category A Rules), which required unanimous agreement from the Australian, State and Territory Governments. According to the DSS (sub. 146, p. 32), it took about 10 months to implement these Rules. The NDIA (sub. PP327, p. 58) also argued it 'experienced similar implementation times with the Registered Providers of Support Amendment Rules and the NSW Prescribed Program Rules'. In a transition period of three years, such timeframes could pose significant operational difficulties for the NDIA.

That said, the South Australian Government (sub. PP354, p. 12) argued that 'while agreement of the [Specialist Disability Accommodation] Rules took time, the final product much better addresses critical issues for states and territories'. The Tasmanian Government also said that, to date, the majority of Category A Rules have been agreed to in a timely manner.

> Despite the one example cited in the PC's position paper, the majority of Category A Rules, covering complex, detailed and technical matters, including how the scheme interacts with state and territory systems, have been developed and agreed by jurisdictions in a highly collaborative and timely manner. (sub. PP247, p. 10)

Can the arrangements be improved?

Some study participants called for changes to the way Rules are made, to make implementation and amendments more responsive and timely. One option supported by some study participants was to relax the requirement that Category A Rules have unanimous agreement from the Australian, State and Territory Governments (for example, AFDO, sub. PP325, p. 10; New South Wales Government, sub. PP230, p. 9). The Victorian Government noted:

> Victoria supports governance arrangements that are as responsive and streamlined as possible. Victoria supports relaxing the requirement of unanimous agreement of all jurisdictions to change some Category A NDIS Rules … to either require majority agreement or, in some cases, consultation. (sub. PP298, p. 21)

However, not all study participants were supportive of this approach. For example, the Tasmanian Government argued that the requirement for unanimous agreement reflects the fact that Category A Rules influence the boundaries of the scheme and, therefore, state and territories' non-NDIS disability and mainstream service provision.

> … NDIS design features such as eligibility and scope of supports have direct and indirect consequences for, and costs to, state systems. It is therefore appropriate that these features, established through the NDIS Category A Rules under the NDIS Act, remain subject to the agreement of all host jurisdictions. The Tasmanian Government does not support any changes to the current Rule-making arrangements with respect to Category A Rules concerning access and reasonable and necessary supports. (sub. PP247, p. 10)

Similarly, the Northern Territory Government said:

> The NT Government recognises the Commonwealth and NDIA's frustration regarding the delay in gaining authorisation from all jurisdictions to make amendments or introduce rule changes to the NDIS. However there is an inherent risk to states and territories relaxing unanimous agreement around rule changes. (sub. PP359, p. 6)

Some non-government study participants also argued against change. For example, Legal Aid NSW said it:

> … acknowledges concerns around delay in changes to the NDIS Rules, but is not supportive of relaxing the requirement for unanimous agreement from the Australian Government and all host jurisdictions. We see this requirement as an important safeguard. If all host jurisdictions were not required to agree to changes, we see a risk that the Commonwealth would make changes to the Rules to contain costs. (sub. PP245, p. 14)

Victoria Legal Aid also cautioned against providing any person (including the NDIA CEO) the power to bypass the usual process for implementing or amending Rules.

> We urge caution in giving the NDIA CEO, or any other person, the power to alter or bypass the process for amending Rules made under section 209 of the NDIS Act. The Rules are the key tool for decision making under the scheme and the process for their amendments reflect the significant impact any changes will have for participants, State Governments and service providers. … In our view it is a key priority to ensure consultation and proper consideration of the impact of changes with potentially wide ramifications for participants of the scheme before they are implemented. (sub. PP367, pp. 3–4)

Another option is to change the process for agreeing to NDIS Rules without relaxing the requirement for unanimous agreement. Some States and Territories were supportive of changing the process to improve its speed. The South Australian Government (sub. PP354, p. 12) stated it is 'open to considering changes that enhance the agility of Scheme governance'. The Northern Territory Government also said:

> … an alternative may be to develop nationally agreed key principles to provide overarching guidance to the consideration of rule changes when they occur. For example, one of the principles could include minimum timeframes for jurisdictions to respond to proposed new rules or changes. (sub. PP359, p. 6)

Risks could be reduced by more timely agreement on Rules

Governance arrangements need to be sufficiently flexible so that the NDIA and governments can respond quickly when circumstances arise that could threaten the financial sustainability of the scheme. Implementing or changing Rules can be a lengthy process, especially as they are subject to the disallowance process. However, changes to the process for agreeing to Category A Rules can be made to help ensure they are implemented in a timely manner.

While relaxing the requirement for unanimous agreement, such as to majority agreement, could decrease the time it takes to implement Rules, there are problems with this approach. Category A Rules cover much of the Act, and the current Category A Rules influence the boundaries of the scheme. For example, the National Disability Insurance Scheme (Becoming a Participant) Rules 2016 (Cwlth) include detail on the processes used to determine eligibility. As the NDIS Rules can influence who becomes a scheme participant, they can also influence who does not become a participant and therefore may need to rely on mainstream or specialist disability support services provided by State and Territory Governments. Many scheme participants will also need to access mainstream and disability service support provided by State and Territory Governments.

The involvement of State and Territory Governments in disability and mainstream service support exposes them to considerable risk and they should therefore continue to have a say over the design and boundaries of the NDIS. Given the State and Territory Governments' considerable experience in disability service provision, they are also likely to have valuable knowledge and expertise for designing and refining the scheme.

The Commission does not recommend that the requirement for agreeing to Category A NDIS Rules be changed from unanimous agreement. Instead, the process should be changed to encourage timely agreement to Rules without diluting the control of States and Territories. This could be done, for example, by requiring governments to state whether they agree or disagree to a proposed rule introduction or change within a certain amount of time. No response could be taken as agreement to the proposal.

RECOMMENDATION 11.1

The *National Disability Insurance Scheme Act 2013* (Cwlth) should be amended to change the process for agreeing to Category A Rules to reduce the time it takes to implement or amend those rules.

The amendment should not change the requirement that there be unanimous agreement among the Australian Government and the host jurisdictions for implementing or amending Category A Rules.

11.4 Structure and governance of the NDIA

It is essential that the NDIA has the correct governance model and appropriate level of independence so that is can effectively manage the NDIS in line with insurance principles.

In 2011, the Commission assessed different options for the NDIA's governance model (PC 2011) and found that the most appropriate model was a corporate governance model, independent from day-to-day government operations with clear accountability and reporting requirements. To achieve this model, the Commission recommended that:

- the NDIA be established as an independent Commonwealth statutory agency (now called a corporate Commonwealth entity) under the *Commonwealth Authorities and Companies Act 1997* (Cwlth) (no longer in force but now covered by the PGPA Act)
- the NDIA be overseen by a skills-based board, chosen by an appointment panel established jointly by the Australian, State and Territory Governments. The Board would have the sole power to appoint and dismiss the CEO
- the Australian, State and Territory Governments establish an advisory council to advise the Board
- the NDIA be provided with its own legislation that specifies its objectives, functions and governance arrangements, and future changes to key features of the scheme should be undertaken only by explicit changes to the Act, in consultation with all State and Territory Governments
- the arrangements between the NDIA and governments be at arm's length, and subject to strict transparency requirements (PC 2011).

The current governance arrangements of the NDIA (as outlined in section 11.1) largely reflect what was recommended in 2011. The NDIA is a corporate Commonwealth entity (box 11.3) under the PGPA Act. And while, under the NDIS Act, the Minister was responsible for appointing the first CEO (in consultation with State and Territory Governments), the NDIA Board is responsible for appointing or dismissing all subsequent CEOs (NDIS Act, s. 160).

The NDIA's high-level structure and level of independence is similar to the corporate structures of the Transport Accident Commission in Victoria and Insurance and Care New South Wales (*State Insurance and Care Governance Act 2015* (NSW); *Transport Accident Act 1986* (Vic)).[88]

There is, however, one key difference in the structure of the NDIA compared with what was envisioned by the Commission in 2011. When discussing the need for the NDIA to be a Commonwealth statutory authority (corporate Commonwealth entity), in 2011, the Commission noted that this type of agency 'would generally not engage staff under the

[88] Insurance and Care New South Wales was established in 2015 to administer the New South Wales Government compensation, insurance and care schemes. It includes the Lifetime Care and Support Scheme (icare 2017).

Public Service Act unless there were good reasons to do so' (PC 2011, p. 423). The NDIA engages its staff under the *Public Service Act 1999* (Cwlth) (NDIS Act, s. 169).

Box 11.3 Governance structures for Commonwealth bodies

The three main types of Commonwealth bodies are non-corporate Commonwealth entities, Corporate Commonwealth entities and Commonwealth companies. The financial and governance arrangements of these different bodies are set out in the PGPA Act and PGPA Rules, the *Corporations Act 2001* (Cwlth), entity-specific legislation or administrative arrangements.

Non-corporate Commonwealth entities

Non-corporate Commonwealth entities are legally and financially part of the Commonwealth. Entities are usually established as a non-corporate Commonwealth entity if they need direct accountability to the Parliament, will be primarily budget funded, need to be subject to Australian Government policies, will raise money or perform regulatory activities under Commonwealth law, or if they need to be classified as part of the general government sector. Government departments are an example of non-corporate Commonwealth entities.

Corporate Commonwealth entities

Corporate Commonwealth entities are separate legal entities from the Commonwealth. They can exercise certain legal rights such as entering into contracts and owning property. Entities might be established as corporate Commonwealth entities if:

- they will operate commercially or entrepreneurially;
- a multi-member accountable authority (such as a board of directors) is needed;
- it would be best that its assets are not owned or controlled by the Commonwealth directly;
- it requires a degree of independence from general Australian Government policies and executive government direction.

Corporate and non-corporate Commonwealth entities are generally subject to the same planning, performance and accountability requirements under the PGPA Act. However, corporate Commonwealth entities may have different provisions, such as those relating to banking, borrowing, and investments. Corporate Commonwealth entities also often have their own legislation that sets out its powers and can impose additional governance, reporting and accountability requirements. Examples of corporate Commonwealth entities include the Reserve Bank of Australia and the CSIRO.

Commonwealth companies

Commonwealth companies are bodies established under the Corporations Act that are controlled by the Commonwealth. An entity will generally be established as a Commonwealth company if two or more of the following apply: it will primarily conduct commercial or entrepreneurial activities and will generate profits for distribution to its members; it will operate in a commercial or competitive environment; or it is likely to be sold off by the Commonwealth in the short to medium term. Examples of Commonwealth companies include the NBN Co and the Australian Rail Track Corporation.

Sources: Department of Finance (2017a, 2017b, 2017c); PGPA Act.

Retention of the NDIA's independence is critical

While governments are responsible for determining the scope of the NDIS and its high-level funding, the NDIA should be given the independence to operate the scheme on a day-to-day basis. Some study participants highlighted the importance of, and raised some concerns about, the NDIA's level of independence (CYDA, sub. 188; National Disability and Carer Alliance, sub. PP344). For example:

> Victoria supports clarifying governance and accountability arrangements so as to provide the NDIA with the operational autonomy that was originally envisaged … The NDIA needs to be properly resourced and operate with sufficient authority so that it can implement the NDIS on the basis of robust insurance principles. (Victorian Government, sub. PP298, p. 21)

> It is also important that NDIA retain its status as an independent statutory authority. The independence of the agency responsible for administering the scheme was one of the key issues during the campaign for the introduction of the NDIS. An independent agency with its own board (including board members with disability) helps to ensure the vision of the scheme is realised and it is not subject to the changing priorities of successive governments. It is also important that the independence of the agency's decision making is not compromised or undermined by interference in day to day operational issues. Structural and systemic issues lie with the governments who work in partnership to deliver the scheme — day to day operational issues should lie with the NDIA. And the NDIA should be held to account by its own board and COAG should they fail to administer the scheme efficiently and effectively. (AFDO, sub. PP325, p. 24)

In addition, Bruce Bonyhady (sub. PP333, p. 20) raised concerns about the Australian Government's control over the NDIA, and the NDIA (sub. 161, p. 108) argued for some changes to the administrative and governance arrangements including greater flexibility to use funding allocated to package costs and greater protection for the role of the NDIA's Operational Guidelines in managing scheme costs.

The Commission identified two aspects of the governance arrangements that could hinder the NDIA's ability to effectively and independently operate the scheme — the cap on its operating costs and staffing-related concerns. (The level of independence regarding funding arrangements is discussed in chapter 12.)

Beyond these, the Commission received insufficient evidence to conclude that any significant changes to governance arrangements are required to ensure the NDIA has enough independence to undertake its functions. The high-level governance structure appears to provide the NDIA with sufficient independence from day-to-day government control. It is nevertheless important that, as the scheme develops, there are no structural barriers to the NDIA exerting an appropriate level of independence and developing a culture conducive to running the scheme in line with insurance principles. The governance of the NDIA and NDIS should be considered as part of the five-yearly reviews into NDIS costs.

The NDIA's capped operating costs

At full scheme, the NDIA's operating costs will be capped at 7 per cent of package costs each year (NDIA, sub. 161, p. 110). The 7 per cent operating cost target is similar to that estimated by the Commission in 2011 (PC 2011, pp. 776–7).

The rationale for capping the operating expenses of the NDIA appears to be to encourage administrative efficiencies. The DSS (sub. 146, p. 24) commented that the 7 per cent cap was 'an aspirational approach designed to encourage best practice and efficient operations'.

However, capping operating expenses could have perverse outcomes in practice. As noted in the NDIA's Annual Financial Sustainability Report, the risks to the scheme's financial sustainability from the setting of operating expense budgets are asymmetric:

> It is worth noting that a 10% increase in the operating budget may result in additional expenditure of approximately $150 million at full scheme, however an increase in package costs of 10% could result in an additional $2 billion at full scheme. (NDIA 2016a, p. 56)

In addition, if the NDIA's operating budget is set too tightly, this could hinder its ability to implement upfront investments, such as in LACs, assessors and planners, which could in turn have a significant effect on package costs and scheme sustainability.

Operating costs made up about 33 per cent of scheme costs in June 2016 (NDIA 2016b, p. 109). To achieve a 7 per cent target by full scheme, the NDIA will need to cut operating expenditure by about 18 per cent ($250 million) between 2018-19 and 2019-20 (box 11.4).

While similar types of schemes operate close to a 7 per cent average when they are close to maturity, they still have significant fluctuations in their annual operating expenses as a proportion of their overall expenses (box 11.4).

A number of study participants argued that the 7 per cent cap at full scheme is too low (for example, AFDO, sub. PP325, p. 24; ABF, sub. 48, p. 15; PDCN, sub. 29, p. 4; Sotica, sub. 67, p. 9). The Victorian Government also said that there are risks to holding the NDIA to a specific operating cost target:

> The NDIA has been set an operating cost target of 7 per cent of total scheme costs at full scheme. Given that the major risk to total scheme costs is package costs, which comprise around 90 per cent of total costs, it would be a mistake to hold the NDIA to an operating cost target if capping administrative costs threatened increases in package costs due to inadequate quality control or oversight. (sub. PP298, p. 10)

While the Commission understands the need to create incentives for administrative efficiencies, a hard cap for operating expenses enforced year in, year out does not align with the way an insurance scheme operates. Greater flexibility (including setting an operating budget that sits within a funding range) would allow investments in administrative functions to be made that reduce lifetime costs (for instance, investing in LACs early to increase participant capacity and readiness which could lower costs in the long term).

Box 11.4 Operating expenses of the NDIA and comparable schemes

The NDIA's operating expense ratio is projected to decrease to less than 7 per cent at full scheme.

NDIS expenses by category ($ millions)[a]

	2015-16 (actual)	*2016-17 (actual)*	*2017-18 (projections)*	*2018-19 (projections)*	*2019-20 (projections)*	*2020-21 (projections)*
Package costs	859.9	2 973.0	8 045.1	14 267.1	17 855.8	19 165.5
Information, Linkages and Capacity Building program	10.7	33.3	68.9	105.3	119.3	118.6
Operating expenses	301.2	704.9	1 033.0	1 393.9	1 143.9	1 096.2
Total scheme costs	1 171.7	3 711.2	9 147.0	15 766.2	19 119.1	20 380.3
Operating expense ratio (%)[b]	35.0	23.7	12.8	9.8	6.4	5.7

[a] Excludes Western Australia. [b] The expense ratios differ from NDIA targets and estimates because the NDIA and the DSS use different projections of scheme costs.

Comparable schemes, such as the New Zealand Accident Compensation Commission and the Victorian Transport Accident Commission have operating expense ratios close to a 7 per cent average, but they have significant fluctuations in their annual operating expense ratios.

Operating expense ratios of comparable schemes (per cent)[a]

	2010-11	*2011-12*	*2012-13*	*2013-14*	*2014-15*	*2015-16*	*Average*[b]
NZ Accident Compensation Corporation	14.34	6.0	22.9	11.2	7.4	4.9	8.3
NSW Lifetime Care and Support[c]	2.7	3.6	3.6	3.7	4.0	8.4	3.3
VIC Transport Accident Commission	8.5	4.6	11.7	7.4	6.0	4.8	6.4
Disability services nationwide[d]	7.6	7.4	6.6	6.5	6.2	6.4	6.8

[a] The ratio of average operating expenses between 2010-11 to 2015-16 to the average total expenses over the same period. [b] The average is calculated as the ratio of the average of operating and total expenses over time. [c] New South Wales Lifetime Care and Support changed its reporting methodology in 2015-16, and therefore, this number may not be comparable with previous years and has been excluded from the calculation of the average operating expense ratio. [d] Data for 2013-14 to 2015-16 are affected by the introduction of the NDIS.

Sources: ACC (2012, 2013, 2014, 2015, 2016); Australian Treasury (2016, 2017d); icare (2016a); LCAS (2012, 2013, 2014, 2015); SCRGSP (2017); TAC (2012, 2013, 2014, 2015, 2016).

One way to balance flexibility with accountability would be to allow a target range for operating expenses, with the expectation that the NDIA would sit at the bottom of this target on average. This would allow the NDIA some flexibility to smooth out year-to-year fluctuations in spending while also placing some limits on administrative spending. A number of study participants were supportive of this approach (for example, AFDO, sub. PP325, p. 11; PDA, sub. PP306, p. 5; Tasmanian Government, sub. PP247, p. 11; VALID, sub. PP332, p. 11; Victorian Government, sub. PP298, p. 10).

Based on similar types of schemes, a target of 7 to 10 per cent appears to be reasonable. The NDIA agreed:

> Providing expenditure flexibility at Full Scheme, within a range of 7 percent to 10 percent of package costs would allow the NDIA to make appropriate upfront investments, consistent with insurance principles. The investments would seek to optimise overall Scheme experience and participant outcomes, while reducing future Scheme outlays. (sub. PP327, p. 65)

Should the NDIA exceed the funding target in a particular year, it should be required to publicly report the reasons why. The NDIA (sub. PP327, p. 65) regarded a requirement to report on why the target had not been met as appropriate.

RECOMMENDATION 11.2

At full scheme, the annual operating budget for the National Disability Insurance Agency should be set within a funding target of 7–10 per cent of package costs with the expectation that, on average, it would sit at the lower end of the band.

The National Disability Insurance Agency should be required, in its annual report, to state the reasons why it has not met this target in any given year.

NDIA staff cap

The NDIA, like most Australian Government agencies, is currently subject to a staff cap, which sat at 1749 in 2016-17 (NDIA, sub. PP327, p. 65). At full scheme it will have a cap of 3000 directly employed staff (DSS, sub. 146, p. 24). It is expected that the NDIA will require a workforce of about 10 000 people to deliver the NDIS at full scheme, which means that about 7000 people will be outsourced to partner organisations (DSS, sub. 146, p. 24; NDIA, sub. 161, p. 63).

The rationale for the cap on directly employed staff appears to be to encourage the NDIA to enter into community partnerships. While it is important that the NDIA works collaboratively with the community to deliver the scheme, it could also lead to poorer outcomes. For example, the NDIA outsourcing a lot of its work can present a particular risk when the agency is so new and needs to build institutional expertise and capability (NDIA, sub. PP327, p. 66). This is especially the case in light of the problems with the planning process (chapter 5).

Independent agencies, such as corporate Commonwealth entities (and state-based equivalents), are usually given the autonomy to independently run their organisations. Similar non-Commonwealth organisations, such as the Transport Accident Commission, also generally do not have staff caps.

The Commission recommends that the Australian Government remove the cap on directly employed staff. This is on the basis that the NDIA is best placed to determine the most

effective and efficient staff mix to deliver the scheme, within the constraints of its capped operating budget.

Reconsidering the staff cap on directly employed staff was supported by some study participants (for example, ABF, sub. PP263; CPSU, sub. PP310, p. 5; PWSAA, sub. PP228, p. 9; Queensland Government, sub. PP345, p. 26; South Australian Government, sub. PP354, p. 13; Tasmanian Government, sub. PP247, p. 11; Victorian Healthcare Association, sub. PP337, p. 4). The Victorian Government said:

> The NDIA should also have more flexibility over its staffing arrangements … This would enable it to rely less on secondments from the Commonwealth Department of Social Services, which risk compromising the NDIA's operational autonomy and may lead it to take an overly welfare-based approach. (sub. PP298, p. 2)

The NDIA (sub. PP327, pp. 65–66) also said that the staff cap might constrain its ability to adopt new service delivery models that could arise from the participant and provider pathway reviews.

In contrast, JFA Purple Orange (sub. PP350, p. 27) did not support reconsidering the staff cap, arguing instead that the NDIA should make greater use of the community sector. The Commission considers there is scope for the NDIA to make greater use of the community sector's expertise, but this can be achieved through other means.

RECOMMENDATION 11.3

The Australian Government should remove the cap on staff employed directly by the National Disability Insurance Agency.

Employment of NDIA staff

As discussed above, the NDIA employs staff under the Public Service Act. This reduces the NDIA's independence in making staffing decisions, particularly around salary and conditions. It could also affect the 'cultural independence' of the Agency and contribute to a perception that it is more of a government agency rather than an independent insurance scheme. As of 1 July 2017, about 65 per cent of corporate Commonwealth entities did not employ staff under the Public Service Act (Department of Finance 2017b).

However, the Commission did not receive any evidence that this staffing arrangement has affected, or is affecting, the NDIA's independence or culture (or scheme costs or participant outcomes). But, as the scheme and the NDIA develop over time, the appropriateness of employing NDIA staff under the Public Service Act should be reassessed.

11.5 Western Australian NDIS

As noted above, Western Australia has not signed up to the national scheme. This section looks at whether the governance arrangements for the WA NDIS will affect financial sustainability. The funding arrangements are discussed in more detail in chapter 12.

Will two schemes affect financial sustainability?

In 2011, the Commission recommended a single national scheme, and a single national agency, to provide disability care and support across the country (PC 2011, pp. 424, 448). There are costs involved in implementing two systems. There is the cost of two sets of legislation — the NDIS Act and the proposed Western Australian legislation. There are also additional costs associated with setting up a separate agency in Western Australia to administer the WA NDIS (in addition to setting up the NDIA), and any associated loss of economies of scale that could ensue from having a single agency. Having two agencies could also mean that it takes longer for lessons learned from the national scheme to be adopted in Western Australia and vice versa.

There could, however, be benefits to Western Australia having its own scheme. For example, a WA NDIS could allow increased flexibility and an ability to quickly adapt to changing Western Australian conditions. While the scheme is intended to mirror the national scheme in many aspects, including most parts of the NDIS Act and the NDIS Rules, the fact that the NDIA has its own detailed operational guidelines for its functions suggests that mirroring the legislation allows for significant flexibility. This flexibility could lead to a divergence in the supports provided to scheme participants and participant outcomes between Western Australia and the rest of Australia.

There were two trials of the NDIS in Western Australia — one managed by the NDIA and the other by the Western Australian Government. There are two reviews that compared the trials in Western Australia.

- One review identified key features for an effective disability support model for Western Australia, and made a number of recommendations to address gaps in processes. It found that the Western Australian-managed trial required fewer changes in policy and processes to achieve an effective model than the NDIA-managed trial (Stantons International 2016).[89]
- The WA NDIS and the NDIS Actuaries also undertook an assessment of the two Western Australian trials. The results of the evaluation are not public.

[89] The limitations of this review should be noted. It compared and contrasted the processes related to plan preparation, activation, operation and review. It did not compare actual outcomes of participants in the two trials — this was not feasible due to the timing of the review — nor did it compare the costs of the different approaches (Stantons International 2016).

Many study participants supported Western Australia joining the national scheme, with their key concern being that inequities in disability support across jurisdictions could emerge if they remain outside the scheme (box 11.5).

Box 11.5 Many study participants supported WA joining the national scheme

Down Syndrome Australia:

> Down Syndrome Australia, as a federation of state and territory Down syndrome organisations, has advocated strongly for WA to be part of the national scheme. DSA is very concerned that people with Down syndrome in WA will not get an equitable level of support, nor the choice and control nor long-term certainty of the national scheme. (sub. 121, p. 20)

Disabled People's Organisations Australia:

> DPO Australia is very concerned about the decision by the previous Western Australian Government to establish its own NDIS. Despite a number of nationally consistent provisions in the bilateral agreement, it is concerning that the WA NDIS will have different funding arrangements and accountabilities and a greater focus on service provider control. This is highly likely to prevent market growth and innovation for people with disability in WA and create inequities in the provision of specialist disability support in WA. (sub. 165, p. 10)

Matt Burrows:

> Without WA signed up to a national Scheme, the entire Scheme is at risk. The entire Scheme is not sustainable as a *national* reform unless all States and Territories are signed up to it. (sub. 7, p. 4)

Community Mental Health Australia:

> The announcement that Western Australia (WA) would be implementing its own state-based system has immediately created a situation where there will not be a nationally consistent scheme … (sub. 11, pp. 1–2)

Queensland Advocacy Incorporated:

> [Western Australia's agreement with the Australian Government] undermines that nationally consistent approach and increases state and territory variation. (sub. 115, p. 18)

Department of Social Services:

> DSS agrees with the Commission's recommendation that WA should join the NDIA-delivered NDIS to ensure national consistency and sustainability … DSS is providing all information requested to support the WA government to make a decision about the NDIS, and is committed to working with WA to ensure that Western Australians have influence over how the NDIS is delivered in their State. (sub. PP318, p. 20)

However, some study participants said there would be benefits in Western Australia having its own scheme. For example, National Disability Services said:

> NDS supports disability service providers in WA who want a nationally consistent NDIS that provides local accountability and that recognises and respects local needs and conditions and the complexities of delivering services in regional, rural and remote areas. WA providers have little confidence that an Agency based in Geelong will be sufficiently responsive to local issues in WA. They would prefer a well-resourced and skilled agency based in WA believing that it would be best-placed to deliver and oversee the transition to the NDIS in that State. (sub. PP295, p. 10)

In April 2017, it was reported that the Western Australian Government was undertaking a review of the decision to implement the WA NDIS and that joining the national scheme was still an option (Emerson, Wearne and Carporn 2017). The outcome of this review had not been reported publicly at the time this report was finalised. Study participants were concerned about the uncertainty this situation created, and highlighted the importance of this decision being publicly communicated as soon as possible.

> WALGA supports that a decision should be made soon as this additional layer of uncertainty further complicates Local Government's current position and stalls any decision making process. Without a decision, clarity around government's roles and responsibilities makes planning difficult and moving forward to serve communities and individuals very limited. (WALGA, sub. PP320, p. 8)

> We agree that any decision on the future scheme to be embedded in Western Australia should be made public as soon as possible. (Activ, sub. PP302, p. 12)

> The ongoing arrangements for the NDIS in Western Australian should be finalised as soon as possible to remove uncertainty for people with disability, their families and carers and providers. (NDS, sub. PP295, p. 10)

Under the Bilateral Agreement between the Western Australian and Australian Governments, there are to be regular reviews of the state legislation, the first occurring two years after the commencement of the WA NDIS (Australian Government and Western Australian Government 2017). While the terms of reference for these reviews are yet to be agreed, they will include the extent to which the WA NDIS is achieving consistency with the agreed provisions in the NDIS Act. If the WA NDIS is to proceed as agreed under the Bilateral Agreement, these reviews will be important for ensuring consistency between the two schemes, and that people with disability in Western Australia are not disadvantaged by not being part of the national scheme.

It is still the Commission's view that there should be a national scheme and Western Australia should be in the NDIS. There are benefits of having a national scheme (as identified in the Commission's 2011 inquiry) and there are additional costs with two schemes. Where there is evidence that different processes in the Western Australian-managed trial have resulted in better outcomes for participants than under the national scheme, these processes should be considered for the national scheme. Regardless of whether Western Australia joins the national scheme or not, it is essential that the outcome of the review and any decisions be made public as soon as possible, to minimise uncertainty for scheme participants, providers and other governments.

RECOMMENDATION 11.4

The Western Australian Government and Australian Government should put in place arrangements for Western Australia to transition to the National Disability Insurance Scheme. Any decision to join the national scheme should be made public as soon as possible.

11.6 Review processes

Processes for resolving disputes are essential to achieving good outcomes and promoting confidence in the scheme. There are two types of *internal review* processes that can be accessed by those dissatisfied with an NDIA decision.

- *An unscheduled plan review* — a scheme participant can request that the NDIA conduct a review of their plan. The NDIA must decide within 14 days whether or not to conduct the review, begin the review within 14 days of that decision, and complete the review as soon as reasonably practicable (NDIS Act, s. 48). (This process is distinct from the periodic plan review discussed in chapter 5.)
- *A review of a decision* — a number of reviewable decisions relating to the NDIA are set out under s. 99 of the NDIS Act, including decisions regarding eligibility, supports provided and registration of providers. When the NDIA makes a reviewable decision, it must give written notice to each person directly affected informing them of the option for review. The person then has three months to request a review and the review must be completed as soon as reasonably practicable (NDIS Act, s. 100).

There are also *external review* processes for resolving disputes. If a person is dissatisfied with the outcome from a review of a decision (not an unscheduled plan review), they can apply to the Administrative Appeals Tribunal (AAT) to undertake a merit review within 28 days of the review decision (or apply for an extension of time). If the entity is dissatisfied with the outcome of the AAT review, they can appeal the decision in the Federal Court, but only if it is a question of law (NDIA 2017aa).[90]

Are the review processes appropriate and effective?

Some study participants argued the review processes are not as appropriate and effective as they could be. First, there is confusion about the two types of internal NDIA reviews. The NDIA said it:

> … is aware that there has been confusion around avenues for reviews of decision[s] (especially given the word 'review' is used in the legislation to refer to two different [processes] in relation to planning). (sub. 161, p. 94)

The Commonwealth Ombudsman also commented:

> … the distinction between an 'internal review' [a review of a decision by the NDIA] and a 'plan review' often seems to be lost on participants and their representatives. This situation was demonstrated in a recent AAT decision, *Bridgland and National Disability Insurance Agency*, where the applicant had sought an internal review and then, remaining dissatisfied, lodged an appeal with the AAT. The Tribunal found that it did not have jurisdiction to review the matter

[90] A question of law can include, for example, whether the AAT denied a person procedural fairness, correctly interpreted or applied the NDIS Act, or applied or identified the correct test. This is also known as a judicial review.

> because the NDIA reviewer had initiated a plan review, resulting in a new plan which attracted internal review rights the applicant had not yet exercised. (sub. 137, p. 12)

This confusion was also noted by EY (2015, p. 70) in its review of the NDIS Act, which recommended that the terminology in the Act be amended to make the distinction between the two types of reviews clearer. The *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017* (Cwlth), which is currently being considered by the Senate Community Affairs Legislation Committee, if passed, would rename plan reviews 'plan reassessments'.

Second, there are concerns about the adequacy of information provided about review options. Down Syndrome Australia (sub. 121, p. 15) said 'it appears that people are not well enough informed about their rights to ask for an internal review within the timeframe'. Scope Australia argued the process is not clear and that the amount of information provided is insufficient:

> … the process for resolving disputes or disagreements is not clear. The Agency rarely provides a contact name for appeals or provides a process by which participants can escalate their concerns. There is only one email address where the information and requests for review can be lodged. This is not customer friendly nor does it encourage participants to best advocate for their rights. (sub. 72, p. 19)

Similarly, Brain Injury SA commented:

> … the information provided to participants about review is unclear and inadequate. There is minimal information about the process and no information about how or where participants can get help with a review. Brain Injury SA delivers presentations to client communities about the support it can provide to participants wanting a review of an NDIA decision and further appeal rights and support. However, NDIA should provide this sort of information to all participants and be consistent about this approach.
>
> Further, Brain Injury SA has received anecdotal evidence from parents and guardians that NDIA has not been informing participants of their right to an internal review or external merits review through the AAT. (sub. 116, p. 10)

Legal Aid NSW also said:

> We have also observed that the right of participants to internal review is not adequately publicised. For instance, in our experience it can be difficult to find information about internal reviews and appeals to the AAT on the NDIA website. It is important that participants are aware of these review and appeal rights so that they can exercise them when necessary. (sub. PP245, p. 9)

Third, study participants expressed frustration about both the overall length and variability of time that reviews take. For example, Brain Injury SA (sub. 116, p. 6) said 'reviews can take between 1 and 8 months'. Others also commented on the delays.

> If people are not satisfied with their plan, they can apply for an internal review of a decision, and if necessary escalate this to the Administrative Appeals Tribunal. However, VCOSS members

> report this process can be confusing and time-consuming, taking months to resolve. (VCOSS, sub. 176, p. 12)
>
> The review process itself is complex and bureaucratic and we have heard of cases where it can take up to 18 months to be completed. Participants who are implementing their second plan are sometimes still waiting for the review of their first plan to be finalized. (Leadership Plus, sub. 128, p. 2)
>
> Although operational guidelines suggest NDIA has 14 days to decide to review a plan, Anglicare Tasmania have examples of cases where reviews have not been resolved for up to seven months. In all cases we have been involved with, timeframes have been very lengthy and involved a huge amount of follow up from families or workers. (Anglicare Tasmania, sub. 145, p. 33)
>
> We are concerned in particular about the length of time that it takes for the NDIA to conduct an internal review. We have clients who have waited five months for an internal review of a 12 month plan. (Legal Aid NSW, sub. PP245, p. 14)

Governments and the NDIA are working to address concerns about review processes. COAG has agreed to implement the recommendation from EY's review of the NDIS Act to review the terminology in the Act to make the distinction between the types of reviews clearer, and to amend the legislation to provide more guidance on the rights of scheme participants to request a review of their plan (COAG 2016, pp. 4–5). The NDIA (sub. 161, p. 94) also said it is working to improve its review processes, including working with the Commonwealth Ombudsman to develop service and process improvements.

It is important that the NDIA continues to improve the transparency, clarity and adequacy of the information it provides about reviews and on the timeliness of its reviews.

Are review processes affecting scheme costs?

Review processes can affect scheme costs in two ways.

- Internal reviews can affect the amount of supports provided or the number of people eligible for the scheme, and thereby affect scheme costs.
- Decisions resulting from external review processes will clarify the eligibility requirements and reasonable and necessary supports, which can impact scheme costs.

In addition, poor planning processes can lead to an increase in the number of reviews being requested (chapter 5). This can be costly for the NDIA and scheme participants, and can divert resources away from other, more valuable activities.

However, while review processes can increase scheme costs, they can also provide benefits when they lead to the reversal of an incorrect decision. Therefore, it does not necessarily follow that reviews that increase scheme costs will also negatively impact financial sustainability and scheme outcomes — they could result in a net benefit.

Some study participants said that a high number of unscheduled plan reviews are being undertaken for certain types of disability. For example, MND Australia stated:

> From June 2016 until January 2017 100% of all Plans for people with MND in NSW and the ACT required review. (sub. 45, p. 7)

The NDIA (2017y, p. 29) reported that, in 2016-17, it conducted 37 020 plan reviews that lasted for 30 days or more. Of these, about 15 per cent were unscheduled. The outcomes of these reviews were not reported, making it difficult to determine whether reviews are increasing costs through changes to plans. That said, the large number of unscheduled plan reviews in a year is a large direct cost itself, and suggests significant scope to improve processes and, therefore, reduce the resources the NDIA dedicates to unscheduled plan reviews.

For internal reviews of decisions, the most recent publicly available data are included in the NDIA's June 2016 quarterly report to the DRC (NDIA 2016p, p. 46). At the end of June 2016, the NDIA had conducted 772 reviews of decisions. Of these:

- 262 related to access decisions and 510 to plan decisions
- about 66 per cent of completed reviews where an outcome was recorded (384 reviews) resulted in the original decision being overturned.

While there is data on the number of internal reviews of decisions and their type, there is no publicly available data on the impact that internal reviews of decisions have had on scheme costs, such as whether they have led to more participants entering the scheme or additional supports included in plans.

There is some publicly available data on external reviews. As at 30 June 2017, there had been 268 external appeals to the AAT, up from 161 as at 31 March 2017 (NDIA 2017y, p. 29). Of the 130 appeals that were resolved by 30 June 2017, 58 per cent confirmed the NDIA's decision, 41 per cent did not confirm the NDIA's decision and 1 per cent were pending. As with the internal reviews of decisions, while participants have successfully appealed many external reviews, it is not clear whether this has led to increased scheme costs.

Two decisions by the AAT were appealed to the Federal Court. The first case, *Mulligan v National Disability Insurance Agency* [2015] FCA 544, was an appeal of an AAT ruling to affirm the NDIA's decision to decline access to the scheme. The Federal Court set aside the AAT's decision and remitted it for another decision by the AAT (NDIA 2017g).

The second case, *McGarrigle v National Disability Insurance Agency* [2017] FCA 308, was an appeal of an AAT decision to affirm the NDIA's decision to partially fund transport to access daily activities (chapter 5). The Federal Court set aside the AAT decision and remitted it for another decision by the AAT. The NDIA appealed this decision (*National Disability Insurance Agency v McGarrigle* [2017] FCAFC 132), but this appeal was dismissed on 21 August 2017.

There is the potential for external review processes to significantly increase costs in the future by expanding eligibility requirements and the scope of supports provided. As the NDIA said:

> Decisions by the AAT (and/or an appeal to the Federal Court) have the potential to vastly increase the scope of both access and reasonable and necessary supports and must be adhered to while in effect, even if the NDIA challenges the decision. (sub. 161, p. 49)

That said, scheme participants need to have access to effective external review processes to ensure that participants have access to the scheme where appropriate and are receiving the right level of support, participant outcomes are being fully realised, and there is trust in the scheme. As noted by Carers Australia Victoria:

> Internal and external reviews are a vital quality safeguard for participants and carers, enabling them to test the lawfulness and merits of NDIA decisions affecting them. Importantly, they also promote transparency in NDIA decision-making. (sub. 131, p. 14)

The NDIA has committed to improving review processes. In addition, the Commission has recommended that a process be implemented for allowing minor amendments or adjustments to plans without triggering a full plan review (recommendation 5.1).

More clarity and transparency around the effectiveness of the review processes and their effect on financial sustainability and outcomes is also required. The NDIA should undertake more detailed public performance reporting on review processes (including on the number of reviews, review timeframes, outcomes of reviews, and participant satisfaction with the review process). This will improve:

- clarity and transparency
- the NDIA's incentive to improve processes
- accountability, making it easier for governments, scheme participants and the community to assess the NDIA's performance in this area.

As argued by Legal Aid NSW:

> Reporting requirements in this area may highlight performance … increase accountability, and prompt system and process improvements at the NDIA. (sub. PP245, p. 14)

Study participants strongly supported the NDIA publicly reporting on review processes.[91] For example, Community Mental Health Australia said:

> CMHA also supports the recommendation that the NDIA publicly report on reviews, including the number of reviews, review timeframes, outcomes of reviews and participant satisfaction with

[91] Study participants who supported the NDIA publicly reporting on review processes included: the ABF (sub. PP263); AEIOU Foundation (sub. PP277); AFDO (sub. PP325); Amaze (sub. PP281); Bruce Bonyhady (sub. PP333); CSSA (sub. PP278); CYDA (sub. PP358); Legal Aid NSW (sub. PP245); Macular Disease Foundation Australia (sub. PP243); Mental Health Australia (sub. PP321); MIFA (sub. PP338); Name withheld (sub. PP237); NDS (sub. PP295); PWSAA (sub. PP228); Queensland Government (sub. PP345); Summer Foundation (sub. PP293); Tasmanian Government (sub. PP247); The Benevolent

> reviews. This has been an issue CMHA has raised significant concerns with … the number of full reviews being triggered and the time being taken for these reviews. CMHA has also raised the need for … indicators other than the number of people receiving plans, including those noted as being suggested by the Commission. (sub. PP270, p. 14)

The NDIA, in its submission to the position paper, said it is working to improve its reporting on reviews:

> The NDIA agrees that it can improve its reporting in this area and has already made progress towards better availability and reporting of the number of unexpected plan reviews. This is being further addressed through the work that is currently underway on improving participant and provider pathways … (sub. PP327, pp. 58–9).

RECOMMENDATION 11.5

The National Disability Insurance Agency should publicly report on the number of unscheduled plan reviews and reviews of decisions, review timeframes, outcomes of reviews and stakeholder satisfaction with the review process.

11.7 Regulation and quality assurance

Regulation and quality assurance arrangements are important for ensuring the quality of the scheme and good outcomes for scheme participants. Currently, the Australian, State and Territory Governments are responsible for regulation and quality assurance in their jurisdictions, and for the programs they fund (Bilateral agreements for the Transition to a National Disability Insurance Scheme, sch. F; DSS 2016d, p. 17). The NDIA also undertakes some regulatory-related responsibilities such as setting NDIS prices and detecting fraud (DSS 2016d; chapter 8).

In December 2016, the DRC endorsed the NDIS Quality and Safeguarding Framework (PMC 2017). Under this framework, nationally consistent regulation and quality assurance processes will be implemented from 1 January 2018 (Australian Treasury 2017b, p. 154). The focus of the framework is on helping scheme participants to exercise choice and control, while ensuring appropriate safeguards are in place.

The Australian Government will be responsible for most of the regulatory functions under the framework, including provider registration, the complaints handling system, serious incident notification, restrictive practice oversight,[92] and investigation and enforcement

Society (sub. PP334); VCOSS (sub. PP264); Victorian Government (sub. PP298); and Women with Disabilities Victoria (sub. PP282).

92 Restrictive practices are 'any intervention that has the effect of restricting the rights or freedom of movement of a person with disability, with the primary purpose of protecting the person or others from harm. They include the use of seclusion, as well as chemical, mechanical and physical restraint' (DSS 2016d, p. 66).

(box 11.6). A number of entities will be established to oversee the Australian Government's regulatory functions including the:

- NDIS Complaints Commissioner, who will be responsible for handling complaints, investigating serious incident notifications and investigating potential breaches of the NDIS code of conduct. The Commissioner will refer complaints to the relevant entity where appropriate, including those about provider standards to the NDIS Registrar
- NDIS Registrar, which will be responsible for registering providers, managing the NDIS practice standards and certification scheme, leading the design and broad policy settings for worker screening, monitoring provider compliance, and monitoring, reviewing and reporting on the effectiveness of the market for supports
- Senior Practitioner, who will be responsible for overseeing approved behaviour support practitioners and providers, providing best practice advice, receiving, reviewing and reporting on providers using restrictive practices, and following up on serious incidents that suggest unmet support needs (DSS 2016d, pp. 16–17).

The State and Territory Governments will be responsible for worker screening and for the authorisation of restrictive practices in their jurisdiction (box 11.6).

The Australian Government also announced that it will establish an NDIS Quality and Safeguards Commission to implement the framework and to undertake some of the Australian Government's regulatory functions listed above, including provider registration and regulation, complaints, reportable incidents, and behaviour support practices (Australian Treasury 2017b, p. 154; DSS, sub. 146, pp. 6–7). The *National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017* (Cwlth), which is currently being considered by the Senate Community Affairs Legislation Committee, if passed, will establish the Commission. However, there is still a lot of work to be done in terms of implementation design and roll out of the arrangements (DSS 2016d).

Do current arrangements pose a risk to the scheme?

Developing an NDIS Quality and Safeguarding Framework is an acknowledgment that the current arrangements will not be satisfactory for full scheme. Study participants raised a number of concerns with the current arrangements, including the:

- requirement for providers to register in each jurisdiction in which it will provide services and the different registration requirements across jurisdictions (ARPA, sub. 28, p. 1; Plan Management Partners, sub. 126, p. 13)
- burden of the registration process on providers (AHPA, sub. 37, p. 5; OTA, sub. 15, p. 6; QAI, sub. 115, p. 16)
- third party verification requirements (APS, sub. 19, p. 2; ARPA, sub. 28, p. 1).

Box 11.6 NDIS Quality and Safeguarding Framework

The NDIS Quality and Safeguarding Framework outlines the national approach to regulation and quality assurance for the NDIS. The DRC endorsed the framework in December 2016. The aim of the framework is to 'help empower and support NDIS participants to exercise choice and control, while ensuring appropriate safeguards are in place, and establishes expectations for providers and their staff to deliver high quality supports' (DSS 2017e, p. 1).

The framework embodies a number of principles.

- Measures within the framework are designed to uphold and respect the human rights of people with disability.
- Developmental measures (measures intended to build capacity) are designed to empower and support people with disability to make informed decisions about providers and supports.
- The framework is designed to ensure that people with disability have the same protection, regardless of where they live in Australia.
- The regulatory requirements for workers and providers are tiered to ensure regulation is proportionate to the level of risk associated with the type of support offered and the needs of the participants supported.
- The framework starts from the presumption that all people with disability have the capacity to make decisions and exercise choice and control.
- The framework streamlines requirements so the system is easier for people with disability to navigate, and red tape is reduced for providers.
- The framework is designed to support the development of an efficient and effective market.

The framework includes a range of measures targeted at individuals, the workforce and providers in three domains — developmental, preventative and corrective.

The Australian, State and Territory Governments will share responsibilities under the framework. The Australian Government will be responsible for provider registration, the complaints handling system, serious incident notification, restrictive practice oversight, and investigation and enforcement. State and Territory Governments will be responsible for worker screening and for the authorisation of restrictive practices in their jurisdiction.

The framework also encompasses a range of other functions including:

- advocacy services, which are funded outside of the NDIS
- systems for detecting fraud and related issues associated with the responsibility for paying providers and verifying that supports have been delivered. These will remain the responsibility of the NDIA
- complaints about the NDIA and Local Area Coordinators, which will be addressed through existing measures
- universal complaints and redress mechanisms, including Fair Trading and professional and industry bodies, which will continue to be available to participants
- anti-discrimination and human rights legislation overseen by the Disability Discrimination and Human Rights Commissioners, which will provide additional avenues for raising a complaint.

The Australian Government has committed $209 million to establish the NDIS Quality and Safeguards Commission to implement the framework.

Sources: Australian Treasury (2017b, p. 154); DSS (2016d, 2017e).

The concerns with the current arrangements highlight the need to implement the new arrangements as soon as possible. It is also important that governments working on the new arrangements take into account current arrangements that could be imposing unnecessary regulatory burdens on providers.

The new framework

There is still a lot of work to be done on the implementation and rollout of the new framework. As a result, the Commission is not in a position to provide detailed commentary on the arrangements. It is also difficult to predict in advance what negative outcomes will arise if the arrangements are not sufficiently robust. That said, the underlying principles used to guide the design of the framework, including the focus on proportionality and the level of risk, are appropriate. Consultation on the framework has also been extensive (DSS 2016d).

But even if the high-level framework and the detailed processes are well-designed, it may not be enough to ensure it is effective. The regulator needs to be sufficiently resourced to undertake its functions. In the 2017-18 Australian Government Budget, $209 million over four years was allocated to establish the NDIS Quality and Safeguards Commission (Australian Treasury 2017b, p. 154).

The NDIS Quality and Safeguarding Framework was only endorsed by the DRC at the end of 2016 which means that the timeframe (like other NDIS timeframes) is ambitious. However, it is imperative that this timeframe be met to ensure quality and safety for scheme participants, and to provide clarity and reduce the regulatory burden for providers. Physical Disability Australia (sub. 38, p. 14) said it is important 'the NDIA develops and implements its national quality framework as a matter of some urgency'.

A timely and robust NDIS Quality and Safeguarding Framework is particularly important given the relative vulnerability of people with disability. As noted in the Framework document (DSS 2016d, p. 7), recent inquiries into abuse of people with disability in institutional settings have found that particular people with disability are at increased risk of violence, abuse and neglect. They include women, people with intellectual or cognitive disability, Aboriginal or Torres Strait Islanders and people from culturally and linguistically diverse backgrounds.

It is also important for safeguarding against less reputable providers entering the new market. In this respect, there may be lessons to be learnt from other reforms that have had significant issues, such as the Vocational Education and Training (VET) reforms (HSU, sub. PP316, p. 4) (box 11.7).

It is also essential that there are safeguards in place to ensure that scheme participants do not engage in fraudulent activity. While the incidence of fraud related to self-managed payments in the United Kingdom and some States and Territories is low, prevention, early detection and control strategies are still critical to maintaining the integrity of self-managed payments (NDIS IAC, sub. 149).

Box 11.7 Vocational Education and Training reforms

In 2009, the Australian Government introduced the VET FEE-HELP scheme. The scheme initially provided income-contingent loans to students undertaking VET courses at institutions that had a credit transfer arrangement with a higher education institution. In 2012, the scheme was expanded and became available to students undertaking courses at other VET providers.

The number of approved providers doubled between 2012 and 2014 and the number of students accessing VET FEE-HELP increased almost fivefold between 2012 and 2015. The increase in the number of students was mainly made up of full-fee paying students enrolled in private training providers and accessing the loans.

While there was more choice for students and more people enrolled in VET, the regulations and safeguards put in place were insufficient and significant quality problems arose. For example, there was no requirement on providers to demonstrate that they were delivering high-quality education. There was also a lack of information on the quality of providers available to students, and some private providers engaged in high-pressure marketing tactics.

Many students signed up for courses that they had little prospect of completing, and if they did, were unlikely to improve their employment outcomes due to their poor quality. Students were also left with large loan debts, and the Australian Government incurred a large fiscal liability.

The criteria for education providers are now tighter and in January 2017, the VET FEE-HELP scheme was replaced with the VET Student Loans scheme. This scheme introduced more stringent access requirements on providers, courses and students, increased monitoring of providers and strengthened compliance and payment conditions.

Sources: Birmingham (2016); Department of Education and Training (2017b); PC (2016).

The Australian National Audit Office and NDIA staff expressed concerns that the scheme lacks sufficient safeguards in the area of self-managed participants (ANAO 2017; Mavromaras, Moskos and Mahuteau 2016, p. 59). There are also questions about whether the NDIS Quality and Safeguarding Framework is appropriate for intermediaries (chapter 10).

Given the significant potential for adverse outcomes for participants, regular monitoring and review of regulation and quality assurance arrangements will be essential to ensure that problems are identified and addressed early. The arrangements should also be independently reviewed periodically once the framework is in place and operating long enough for issues to be identified. There will need to be sufficient systemic data collection so that problems can be identified.

RECOMMENDATION 11.6

The *NDIS Quality and Safeguarding Framework* and associated regulatory arrangements should be examined as part of the first five-yearly review into National Disability Insurance Scheme costs in 2023.

11.8 Performance reporting and monitoring

Performance reporting requirements can influence scheme costs by improving transparency and accountability, and providing the NDIA and governments with additional incentive to effectively manage the scheme. It is especially important that governments and the community have sufficient oversight through an effective performance monitoring mechanism given that the NDIS is projected to cost $22 billion at full scheme (chapter 12), and the NDIA's level of independence from day-to-day government control.

What are the performance reporting requirements?

The NDIA is subject to a number of performance reporting and monitoring mechanisms under both the PGPA Act and the NDIS Act, including the:

- Quarterly Report to the DRC
- Scheme Actuary's monitoring and reporting on the financial sustainability of the scheme, mainly through the Annual Financial Sustainability Report
- Annual Report and Corporate Plan.

The Annual Report and Corporate Plan are standard reporting practices for Commonwealth entities. The Quarterly Report and the Annual Financial Sustainability Report are requirements under the NDIS Act. The scope and effectiveness of the Quarterly Report, and the financial sustainability monitoring and reporting are discussed in more detail below.

Quarterly report

The Bilateral Agreements for the transition, agreed to by the Australian, State and Territory Governments, set out the framework for the NDIA's quarterly report (table 11.1).

The NDIA is not yet reporting against all of the performance measures or indicators in the reporting framework, as it has not yet built into its systems the capability to measure some of the indicators. For example, the NDIA is not reporting detailed data on the proportion of participants who attain the goals outlined in their plans, the time between requesting access and receiving support, and the number of participants and other people with disability supported by LACs (NDIA 2016r, 2017y).

Also, only limited baseline (not longitudinal) data are presented for some indicators, such as the proportion of participants, and their families and carers, who report improved economic and social outcomes (NDIA 2016r, 2017y).

As the NDIA is still developing its performance reporting against the integrated framework, it is too early to judge whether the performance reporting will be sufficient to shed light on whether the scheme is meeting its objectives. That said, the Commission has identified some gaps in the framework and the current performance reporting against that framework.

Table 11.1 **NDIA operational performance outcomes, measures and indicators**

Outcome	*Measures*	*Indicators*
1. People with disability lead lives of their choice	1.1. Outcomes for participants and their families	1.1.1. Proportion of participants, and their families and carers who report improved economic and social outcomes (as measured by the NDIS Outcomes Framework)
		1.1.2. Proportion of participants who attain the goals outlined in their plans (as measured by the NDIA's Goal Attainment Scale)
		1.1.3. Participant satisfaction
	1.2. Provision of support in response to assessed need	1.2.1. Number of registered service providers by characteristics and market profile
		1.2.2. Access request to receiving support within different timeframes
2. NDIS is a financially sustainable and insurance-based	2.1. Participant characteristics and their families	2.1.1. Access requests made by outcome
		2.1.2. Eligible participants against bilateral targets, including key characteristics
		2.1.3. Participants with approved plans against bilateral targets
		2.1.4. Trends in plan approvals
		2.1.5. Access request to plan approval within different timeframes
		2.1.6. Ineligible participant numbers and key characteristics
	2.2. Support packages	2.2.1. Committed support
		2.2.2. Actual payments
		2.2.3. Average and median package costs by sub-groups of the population and for all participants compared with the expected averages and medians, including trends
		2.2.4. Details of participants with second plans, including length and value of supports
		2.2.5. Distribution of package costs
	2.3. Projections	2.3.1. Cost of the NDIS in dollar terms and as a percentage of GDP (split by participants aged under 65 years and over 65 years). This measure will include NDIS operating costs
3. Greater community inclusion of people with disability	3.1. Mainstream services	3.1.1. Number of participants accessing mainstream services by service type
	3.2. Local Area Coordination	3.2.1. Number of participants and other people with disability supported by LACs by participant characteristics
		3.2.2. Description of activities undertaken on ILC including dollars spent by regions and activities
	3.3. Information, Linkages and Capacity Building (ILC)	3.3.1. Number of participants and other people with disability supported by ILC activities by participant characteristics
		3.3.2. Description of activities undertaken on ILC including dollars spent by regions and activities.

Sources: Bilateral Agreements for the Transition to a National Disability Insurance Scheme, sch. G.; NDIA (2016r).

There are also limited indicators on mainstream services, Information, Linkages and Capacity Building (ILC) and LACs, and for the indicators that do exist, the NDIA is not yet reporting against some of them (NDIA 2016r, 2017z). Given the importance of understanding the interaction between the NDIS and mainstream services, and the critical role that ILC and LACs play in the scheme (chapters 6 and 10), data on these activities should be an important component of reporting on scheme performance.

There is also not a strong enough focus on quality in the framework, including the quality of plans and review processes (recommendation 11.5). Over time, the NDIA intends to develop its monitoring of, and reporting on, outcomes. Evidence of good outcomes will be evidence of good performance and good plans. However, it could be some time until this reporting is of a sufficient standard. Until then, reporting on quality is needed. Given the problems with the planning process (chapter 5), and the fact that many are exacerbated by the rollout schedule (chapter 2 and section 11.9), the NDIA should begin reporting indicators and measures of quality by June 2018. This could include indicators such as participant satisfaction with their plans and their planning experience, the number of plans completed by phone and face-to-face, and the number and nature of plan reviews.

Many study participants supported the NDIA continuing to develop and expand its performance reporting.[93] For example, the South Australian Government said:

> SA supports the NDIA strengthening its reporting on Scheme outcomes, in particular in relation to plan quality, the timeliness of plan development and review, and LAC and ILC activities. (sub. PP354, p. 12)

The NDIA (sub. PP327, p. 60) said it is already taking steps to develop its reporting in these areas.

The performance reporting framework should be regularly reviewed and refined over time. The current Bilateral Agreements state that the framework is to be reviewed annually (Australian Government and Queensland Government 2015, sch. G, p. 2). Improvements could also be introduced under the next performance reporting framework to be detailed in the Bilateral Agreements for full scheme. The framework should be assessed in terms of both whether additional indicators and data are required, and whether the data collected passes a cost-benefit test.

[93] Study participants who supported the NDIA continuing to develop and expand its performance reporting included: ADACAS (sub. PP260); ABF (sub. PP263); AFDO (sub. PP325); Amaze (sub. PP281); CMHA (sub. PP270); Macular Disease Foundation Australia (sub. PP243); Mental Health Australia (sub. PP321); MIFA (sub. PP338); Name Withheld (sub. PP237); NDS (sub. PP295); NMHC (sub. PP319); OTA (sub. PP285); PWSAA (sub. PP228); Queensland Government (sub. PP345); Richard Madden (sub. PP307); Summer Foundation (sub. PP293); Tandem (sub. PP212); Tasmanian Government (sub. PP247); VCOSS (sub. PP264); and Women with Disabilities Victoria (sub. PP282).

RECOMMENDATION 11.7

The National Disability Insurance Agency (NDIA) should continue to develop and expand the performance reporting against the *Integrated NDIS Performance Reporting Framework*, including on outcomes, and Local Area Coordination and Information, Linkages and Capacity Building activities.

The NDIA should also fill gaps in its performance reporting, including reporting on plan quality (such as participant satisfaction with their plans and their planning experience, plans completed by phone versus face-to-face, and plan reviews). This work should be made a priority. The NDIA should begin reporting on measures and indicators of quality by June 2018.

The *Integrated NDIS Performance Reporting Framework*, and any additional reporting outside this framework included in the Quarterly report to the COAG Disability Reform Council (DRC), should be regularly reviewed by the DRC and refined as needed.

Monitoring and reporting on financial sustainability

Under the NDIS Act, each time an annual report is prepared, the Scheme Actuary is to:

- assess financial sustainability and identify risks to financial sustainability, and any trends in the provision of supports to people with disability
- consider the causes of those risks and trends
- estimate the future expenditure of the NDIS
- prepare a report of that assessment, consideration and estimation
- prepare a summary of that report that includes the estimates of future expenditure (NDIS, sub. 161, p. 115).

The Scheme Actuary prepares an annual financial sustainability report, which includes detailed data and information on the financial sustainability of the scheme. This report is not released publicly, although a summary is included in the NDIA's annual report (NDIS Act, s. 172). The Annual Financial Sustainability Report is also reviewed annually by an actuary independent of the NDIA and the scheme actuary (NDIS Act, s. 180E). As discussed above, performance reporting, and independent and robust review of performance reporting, is important for transparency and accountability and providing incentives to improve performance. As much data and analysis on financial sustainability as possible should be made public.

11.9 The rollout

As discussed in chapter 2, the rollout schedule for bringing participants into the scheme is already falling behind the expected pace, and if the current trend continues, the timetable will not be met. This means that 'full scheme' (the time when everyone eligible to enter the NDIS will be able to do so and have an approved plan) will be delayed beyond 2019-20 — that is, beyond the date anticipated in the Bilateral Agreements.

A refocus is needed, making the timetable even more unrealistic

This report highlights many areas where the participant intake schedule is compromising the NDIA's ability to implement the NDIS as intended. Governments need to move the focus of the rollout away from participant intake towards the quality of plans and participant outcomes. A change in focus was supported by many study participants (for example, Amaze, sub. PP281, p. 5; CSSA, sub. PP278, p. 7; NDS, sub. PP295, p. 10; NDIA, sub. PP327, p. 60; OTA, sub. PP285, p. 9).

There is some evidence that the NDIA is already shifting focus. The NDIA recently reviewed its participant and provider pathways and is currently testing 'options for improved service delivery' (sub. PP327, p. 2). The NDIA's new approach is expected to have a greater focus on outcomes, more active involvement with communities, more face-to-face communications, and improved interaction with providers and disability organisations. The NDIA also plans to make improvements to its call centre, and portal to make the portal easier to navigate (NDIA, pers. comm., 22 May 2017).

The NDIA said it is 'working actively to deliver on the bilateral estimates, while providing participants with a quality experience' (sub. PP327, p. 2) and is:

> … unequivocally committed to delivering a quality experience for participants and providers centred on an outcomes-focused approach. This is the overarching objective of the NDIS, which must guide the NDIA's decision-making and the speed of roll-out, while recognising the undoubted benefits that participants gain from entering the Scheme. (sub. PP327, p. 6)

The latest Statement of Strategic Guidance,[94] issued in March 2017, includes participant and community outcomes as one of the six areas the DRC expects the NDIA Board to focus on.[95] The DRC also notes that it has requested 'additional work on indicators to understand and monitor the experience of participants and providers that include measures of participant satisfaction and the quality of planning' (DRC 2017b, p. 2).

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[94] Under section 125 of the NDIS Act, the Minister for Social Services, with agreement from the Australian, State and Territory Governments, may give the NDIA Board a statement setting out strategic guidance for the agency. The Board must have regard to this statement when performing its functions.

[95] The other areas include: building and maintaining stakeholder confidence; identifying strategic risks early and managing risks well; supporting market development; safeguarding the sustainability of the NDIS; and developing a high performing NDIA (DRC 2017b).

Without a refocus away from participant intake, the objectives of the scheme will not be achieved. The rebalancing should be explicitly tied to quality indicators that are publicly reported on (recommendation 11.7), so that the expectations set for the NDIA are clear, and the NDIA is held accountable.

RECOMMENDATION 11.8

The National Disability Insurance Agency should better balance participant intake, the quality of plans and participant outcomes. This rebalancing should be explicitly tied to quality indicators that are publicly reported on (as per recommendation 11.7).

The required rebalancing will make it more difficult to meet the bilateral estimates for the transition. In addition, the Commission has made a number of recommendations in this report aimed at improving the quality of planning and participant outcomes. Implementing the Commission's recommendations and the NDIA's new approach will increase the NDIA's workload over and above the 'businesses as usual' case of bringing new participants into the scheme and reviewing existing plans.

All of the above factors make the existing timetable for participant intake unrealistic, and full scheme will be delayed. The changed timetable must be planned for now.

Study participants' views on the implications of a slowdown

While it is now apparent that a slowdown in the participant intake is inevitable, in the position paper, the Commission sought feedback on the most effective way to operationalise a slowdown and the implications of slowing the timetable. The Commission received strong, but mixed, feedback from study participants on whether a formal slowdown was needed.

Many study participants argued a slowdown was necessary (box 11.8). For example, One Door Mental Health pointed to the extra time it would give the NDIA to implement positive changes and potential participants to apply:

> The implications of [a slowdown] are positive. From a planning perspective, NDIA planners and LACs struggling with capacity … have time to catch up, the NDIA has time to implement positive changes to emerging issues, governments have the opportunity to ensure that alternative supports are in place for those who do not qualify and service providers are given extra time to implement changes and encourage clients to apply. From a participant point of view, a slow-down will result in better quality plans and services. For those who do not qualify for a plan, there will be an extension of time in which they can access alternative supports to replace those that will no longer exist following transition. (sub. PP266, p. 16)

However, many other study participants were opposed to formally slowing down the rollout (box 11.9). For example, the Australian Federation of Disability Organisations said:

> Some in the sector have responded by arguing for a slow down of the roll out and to lengthen the transition period. To AFDO and its members, this would be completely unacceptable. For many

people with disability, the wait has already been too long. For people who have had little or no support for many years, the NDIS cannot come quickly enough. Slowing down the roll out is therefore not an option. (sub. PP325, p. 7)

Box 11.8 Some study participants highlighted the benefits of slowing the rollout …

Australian Psychological Society:

> Given the current issues with the NDIS, the APS is of the view that the ambitious timetable for the rollout presents a risk to consumers, and ultimately to the success and financial sustainability of the scheme. Slowdown would also allow more time for cross-sectorial planning and systems review in relation to the transfer of psychosocial supports for people with mental illness to the NDIS. … the APS has serious concerns about the capacity of the NDIS to provide sufficient, appropriate and effective services for people with a psychosocial disability. A slowdown would enable the necessary planning to take place to ensure consumer needs are appropriately met. (sub. PP229, p. 3)

David Parkin:

> The rollout to new areas needs to be slowed. Get the current system as right as it can be. There are enough participants now … who are actually using the system to understand where the effort needs to be applied. The NDIS has to listen to people and Providers. (sub. 177, p. 10)

Macular Disease Foundation Australia:

> The Foundation supports a slow-down in the NDIS rollout in order to assist the National Disability Insurance Agency in finding a better balance between participant intake, the quality of plans, participant outcomes and financial sustainability. … there are currently issues with the NDIS that have resulted in poor participant outcomes. Priority should be placed on addressing and resolving these issues to improve participant outcomes. Delaying the rollout may be the best option to prevent further uptake of sub-optimal plans, which not only negatively impact participants' lives, but also waste taxpayers' money and erode public trust in the NDIS. (sub. PP243, p. 5)

Royal Australasian College of Physicians:

> The rollout should be slowed as necessary to ensure that each new and existing participant can undergo effective and comprehensive planning, and receive necessary interventions throughout this process. (sub. PP299, p. 2)

JFA Purple Orange:

> Given the current difficulties in scheme design and implementation, especially those brought about by the contents of the bilateral agreements, we think there is merit in NDIS implementation slowing down. This is because we are concerned that the Scheme may develop less helpful features that are out of step with the Scheme's values and which, once 460,000 participants are enrolled will be very hard to change. This crystallisation will profoundly compromise the hoped-for benefits of the NDIS. (sub. PP350, p. 25)

There was also very little appetite from governments to delay the rollout — of the governments that provided submissions in response to the position paper, the only one to support it was the Northern Territory Government (sub. PP359, pp. 6–7). The Victorian Government (sub. PP298, p. 1) said 'there are challenges with the transition that can and should be addressed without the need to delay scheme rollout'. And the Queensland Government said:

> The Queensland Government's bilateral agreement with the Commonwealth provides for Queensland to transition in three years. Queensland does not resile from its commitment,

particularly to transition all its existing clients within the three year timeframe. Queensland would consider any extension to its transition timeframe to be a dis-benefit to Queenslanders given Queensland's transition phasing, funding decisions, contractual arrangements with funded providers and its workforce arrangements. Queensland would also prefer to avoid undue anxiety for existing service users and potential providers, and to avoid continuing to operate duplicate systems past June 2019. (sub. PP345, p. 23)

Box 11.9 … while others highlighted the costs

Name Withheld:

> … I request you recommend limiting as much as possible any slowdown in the rollout of NDIS. Many families have suffered severe hardship under inadequate state disability services and have been waiting patiently for the NDIS over the seven years since your inquiry began the NDIS process. (Name Withheld, sub. PP237, p. 5)

Victorian Advocacy League for Individuals with Disability:

> VALID does not agree that slowing down the roll out is the only response to the current implementation issues. VALID's preferred response would be to identify the issues that require resolution, prioritise their resolution, look at proposed solutions and then decide if [a] slow down is the only way to [an] appropriate resolution and the only way to achieve agreed goals. (sub. PP332, p. 10)

Queenslanders with Disability Network:

> QDN also firmly believes that the full implementation of the scheme needs to be consistent with the original principles and intent of the NDIS and supports actions that deliver on this, however QDN does not support actions to slow down the roll out of the NDIS. QDN does not support actions that compromise the long awaited access to supports that many people with disability have been waiting decades for, particularly in Queensland. (sub. PP335, p. 3)

EACH:

> The consideration of slowing the rollout of the NDIS due to both government and non-government conformance or adaptability to the Scheme should not be seen as a viable option to address these areas of concern. The rollout is based on a progressive schedule across the country, which was informed by evaluation of need and the individual requirements of potential participants. It would be unreasonable to expect potential participants to continue to wait for services purely because 'scheme design' and 'scheme roll out' has not been effectively managed or achieved. (sub. PP276, p. 16)

Richard Madden:

> The vital issue is that all Australians who are eligible have the right to enter the NDIS in accordance with the current rollout schedule. Any delay in the rollout removes entitlement from some who will be forced to wait with no supports or inadequate supports. This is wrong as a matter of social justice. (sub. PP307, p. 5)

The Department of Social Services (sub. PP318, pp. 5–6) argued that a slowdown is not required, but rather, existing flexibility within the current arrangements could ease implementation pressures while preserving the rollout schedules. It raised the examples of:

- South Australia — where the Bilateral Agreement estimates were adjusted to allow more new participants to enter the scheme
- Queensland — where it was agreed that three regions could commence transition earlier than originally planned.

There were a number of concerns raised about a slowdown, by both those who did and did not see the need for a slowdown. The main concern was potential participants waiting longer for NDIS support (Parkinson's Australia, sub. PP232, p. 6; YDAS, sub. PP262, p. 2), which would affect some people with disability more than others, including:

- those with urgent and complex needs (NDS, sub. PP295, p. 10; PWSAA, sub. PP228, p. 8)
- those not currently receiving support, or receiving inadequate support, outside the NDIS (JFA Purple Orange, sub. PP350, p. 25; PWSAA, sub. PP228, p. 8; Richard Madden, sub. PP307, p. 5)
- children (ECIA Victoria/Tasmania, sub. PP301, p. 7; NDS, sub. PP295, p. 10)
- those who turn 65 years while waiting and, unless eligibility criteria change, will not be eligible for the scheme when they otherwise would have been (ABF, sub. PP263, p. 14; BCA, sub. PP351, p. 5; Macular Disease Foundation Australia, sub. PP243, p. 5).

Another concern was that some Australian, State and Territory Government programs are already being withdrawn and a slowdown could leave some potential scheme participants without support at all (Anglicare Australia, sub. PP339, p. 11). The Australian Psychological Society said:

> A slowdown would need to be managed carefully as consumers in several jurisdictions are already experiencing a close down/transfer of all state-funded disability services. This is particularly the case in NSW, but also in Victoria with regard to the closure of mental health community-based services. A slowdown must not leave consumers without access to services. (sub. PP229, pp. 3–4)

To address these issues, study participants emphasised the importance of continuity of support arrangements (chapter 6) (The Benevolent Society, sub. PP334, p. 3; MIFWA, sub. PP221, p. 5; One Door Mental Health, sub. PP266, p. 16; Legal Aid NSW, sub. PP245, p. 15). For example, Occupational Therapy Australia said:

> … if a decision is made to delay the transition to the NDIS in some areas, slow down the scheme's rollout across the board, or prioritise some participants over others, any such decision must not adversely impact would-be participants. Once again, it falls to state and territory governments — who would presumably be party to any such decision — to ensure they have the necessary supports and services in place for those people put at risk by any changes to the scheduled rollout of the NDIS. (sub. PP285, p. 9)

Others argued that a slowdown could hinder market development (Victorian Government, sub. PP298, p. 1) due to a slowdown in the rate at which suppliers respond and enter the market. The ACT Government, for example, said:

> Proposals to slow the pace of the NDIS rollout to full scheme could further inhibit provider sustainability, and consequently market supply, where access to a regional or national market may enable providers to develop stronger ongoing business models. (sub. PP312, p. 8)

Study participants also discussed the potential impacts on public support for the scheme. On the one hand, Legal Aid NSW (sub. PP245, p. 15) and the Health Services Union (sub. PP316, p. 4) argued that public support could decline if the rollout is *not* slowed. However, the Victorian Government (sub. PP298, p. 8) said 'delaying scheme roll out could also reduce public confidence in the NDIS'.

Study participants agreed that there should not be an across the board slowdown, and instead certain groups should be prioritised, such as those with urgent and complex needs (Activ, sub. PP302, p. 12; Bruce Bonyhady, sub. PP333, p. 5; Inclusion Australia. sub. PP357, p. 26; Quality Living Options Bendigo, sub. PP220, p. 2; Speech Pathology Australia, sub. PP303, p. 10). For example, one study participant said:

> If slowdown must occur it should only be targeted to apply to people with low support needs. People with complex or higher support needs, or needing early intervention, would be at greatest risk from slowdown. I know from experience how desperate some families can feel under inadequate state disability services. Even a delay of one year could precipitate a significant tipping point for some people. A delay in transition to the NDIS may cause a spike in families relinquishing the care of people with high support needs.
>
> Slowdown should not be applied across the board nor to particular geographical areas. (Name Withheld, sub. PP237, pp. 5–6)

It is time to start planning now for a changed timetable

As noted above, a slowdown to the participant intake timetable is inevitable — the reality is that a slowdown is already taking place, and the work needed to better balance participant intake, the quality of plans and participant outcomes will only slow this down further.

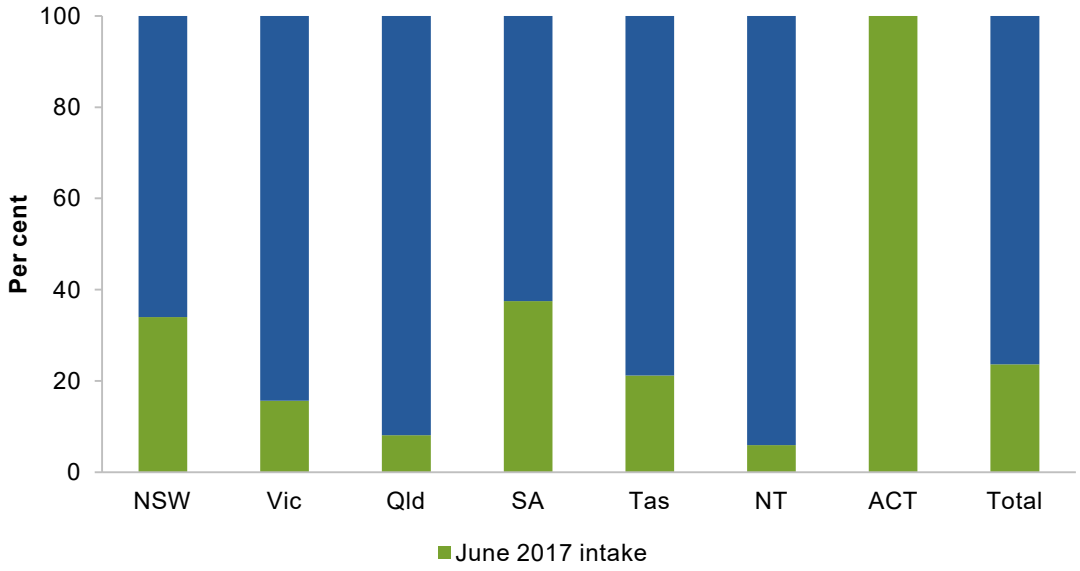
The NDIA and the Australian, State and Territory Governments need to recognise that the current timetable for participant intake will not be met. Action needs to be taken now to implement what is required to ensure the scheme meets its objectives, especially in light of the ramp up in participant numbers expected over the next two years in a number of jurisdictions. Any adjustments to the intake schedules will need to be made on a state-by-state basis, as jurisdictions are at different stages of the rollout (figure 11.2).

Any change in the timetable will have implications for scheme participants, providers, governments and the NDIA, as well as other parts of the scheme, including the impacts on market stewardship, non-NDIS service provision (mainstream services and disability services) and funding arrangements. For example, if the slowdown is not managed well, it could leave some potential scheme participants without adequate support. Governments are currently winding back some services as people with disability transition to the NDIS. Governments will need to alter their withdrawal plans and ensure that adequate continuity of support arrangements are in place.

A slowdown could also have implications for the development of the market and the supply of disability supports. The Commission has made a number of recommendations on market

development and participant readiness (chapters 7–10). But a slowdown could have additional effects on market, provider and participant readiness that will need to be managed.

Figure 11.2 **Scheme intake as a proportion of the total bilateral estimate by state, as at June 2017[a,b]**



[a] Excludes Western Australia. [b] ACT is at full scheme. Its current intake of 6047 participants has exceeded the bilateral estimate of 5075 participants.

Sources: Bilateral Agreements for the Transition to a National Disability Insurance Scheme; NDIA (2017y).

The way that funding arrangements are tied to participant phasing schedules, and whether changes to the full scheme funding arrangements are required given the slowdown, will also need to be considered.

The NDIA and governments also need to assess whether additional resources are required to implement the scheme successfully. Some study participants raised providing additional resources as another option to help deal with the current problems, and in some cases an alternative to slowing down the rollout.[96] But simply providing more money will not solve many of the immediate problems, as any additional staff will need training and experience, making this untenable as a quick fix.

[96] Study participants who raised the option of providing additional resources included: MIFA (sub. PP338); National Disability and Carers Alliance (sub. PP344); Parkinson's Australia (sub. PP232); Richard Madden (sub. PP307); Summer Foundation (sub. PP293); Victorian Government (sub. PP298); and YPINH (sub. PP326).

Decisions need to be communicated

It is critical that any decision made to change the participant intake schedule, together with any changes made to the scheme in response to this report's recommendations, are clearly and publicly communicated (Mental Health Coalition of South Australia, sub. PP308, p. 6; Vision Australia, sub. PP252, p. 13).

RECOMMENDATION 11.9

The Australian, State and Territory Governments should immediately start planning for a changed timetable for participant intake for the National Disability Insurance Scheme.

In doing so, the Australian, State and Territory Governments should ensure that adequate continuity of support arrangements are in place and assess whether additional resources are required to ensure the scheme meets its objectives. The issue of resourcing disability services under the changed timetable should be dealt with by the Treasurers and Ministers responsible for the disability portfolio in each jurisdiction, at the next COAG Disability Reform Council meeting.

12 NDIS funding arrangements

Key points

- Responsibility for funding the National Disability Insurance Scheme (NDIS) is shared between the Australian, State and Territory Governments. There are different funding arrangements for transition and full scheme.
  - During transition, the Australian, State and Territory Governments each contribute an agreed amount per participant based on the intake of participants in each state and territory. The package cost contributions equate to about a 40-60 split respectively. All cost overruns are to be funded by the Australian Government.
  - In the first year of full scheme, State and Territory Governments will contribute $10.3 billion to the NDIS. This amount will be escalated at 3.5 per cent each year. The Australian Government will fund the remainder (estimated to be $11.1 billion in 2019-20) and will have primary responsibility for cost overruns (covering at least 75 per cent).
- The funding arrangements for the NDIS need to provide funding certainty and allow the scheme to operate in line with insurance principles. This requires: sufficient funding for the National Disability Insurance Agency (NDIA) to take a lifetime approach to participant needs and support requirements; predictable funding that gives people with disability (and their families), and those who may acquire disability, certainty that they will receive reasonable and necessary supports over their lifetime; incentives for the NDIA to efficiently and effectively operate the scheme; and incentives for governments to take a collaborative approach to mainstream interfaces.
- Funds from the first 0.5 percentage point Medicare levy increase for the NDIS are credited to the DisabilityCare Australia Fund (DCAF). The DCAF is an investment account managed by the Future Fund and subject to management fees. State and Territory Governments can receive some funds from this account to put towards their NDIS contributions.
  - The DCAF should not be continued past 2023-24, as it is unlikely to be efficient to hold these funds in an account subject to management fees when 'churn' (from State and Territory Governments withdrawing a substantial proportion of the funds) is high.
  - Money from this Fund should instead be paid into the NDIS Savings Fund when it is established (along with funds from the proposed second 0.5 percentage point Medicare levy increase for the NDIS). The NDIS Savings Fund is ring-fenced within consolidated revenue and not subject to management fees (making it more suitable when churn is high).
- Given the limited and less efficient taxes available to State and Territory Governments (compared to the Australian Government), escalation parameters should be set on the basis of population growth and inflation. This will maintain constant real per capita contributions from State and Territory Governments over time. This means the Australian Government will bear a greater proportion of the total scheme costs over time.
- To give the NDIA greater capacity to operate the NDIS more in line with insurance principles, a commitment should be made now to build a pool of reserves over the medium to long term.

The National Disability Insurance Scheme (NDIS) involves a significant increase in funding provided to people with disability. When the NDIS is fully rolled out in 2019-20, it is expected to cost about $22 billion per year. This is an increase in total government spending on disability supports from $8.4 billion in 2015-16 (or just over 150 per cent) (SCRGSP 2017, p. 15.4).

This chapter examines the NDIS funding arrangements with a focus on reforming full scheme funding arrangements. Section 12.1 looks at how the NDIS is currently funded. Section 12.2 sets out a framework for evaluating funding arrangements. This framework is used to assess the way that funds are currently raised to pay for the NDIS (section 12.3), the setting of escalation parameters (section 12.4), and cost overrun and reserve arrangements (section 12.5).

12.1 How is the NDIS funded?

The complex funding arrangements for the NDIS are set out in a range of intergovernmental agreements between the Australian and State and Territory Governments. These agreements outline, among other things:

- the funding responsibilities of the Australian and State and Territory Governments in transition
- how these arrangements will change at full scheme — although full scheme arrangements are yet to be finalised and are subject to negotiation between the Australian and State and Territory Governments
- the arrangements for ongoing review of the funding agreements.

Transition funding arrangements (2016-17 to 2018-19)

During transition, package costs are shared between the Australian and State and Territory Governments. The Australian Government covers about 40.6 per cent of the 'agreed package costs'[97] for participants under 65 years, and the State and Territory Governments fund the remainder (about 59.4 per cent of the agreed cost) (table 12.1).

The Australian Government pays 100 per cent for non-Indigenous participants aged 65 years and over, and Indigenous participants aged over 50 years, in the scheme. It also funds the Information, Linkages and Capacity Building (ILC) activities and the National Disability Insurance Agency's (NDIA) operating expenses.

All cost overruns in the transition period — including those from average package costs consistently exceeding agreed amounts, or consistently higher than expected numbers of

[97] These agreed package amounts are the midpoint of Commission estimates from 2011. The Australian Government contribution is paid upfront monthly, while State and Territory Government contributions are paid monthly in arrears.

participants — are to be funded by the Australian Government (as per the Heads of Agreement).

Table 12.1 **Agreed average package costs and intake during transition**

	2016-17	*2017-18*	*2018-19*
Agreed average cost per participant ($)	39 667	41 383	43 163
Agreed (capped) participant intake[a]	78 642	123 681	153 443

[a] Excluding Western Australia and those aged over 65 years.

Sources: The Bilateral Agreements between the Australian, State and Territory Governments on the transition to the National Disability Insurance Scheme.

During transition, the NDIA is subject to a jurisdiction-by-jurisdiction cash ceiling equal to three months of agreed annual funding contributions for scheme participants in each state and territory. When the NDIA reaches this ceiling, contributions from the relevant jurisdiction and the Australian Government are reduced to ensure that the ceiling is not exceeded.

The NDIA is also subject to a jurisdiction-by-jurisdiction cash floor equal to the previous month's agreed contribution for that jurisdiction. Once this floor is breached, the Australian Government is expected to make a cash contribution to the Agency to ensure the cash holdings do not go below the nominated floor.

Funding arrangements at full scheme

At full scheme, State and Territory Government contributions to the NDIS are calculated as predetermined fixed dollar amounts, rather than shares of agreed costs for each participant. In 2019-20, State and Territory Governments, excluding Western Australia, will contribute about $9 billion (table 12.2).[98] The Australian Government will contribute the remainder of the budgeted amount. The Australian and New South Wales Governments have agreed to a fixed contribution from New South Wales of $3133 million in 2018-19. The fixed funding contributions of the other states and territories were calculated to equal the per capita contribution of New South Wales (table 12.2) (Australian Government and New South Wales Government 2012, p. 3).

[98] Estimated to be $10.3 billion should agreement with Western Australia be reached (DSS, sub. 146, p. 17).

Table 12.2 **State and Territory Government funding commitments in 2019-20**

State or Territory	*Contribution ($ million)*
NSW[a]	3 243
Vic	2 510
Qld	2 030
SA[a]	748
Tas	232
NT	99
ACT	167
Total[b]	9 029

[a] Not stated directly in the Heads of Agreement. Instead a figure of $3133 million is given for 2018-19, which was escalated at 3.5 per cent for the 2019-20 figure. The same calculation was performed for South Australia based on $723 million for their contribution in 2018-19. [b] The total excludes what Western Australia's contribution would be if it joined the national scheme.

Sources: Heads of Agreement with each State and Territory Government (except Western Australia).

State and Territory Government contributions can include in-kind services. These sometimes take the form of large capital investments made (like large residential centres or group homes) or contracts entered into prior to the NDIS. State and Territory Governments usually retain policy and administrative control over these in-kind services, including any decision to replace them with a financial contribution. Over time, and as these assets age, it is expected that they will be phased out. In-kind services are discussed in more detail in chapter 7.

The Heads of Agreement state that, at full scheme, State and Territory Government contributions will increase by 3.5 per cent per year (subject to the response to the recommendations of this study). These escalation parameters are calculated based on assumed net population growth of 1 per cent per year and the midpoint of the Reserve Bank of Australia's consumer price index medium-term inflation target of 2–3 per cent (Australian Government and New South Wales Government 2012, pp. 2–3).

Over the medium term, scheme costs are expected to increase above long-term inflation and population growth trends due to the impact of people aged over 65 years in the scheme (DSS, sub. 146, p. 17). The cost of the NDIS is expected to increase to just over $32 billion by 2029, with the Australian Government share of funding increasing from 52 per cent in 2019-20 to 56 per cent in 2028-29 (table 12.3).

Table 12.3 **Projections of the funding split over time**
$billion

	2019-20	*2020-21*	*2021-22*	*2022-23*	*2028-29*
Estimated total scheme costs[a]	21.5	22.8	24.0	25.1	32.1
Participant package costs	20.0	21.5	22.6	23.7	30.6
ILC block grants	0.1	0.1	0.1	0.1	0.1
Admin and other	1.3	1.3	1.3	1.3	1.4
Commonwealth contributions	**11.1 (52%)**	**12.0 (52%)**	**12.7 (53%)**	**13.5 (54%)**	**17.9 (56%)**
State and Territory contributions	**10.3 (48%)**	**10.9 (48%)**	**11.2 (47%)**	**11.6 (46%)**	**14.3 (44%)**

[a] These are gross figures based on the DSS model.

Source: DSS (sub. 146, p. 17).

While arrangements for cost overruns at full scheme are still to be finalised, the Heads of Agreement for each State and Territory (excluding Western Australia), note that the Australian Government will:

> … assume 100 per cent of the risk for full scheme … subject to the review [of scheme costs by the Productivity Commission] noting the Commonwealth is committed to always assuming a minimum of 75 per cent of risk … for client support costs … (Australian Government and New South Wales Government 2012, p. 4)

As discussed in chapter 11, Western Australia has opted for a locally administered scheme and has different funding arrangements to the other states and territories (box 12.1).

Sources of NDIS funding

Australian Government funding for the NDIS comes from a number of sources (figure 12.1).

- Funds redirected from previous Australian Government disability service programs to the NDIS (DSS 2016f, p. 2).
- Funds previously provided to State and Territory Governments under the National Disability Agreement and the 2011 National Health Reform Agreement (DSS 2016f, p. 2).
- A 0.5 percentage point increase in the Medicare levy on personal taxable income (estimated to raise about $4 billion per year in 2018-19) which provides funding via the DisabilityCare Australia Fund (DCAF) (box 12.2) (Australian Treasury 2017a, p. 130).
  - A maximum of $9.7 billion over 10 years will be allocated to the States and Territories, with the remainder available to the Australian Government (*DisabilityCare Australia Fund Act 2013* (Cwlth), s. 13).

- Debits from the yet-to-be-established NDIS Savings Fund (box 12.2), which will source funding from:
  - an additional 0.5 percentage point increase in the Medicare levy on taxable income (subject to legislative passage) (estimated to raise about $4 billion per year in 2019-20) (Australian Treasury 2017a, p. 130)
  - underspends and realised savings from the NDIS (through, for example, changes to budget forecasts reflecting cost saving measures by the NDIA)
  - uncommitted funds from the Building Australia Fund and Education Investment Fund (to be legislated)
  - other redirected savings at the discretion of the Australian Government
- consolidated general government revenue.

Box 12.1 Funding arrangements in Western Australia are different

Western Australia has so far opted not to join the national scheme, but rather to have a separate Western Australian National Disability Insurance Scheme (WA NDIS) (chapter 11).

WA NDIS during transition

During the transition period, as in other jurisdictions, the WA Government will contribute about 59.4 per cent of care and support package costs for an agreed number of eligible participants each year.

The Western Australian Government will cover a larger proportion of cost overruns than other State and Territory Governments.

- The Australian Government will bear a maximum of 25 per cent of any cost overruns for the WA NDIS when those overruns are due to a higher than expected number of participants or higher package costs.
- Cost overruns due to any other reasons will be funded by the WA Government.
- If there are lower than expected package costs or participant numbers, the remaining funds will be split according to the contributions of each government.

The WA Government and Australian Government will share equally in the cost of Information, Linkages and Capacity Building grants and Local Area Coordinators in that state. The WA Government will fund the administrative costs of the WA NDIS. And, as in the other states and territories, the Australian Government will fund supports for participants aged over 65 years who choose to remain in the scheme, and Indigenous participants aged over 50 years old.

WA NDIS at full scheme

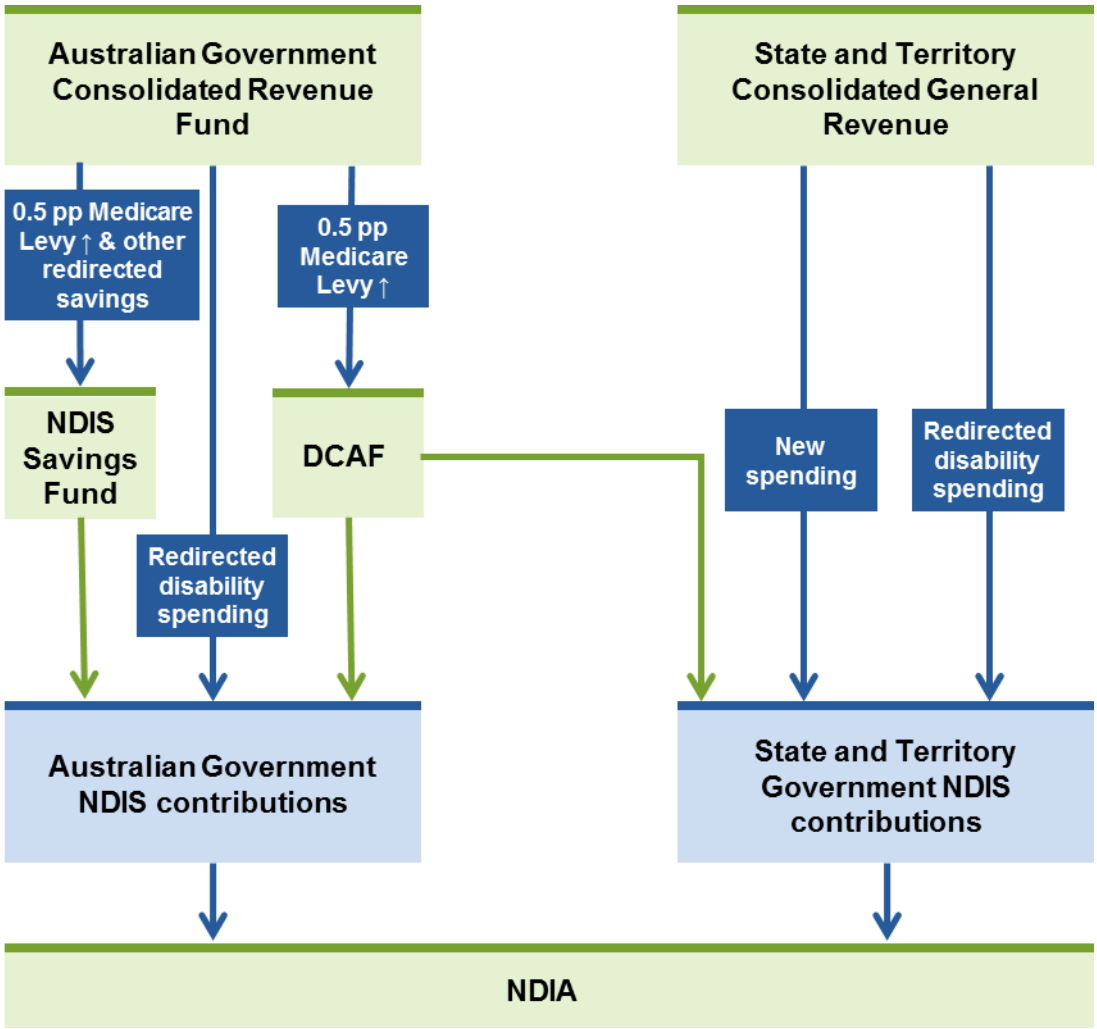
Limited details about the WA NDIS at full scheme are available, but the Bilateral Agreement does state that if the WA Government maintains a separate scheme after transition, the Australian Government will make a fixed per person contribution towards the cost of the scheme in Western Australia and this amount will escalate at 3.5 per cent per year.

Source: Australian and Western Australian Governments (2017, p. 14).

State and Territory Government contributions are funded through (figure 12.1):

- redirected funding previously used for legacy specialist disability services
- funds allocated to the States and Territories from the DCAF — the maximum amount of credits for the States and Territories is $9.7 billion over 10 years (*DisabilityCare Australia Fund Act 2013* (Cwlth), s. 13)
- consolidated State and Territory Government general government revenue.

Figure 12.1 **Proposed NDIS funding model in 2019-20[a,b]**



[a] The NDIS Savings Fund and the increase in the Medicare Levy to be put into the NDIS Savings Fund are subject to legislative passage. The abbreviation 'pp' stands for percentage point. [b] State and Territory Government consolidated general revenue is referred to by different names in different jurisdictions' constitutions.

Sources: Australian Treasury (2017b), Heads of Agreement with each State and Territory Government (except Western Australia).

Box 12.2 The DisabilityCare Australia Fund and the NDIS Savings Fund

The Australian Government increased the Medicare levy by 0.5 percentage points from July 2014-15 to provide funding for the NDIS. The funds from this increase to the Medicare levy are credited to the DisabilityCare Australia Fund (DCAF) to partially reimburse the Australian and State and Territory Governments for their contributions to the NDIS.

As set out in the *DisabilityCare Australia Fund Act 2013* (Cwlth) (DCAF Act), from 2014-15, the maximum amount of credits available for State and Territory Governments from the DCAF is $825 million per year in 2014-15. This amount will increase at 3.5 per cent each year until 2023-24. Over 10 years (ending 2023-24), the maximum amount of credits available for the State and Territory Governments is a total of $9.7 billion between them, to partially reimburse their NDIS contributions.

Governments have not yet negotiated whether the States and Territories will continue to receive these payments after 2023-24, but the operation of the DCAF Act is due to be reviewed before June 2024 (DCAF Act, s. 55).

State and Territory Governments can be paid an amount from DCAF in order to reimburse them for expenditure incurred in relation to the *National Disability Insurance Scheme Act 2013* (Cwlth). Funds not allocated to State and Territory Governments can be used by the Australian Government to reimburse it for expenditure incurred in relation to the National Disability Insurance Scheme Act.

As at 31 March 2017, the DCAF had $6.2 billion in assets.

The Australian Government's 2017-18 Budget includes plans to increase the Medicare levy by (a further) 0.5 percentage points. Revenue generated from this increase will be credited to the yet to be established NDIS Savings Fund, alongside other redirected savings, contributions from NDIS underspends, and recommitting funds from the Building Australia Fund and Education Investment Fund (subject to legislation). The NDIS Savings Fund and the increased Medicare levy are also subject to legislation passing through Parliament. The NDIS Savings Fund will ring-fence — or hypothecate — funding specifically for the NDIS.

Sources: Australian Treasury (2017b, 2017e), Australian Government (2013a), Australian Government and New South Wales Government (2012), the *National Disability Insurance Scheme Act 2013* (Cwlth), the *DisabilityCare Australia Fund Act 2013* (Cwth), and Porter and Cormann (2016)

Most funds are for individualised supports

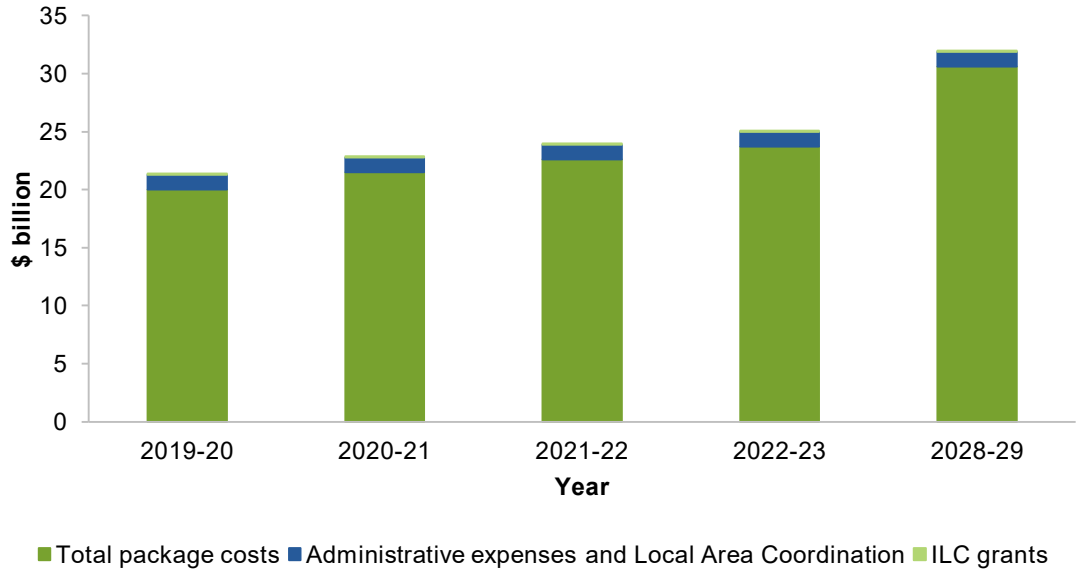
The Australian and State and Territory Governments' funding contributions to the NDIS are used for three categories of expenditure:

- individualised support costs (participant packages) — these are expected to be more than 93 per cent of the NDIS expenditure at full scheme
- operational expenses of the NDIA, including funding for assessment, planning and Local Area Coordination (LAC) — these are expected to account for less than 7 per cent of the budget at full scheme

- the Information, Linkages and Capacity Building (ILC) grants (chapter 6) — these make up the remainder of the budget, at less than 1 per cent at full scheme (table 12.3, figure 12.2).

During transition, the NDIA's operating expenses and ILC are funded by the Australian Government (Australian Treasury 2017d, p. 140). However, at full scheme, the Heads of Agreement indicate that State and Territory Governments may contribute towards ILC and LAC funding.

Figure 12.2 **The allocation of full scheme funding over time**[a]



[a] While most chapters in this report use modelling based on the NDIA's models and data, this chapter uses a funding and costs model provided by the Department of Social Services.

Source: Estimates provided by the DSS (sub. 146, p. 17) based on MYEFO 2016-17 data.

12.2 A framework for evaluating funding arrangements

As an insurance-based scheme, the NDIS should be designed to take a lifetime approach to disability care and support. As discussed in chapter 1, the NDIS is intended to provide assurance to both those with permanent and significant disability, and those who may acquire such disability in the future, that they will receive the support they require for as long as they need it. This is only possible if the funding source is both sufficient and predictable. It should also take a lifetime view of participants' needs by, for instance, seeking early investment and intervention for people in order to maximise their independence and social and economic

participation, and reduce their support requirements in the future. As the Commission's 2011 *Disability Care and Support* report said:

> Whatever its exact form, the financing mechanism must give people with a disability certainty about getting reasonable supports over their lifetime. Moreover, a stable revenue stream is needed to underpin a proper governance arrangement for the NDIS … Accordingly, funding for disability must move away from the uncertainty underlying the annual determination of government budgets for disability support. (PC 2011, p. 33)

The funding arrangements for the NDIS also need to be efficient, transparent and create the right incentives for effective management of the scheme over time.

Funding needs to be sufficient

The consequences of an insufficient source of future funding for the NDIS are considerable. As the Commission said in 2011:

> … the consequences of insufficient future benefits are worse than in many other cases where people seek assurance — uncertainty about the timely replacement of an ageing and increasingly worn-out wheelchair; unmanageable carer pressures; and the fear of inadequate or low quality care without respect or dignity for a partner or a child. Accordingly, while people value the supports they might get today, they value highly the guarantee that they will get adequate supports tomorrow too. This implies that a properly designed NDIS must reflect those preferences. (PC 2011, p. 647)

The objective of the NDIS is to fund the reasonable and necessary supports for people with disability. The scheme was designed to be uncapped in order to achieve this (noting, as discussed in chapter 1, that the ultimate cap is taxpayers' willingness to continue to pay for the scheme). This means that allocated funding needs to be sufficient to meet the cost of reasonable and necessary supports for all scheme participants. Sufficient funding is essential if the chronic underfunding and unmet demand of the previous disability support system is to be avoided.

Sufficient funding also suggests the need for access to extra funds for investments that will reduce the long-term costs of the scheme, and for managing risk in times of volatility and uncertainty.

Funding needs to be predictable

Funding predictability relates to certainty about the ongoing availability of funds. Under the previous disability support system, people with disability were typically uncertain about whether they would get the support they needed over their lifetime:

> People with disabilities and their carers do not get the certainty of lifelong support needed for proper life planning and cannot avoid the extreme anxiety about the adequacy of future funded support when informal care is no longer reasonable or feasible. Current funding for disability comes from two levels of government, which are subject to annual budget cycles — making it

> hard to give people with disabilities any certainty that they will get reasonable care and support over the long run. (PC 2011, p. 6)

A lack of funding certainty imposes costs on people with disability and their carers and families — not just the costs of inadequate care, but also the psychological costs of uncertainty (such as fear of inadequate or low quality care for a partner or child, which can create incentives for exaggerating problems when funds are severely rationed and allocated mainly to crisis support).

A predictable revenue stream is also essential if the NDIA is to take a forward-looking approach to systematically manage demand and price pressures to minimise the long-term costs of the scheme. Making long-term decisions is not feasible when future revenue sources are subject to the unpredictable processes of annual budgets (PC 2011, pp. 647–648). As the Governments of Victoria, Queensland, South Australia and the ACT said:

> To deliver on its objectives of improved social and economic participation, and to ensure equity in application and integrity of the Scheme, the NDIS must be free from the influences of evolving budget pressures. The Scheme is an insurance-based model and participants require confidence that their supports will be provided for as long as required. Decisions about eligibility and reasonable and necessary supports should not be subject to ongoing revisions to align costs with a targeted funding level. (sub. 201, p. 3)

'Predictability' requires binding commitments from governments for funds allocated to the NDIS. This suggests either an agreed amount of revenue or a specific tax dedicated to the NDIS (hypothecation is discussed further below).

Funding arrangements need to create the right incentives

Incentives to effectively and efficiently operate the scheme

Funding arrangements should allow the NDIA to operate the NDIS as an insurance-based scheme (chapter 1). For example, they should provide incentives to make investments that reduce future claims on the scheme, and be able to meet unexpected cost fluctuations.

The arrangements also need to provide incentives for the Agency to operate the scheme efficiently. For example, allowing the NDIA some flexibility to make decisions about the efficient operation of the NDIS may help to minimise costs.

And while the NDIS is funded by an annual appropriation, governments (and taxpayers) will not commit to just any level of funding. As the Commission said in 2011:

> That would provide an excuse for lax cost control and permissive benefit levels by the scheme. Any scheme that did not control premium [funding] pressures would not be sustainable or acceptable to governments and taxpayers. (PC 2011, p. 573)

Incentives for federal-state collaboration

The NDIS is funded in part by redirecting existing disability funding. However, the NDIS is not designed to cover all Australians with disability (chapter 1). The scheme is also designed to operate in conjunction with, not replace, mainstream services.

Ideally, the NDIS would operate as part of a seamless system of mainstream and disability services that takes a lifetime, insurance-based approach. That is, early interventions and well-targeted preventative care would occur in a coordinated way to minimise the overall costs of mainstream and disability services, and maximise the wellbeing of participants in those systems. However, as discussed in chapter 6, these interactions are not always seamless. Gaps in the NDIS can impose costs on mainstream services, and vice versa.

The design of funding arrangements for the NDIS can affect how these interactions play out. Arrangements need to ensure that the amount of funds available for mainstream services and continuity of support obligations is adequate.

Revenue raising needs to be efficient

Government funds for the NDIS can be sourced either from reducing expenditure on other programs, or from an increase in tax revenue (borrowing is not considered a feasible long-term option). Reducing government spending on other programs has its attractions, and it is likely that spending on disability services will have a high net benefit compared to some other government expenditure (PC 2011, p. 643).

Where tax increases are required, tax revenue should be raised in the most efficient way possible.

Transparency is important

Transparent funding arrangements are also important, particularly in the context of holding the NDIA and the Australian, State and Territory Governments accountable for decisions they make. Transparency provides the NDIA and the community with certainty that the NDIS will have access to sufficient revenue in the future by making it more difficult for governments to renege on their funding commitments.

12.3 Raising funds to pay for the NDIS

A shared funding arrangement was agreed

In 2011, the Commission's preferred funding option was for the Australian Government to be the single funder of the NDIS. This option was preferred because it would:

- provide certainty and clear lines of funding responsibility
- avoid the inefficiencies of the Commonwealth-State 'blame game' that afflicts some other shared funding arrangements
- reflect the Australian Government's capacity to raise efficient and sustainable taxes of the magnitude required (PC 2011, pp. 673–8).

This option was subject to State and Territory Governments reducing their taxes to avoid increasing the tax burden on Australians beyond what is necessary to provide additional funding to the NDIS.

The Commission also recommended that the Australian Government direct payments from consolidated revenue into a National Disability Insurance Premium Fund, using a legislated formula that provided stable revenue to meet the actuarially assessed reasonable needs of the NDIS and included funding for adequate reserves (PC 2011, p. 659).

However, the Australian, State and Territory Governments agreed on a pooled funding approach for the NDIS, with contributions from State and Territory Governments agreed in bilateral agreements (chapter 1). And there is no pool of reserves.

Concerns raised about the shared funding arrangements

The shared funding arrangements for the NDIS were raised as a concern in the context of ensuring secure funding for the NDIS. For example, Physical Disabilities Australia, said:

> PDA does not believe the current funding arrangements between the Commonwealth and the States and Territories secure the NDIS' future. Instead, we believe they will threaten the Scheme's viability. Whilst the funding commitments are shared in this way, politicians at all levels will continue to threaten the Scheme's future by claiming the other entities 'aren't paying their fair share' or are 'exploiting [their jurisdiction's] better run economy'. (sub. 38, p. 17)

However, any potential instability from shared federal-state funding is expected to be counteracted by the extraordinary commitment to the success of the NDIS by the State and Territory Governments and the support for a shared funding approach. The Victorian Government, for example, said:

> Victoria supports the continuation of a joint approach to funding the NDIS that involves Commonwealth funding of the scheme, supported by contributions from the states and territories agreed bilaterally. This approach is most likely to ensure a sustainable source of funds and offers the best prospect of delivering NDIS objectives effectively and equitably. (sub. 174, p. 23)

The South Australian Government also said:

> SA remains strongly committed to the NDIS. The issues that SA has raised in response to the Commission's Position Paper are to ensure that the Scheme is successfully implemented and sustainable in the long term for both Commonwealth and state and territory governments. This will provide people with disability the confidence that the NDIS will deliver the benefits for which it was designed. (sub. PP354, p. 15)

Others pointed to the benefits of having State and Territory Governments involved in the scheme. Bruce Bonyhady, for example, said:

> The preferred method of funding in the Productivity Commission Report in 2011 was for the Commonwealth and States to engage in a tax-swap and for the Commonwealth to fully fund the NDIS from general revenues. … However, acceptance of this recommendation would have meant that once the NDIS was fully implemented, the States and territories would not have had any 'skin in the game' and so risked the States not having an interest in the NDIS or engagement with people with disability. This would have been a mistake. … It is clear from the implementation of the NDIS to date that the shared funding model has contributed very positively and significantly to the national governance arrangements and ensured that all governments have maintained their strong commitments to the NDIS. (sub. 100, pp. 11–12)

Hypothecation

Highly volatile and inadequate disability spending was a feature of the previous disability system. In light of this, the Commission in 2011 argued that such a tax could provide greater certainty for funding the NDIS (while noting that economists and Treasury departments, often question the appropriateness of hypothecated taxes):

> A genuinely hypothecated tax can be a way of increasing certainty that government would provide adequate funding in the future … Just identifying the tax as something like a 'National Disability Insurance Premium' would make it hard to eliminate the tax or to divert it to other purposes, since most would accept the legitimacy of dedicated public funding in this area. (PC 2011, p. 659)

The Commission also noted that an alternative to a hypothecated *tax* is hypothecated or 'earmarked' *funding* — rather than specifying the tax base to be hypothecated, the Australian Government diverts a specific funding amount from consolidated revenue into a hypothecated, or earmarked, fund for the NDIS specified in legislation.

Having hypothecated funding, rather than a hypothecated tax, has two main benefits. It:

- does not lock in a particular tax base as the source of revenue for the NDIS
- minimises the need for tax increases by leaving open the option of reducing wasteful or unnecessary expenditure.

But the amount earmarked for the fund would need to include an escalation factor to reflect the anticipated growth in scheme costs over time, rather than an absolute dollar amount which falls relative to NDIS costs over time.

Hypothecation of funds — whether through a hypothecated tax or earmarked fund — can make it more difficult for governments to renege on their commitments by providing an upfront transparent commitment to the way that a pool of money will be used.

Earmarked Medicare levy increases will be used to partially fund the NDIS. There are a number of benefits from hypothecating funds from the Medicare levy for the NDIS, including:

- increasing certainty that funds are available for the NDIS by providing a transparent allocation of funds to be used for a particular purpose
- reducing reliance on State and Territory Governments to raise their own funds (displacing inefficient State and Territory Government taxes with more efficient Australian Government taxes).

As discussed above, the money raised for the NDIS from the first Medicare levy increase is currently credited to the DCAF and the proposed (second) Medicare levy increase will be credited to the proposed NDIS Savings Fund. The DCAF is an investment account managed by the Future Fund and subject to management fees. The NDIS Savings Fund is ring-fenced within consolidated revenue.

While the DCAF is an earmarked fund with transparency around what goes into the fund, it is not without its problems.

- It is subject to management fees (Future Fund Board of Guardians 2016, p. 66). At full scheme, when there is expected to be a lot of 'churn' in the funds under management from the Australian, State and Territory Government withdrawals. These management fees may erode the returns on the fund because being able to make funds readily available for withdrawals means they have to be invested in liquid assets.
- There is little transparency around how the funds are used, and how they are allocated to State and Territory Governments — the DCAF Act does not provide any certainty around when State and Territory Governments can access funds.
- It is a complex arrangement — the Medicare levy increases are to be put into two separate hypothecated funds and other Australian Government contributions come directly from consolidated revenue (not hypothecated).

These features may not be an issue in transition where the funding requirements of the NDIS are lower, and funds are building in the DCAF (reducing the impact of management fees). However, it will be difficult to justify renewing the DCAF arrangements after State and Territory Governments have made withdrawals from the DCAF, because of the increased 'churn' in funds and erosion on the fund returns. For this reason, the Commission is of the view that in 2023-24, when the DCAF arrangements are reviewed, the money raised by the Medicare levy increases intended for the NDIS should instead be put into the NDIS Savings Fund until the Australian Government needs to contribute it to the NDIS.

The benefit of the NDIS Savings Fund is that it is not subject to management fees (unlike the DCAF). And while it is not truly hypothecated (in that it remains part of consolidated

revenue), the transparency of the NDIS Savings Fund makes it a commitment that is difficult for governments to renege on. Other Australian Government contributions could also be put into the NDIS Savings Fund before they are provided to the NDIA to ensure transparency and certainty over funds committed to the NDIS.

If the Australian Government wishes to partially pay for the contributions of the State and Territory Governments — and it might be efficient to do so if it avoids some State and Territory Governments raising additional funds through inefficient state and territory taxes — it should do so by reducing the State and Territory contributions directly. This would be simpler than the DCAF, improve transparency and predictability of the funding arrangements, while also realising the benefits of hypothecation.

State and Territory Governments are likely to continue to provide funds to the NDIA directly, rather than putting them in a pool with Australian Government funds.

RECOMMENDATION 12.1

The DisabilityCare Australia Fund (DCAF) should be discontinued after 2023-24. All the Medicare levy funds hypothecated for the National Disability Insurance Scheme (NDIS) should be put in the proposed NDIS Savings Fund.

The reimbursement arrangements that currently apply under the DCAF should not be continued after 2023-24. If necessary, the impact of such reimbursements should be reflected directly in reduced contributions from the State and Territory Governments.

12.4 Escalation parameters

The NDIS is designed to be a no-fault scheme that covers the entire population, and the funding contributions of governments to the NDIS can be thought of as 'insurance premiums' paid by individuals through their taxes (PC 2011, p. 976). At full scheme, these insurance premiums will be made up of contributions from the Australian Government, and the agreed fixed funding contributions of State and Territory Governments which are escalated at 3.5 per cent per year.

The Heads of Agreement state that the DRC may agree to revise the escalation parameters based on the advice of this study. The Agreements also state that the calculations of per capita funding will be updated every five years to take into account each new Census. The first re-basing is expected to occur from 2023, based on 2021 Census figures.

The terms of reference for this study ask the Commission to look at changes in the agreed escalation parameters.

What are the objectives of the escalation parameters?

There were different views put to the Commission about what the escalation parameters are designed to achieve.

The New South Wales Government, for example, argued that the parameters should remain unchanged:

> … escalation was intended to represent a fair and fixed rate of growth to NSW's contribution. Again, it was not intended to maintain a specified cost share basis, nor meet actual cost or activity growth, nor necessarily maintain a real per capita contribution. Rather it was an agreed growth rate based on a fixed population growth factor (1.0%) and a fixed cost escalation factor (2.5% - equal to the RBA long term inflation target). (sub. PP230, p. 11)

The Tasmanian Government (sub. 247, p. 11) and South Australian Government (sub. PP354, p. 14) were also opposed to any changes to the escalation parameters.

The Victorian Government argued that escalation parameters should be used to maintain their current per capita contributions to the NDIS in real terms:

> Victoria considers it is clear from the wording of the bilateral agreements that the objective of the escalation factor to be applied to state contributions to NDIS costs was to maintain the real value of those contributions over time against growth in population and economy-wide movements in prices and wages.
>
> The states clearly did not agree to meet increased costs arising from a higher than expected participant numbers and/or higher average per person care and support costs. Under the bilateral agreements, 100 per cent of the risk of scheme cost overruns due to such factors was clearly apportioned to the Commonwealth. (sub. PP298, p. 33)

The ACT Government was also open to the parameters being explicitly defined to maintain constant real per capita contributions:

> If there is a departure from the current indexation rate of 3.5 per cent, the ACT suggests that [the] most appropriate alternative would be to set rates on the basis of maintaining a real per capita contribution to the NDIS as this is in line with the design of the scheme and the original agreement. (sub. PP312, p. 13)

Both the Queensland Government and the Victorian Government highlighted the importance of escalation parameters being certain once agreed on:

> The agreed fixed rate provides certainty for states and territories which is important in the context of smaller state budgets. Introduction of variable escalation rates may require states to set aside funds in contingencies in case of higher than expected cost pressures. Such funds could be better utilised for mainstream services or elsewhere in the economy. (Queensland Government, sub. PP345, p. 24)
>
> States' NDIS contributions have been carefully formulated and agreed. The Commonwealth cannot keep shifting the goalposts. (Victorian Government, sub. PP298, p. 33)

Others, such as the DSS, argued that the parameters should be used to increase State and Territory contributions in line with changes in scheme costs:

> … contribution levels should be linked to underlying growth in NDIS costs, including short to medium term financial implications such as expanding market and wage increases for the Social and Community Services sector. In addition, should there be an adverse impact on the pricing of supports, escalation rates should be adjusted to reflect those changes. Escalation rates should therefore be based on an economic projection of cost escalation, with any costs incurred outside of these settings considered in the context of risk sharing arrangements. (sub. PP318, p. 21)

This would require the escalation parameters to reflect the increase in NDIS costs over time. However, existing escalation parameters are unlikely to do this, as NDIS costs are expected to grow at a faster rate than inflation and population (DSS, sub. 146, p. 17). As the NDIA said, it:

> … can observe that wage inflation and the Equal Remuneration Order (ERO) are likely to result in an increase above 3.5 per cent in the short-term, which will result in a skewing of the contributions. Longer-term assumptions should be set considering wage inflation levels, population growth rates, and efficient prices. (sub. 161, p. 114)

If escalation parameters do not reflect cost increases over time, the Australian Government will, over time, bear a higher share of NDIS costs for participants aged under 65 years. The Queensland Government (sub. PP345, p. 24) argued that it was 'reasonable for the Australian Government to gradually assume a greater share of scheme costs over time, considering its greater revenue base', noting that 'this would be a move closer to the funding arrangements originally proposed by the PC in 2011'.

The DSS also suggested that the escalation parameters should be adjusted to take account of the State and Territory Governments' roles and responsibilities, including the extent to which these governments support and fund mainstream services:

> Under first principles, financial contributions from all parties should reflect, where possible, the roles and responsibilities of those parties. The architecture of the NDIS is a unique arrangement in the relationship between the Commonwealth and State governments, with current governance arrangements providing States with a significant and ongoing funding and stewardship role in the NDIS, the effective implementation of the interface of the NDIS with mainstream service systems and stimulating the appropriate workforce to deliver disability services. (sub. PP318, p. 21)

The threshold issue for determining the objective of escalation parameters is whether or not State and Territory Government contributions at full scheme and beyond should keep pace with scheme costs, or maintain existing real per capita contributions.

The argued benefit for State and Territory Government contributions to track scheme costs is to give them some 'skin in the game' to control costs, for example, by giving them additional incentives to agree to cost-saving changes in the rules. However, there are a number of factors that contribute to increasing scheme costs, and most of these are not within the control of State and Territory Governments. It is also unclear how State and Territory

Government decisions could impact many of the cost drivers that would be used to set escalation parameters, including equipment costs and social and community workers' award wages.

But, as noted by some State and Territory Governments, higher escalation parameters could impose a greater cost on taxpayers if State and Territory Governments are required to raise additional funds (because they have access to narrower and less efficient tax bases than the Australian Government) and/or affect the delivery and quality of mainstream services which are necessary for the sustainability of the NDIS (box 12.3). And limited State and Territory Government tax bases mean that guaranteeing the sufficiency of funds may be difficult when State and Territory Governments have to raise significant amounts of additional revenue.

Box 12.3 State and Territory Governments point to their access to less efficient taxes and more limited revenue bases

Victorian Government:

> … increasing the proportion of state funding or the indexation of the state contribution would increase budgetary pressures on states and may affect the delivery, quality and access to mainstream services, which are also necessary for the sustainability of the NDIS.
>
> … Increasing the NDIS' dependence on smaller state budgets that rely on Commonwealth grants and less efficient taxes may result in a backwards step — towards an NDIS that is not fully funded. (sub. PP298, p. 34)

Tasmanian Government:

> State funding contributions to the NDIS during transition and at full scheme are fixed and capped, in recognition of states' need for budget certainty and their limited capacity to raise additional funds. As pointed out in the New South Wales submission to the PC's earlier Issues Paper, state contributions were never intended to cover the costs of the scheme. (sub. PP247, p. 10)

Governments of Victoria, Queensland, South Australia and the ACT:

> Increasing the proportion of state funding or the indexation of the state contribution would add to the revenue burden on states, and may result in a reversion to the previous rationed and waitlisted disability system that was 'underfunded and inefficient', with disability funding once again competing with other state service delivery obligations. It is worth remembering that, in part, it is this concerted attempt to move away from uncertainty of supports that has driven the design of the NDIS to be one that provides participants with confidence about the services that will be available in the future. (sub. 201. p. 3)

Governments have agreed to fixed funding contributions from States and Territories at full scheme, and the Commission recommends keeping those agreed contributions constant on a real per capita basis over time. This requires calculating escalation parameters with reference to inflation and population growth.[99] In broad terms, this should mean that State and Territory Governments are unlikely to need to increase tax rates as inflation and population growth are expected to increase State and Territory Governments' nominal tax revenues.

[99] A broad measure of inflation is more appropriate than services sector inflation, or other measures of cost growth in the disability services sector, given that the objective of escalation parameters is not related to tracking scheme costs.

That said, funding splits are ultimately a reflection of what governments can afford and are prepared to contribute to the NDIS at a given time. Securing agreement is an important part of ensuring that funding is predictable. And making these agreements transparent also helps to prevent governments from reneging on their commitments.

How should the escalation parameters be set?

On the basis that escalation parameters should be set using inflation and population growth, the agreed 3.5 per cent per year would seem to be at the lower end of the likely range for these combined factors using reasonable assumptions. Using the last few years of low inflation as a short-term estimate, the agreed escalation parameters seem a little high, but it is questionable whether this low inflation will continue post 2019-20 (table 12.4). The assumed population growth of 1 per cent per year is significantly below projected and historical rates.

If population growth falls within the bounds of projections from the Australian Bureau of Statistics, and inflation falls within the Reserve Bank of Australia's medium-term target, then an escalation parameter of about 4 per cent per year (approximate midpoint of the 3.3-4.8 per cent range) would seem more appropriate for the period to 2023. This is the period over which the escalation parameters are to be set in the forthcoming bilateral agreements, with a review to be undertaken to reassess the parameters post 2023. This review should revise estimates of population and inflation for the next five-year period.

Table 12.4 **Possible population growth and inflation assumptions**
Different assumptions produce very different parameters (per cent)

	Population growth	*Inflation*	*Implied escalation parameter*[a]
Historical 3 year average annual growth (2014–2016)	1.5	1.6	3.1
Medium-term projections (2020–2023)	1.3–1.8[b]	2–3	3.3–4.8 (midpoint of 4.05)
Long-term projections (post-2050)	0.2–1.3	2–3	2.2–4.3

[a] Sum of population growth and inflation. [b] The Australian Bureau of Statistics projections have three different scenarios to project population growth. The numbers presented here are the range implied by their estimates.

Sources: ABS (*Australian Demographic Statistics, Dec 2016*, Cat. no. 3101.0; *Consumer price index Australia, June 2017*, Cat. no. 6401.0; *Population projections, Australia, 2012 (base) to 2101*, Cat. no. 3222.0).

Should escalation parameters vary by jurisdiction?

A potential issue with setting the escalation parameters on a national basis is that some states and territories can be expected to have faster population growth rates than others or differing

levels of economic growth. This could lead to different effective burdens upon some State and Territory Governments in funding their NDIS contributions. As the Northern Territory Government said:

> … for the NT the equivalent long term annual population growth is estimated at 1.5% and the average forecast CPI over the next five years is estimated at 1.2% per cent. Therefore, the 3.5% that the Territory has agreed to is higher than the growth expected in the NT. (sub. PP358, p. 7)

However, as mentioned above, the base funding allocation between State and Territory Governments will be adjusted to reflect Census population data in 2023.

RECOMMENDATION 12.2

From full scheme, the escalation parameters that determine the growth of State and Territory Government financial contributions to the costs of the National Disability Insurance Scheme should be set on the basis of population growth and inflation. This will maintain constant real per person contributions from the State and Territory Governments.

The Commission's assessment of projections of population and inflation over the period 2019-20 to 2023-24 suggests the escalation parameters should be set at 4 per cent, rather than the currently agreed 3.5 per cent.

The escalation parameters should be reassessed for the period beyond 2023-24, at 5 yearly intervals, based on the most contemporary projections of population and inflation at that time. The funding shares among the States and Territories should also be rebased according to the most contemporary census population data available at that time.

12.5 Funding an insurance-based scheme

When someone enters into an insurance contract, there is generally a guarantee that any valid claim will be honoured by the insurance company. Insurers therefore face significant risks that need to be managed — they need to satisfy all valid claims, but they do not know the actual costs of the claims that they will have to pay in any given year. They can also face very long-term liabilities when claims are granted.

Insurance schemes typically prepare actuarial forward estimates of costs over a period of time and adjust their insurance premiums in line with these estimates.

Insurers carry reserves to set aside money for future claims (box 12.4). These reserves can be used to respond to cost fluctuations, including in instances where those fluctuations may be temporary due to one-off events, or where actions need to be taken to ameliorate emerging cost pressures. This means that insurance premiums only need to be adjusted when it is clear that the cost fluctuations are sustained over the long term.

For public insurance schemes, having a funding buffer gives flexibility to respond to the inevitable annual fluctuations of costs, and so avoid governments needing to inject funds from general revenue or ration supports. A reserve also allows insurers to make upfront investments to reduce scheme costs over the longer term. However, it is important that any funds allocated to a reserve are raised efficiently, and there is transparency around access to and use of the funds.

Box 12.4 Reserves are built up through adjusting premiums

A key principle of insurance is that the liabilities created by claims should be backed by sufficient financial assets. Holding a pool of reserves is the typical way to achieve this.

In private insurance schemes, premiums are set to cover the expected cost of claims (often with a buffer to limit potential losses), administrative costs and a profit margin. For insurance where a claim has a life longer than a year, premium revenue is typically designed to exceed the annual cost of claims so that the insurance company can build up reserves. Provided the reserve assets are as large as the liabilities from outstanding claims, the insurance firm will remain solvent.

This principle is also applied in public insurance schemes, such as Victoria's Transport Accident Commission (TAC), New South Wales' Lifetime Care and Support (LCAS) (now part of icare), the Australian Government's ComCare, and New Zealand's Accident Compensation Corporation (ACC). In these schemes, levies or charges are used to collect enough revenue to cover a proportion of the full (lifetime) cost of current and expected new claims in the following year. The reserves are usually invested in financial markets by professional managers outside of the scheme.

The level of reserves held varies among schemes. For example, LCAS has financial assets approximately one and half times as large as their lifetime claim liabilities, while ComCare's financial assets are only about 80 per cent of its lifetime claim liabilities. These differences reflect a range of factors including differing: policies regarding the size of the asset base, assumptions regarding the size of liabilities and returns on investment, and performance of invested funds.

Reserve ratios of other public insurers in 2016

	Total financial assets	*Participant lifetime cost*	*Ratio*
	$ m	$ m	%
LCAS	4 371	2 939	149
TAC	11 973	13 901	86
ComCare	2 307	2 757	84
ACC[a]	37 859	36 663	103

[a] In New Zealand Dollars.

Sources: ACC (2016), ComCare (2016), icare (2016b) and TAC (2016).

But unlike other insurance schemes, the NDIA does not set its own premiums. As discussed earlier, it relies on funding contributions by the Australian and State and Territory Governments. And the financial risk associated with satisfying all valid claims for

reasonable and necessary support needs to be managed (without knowing exactly how much that will be in any given year, chapter 1).

Allowing the NDIA to manage discrepancies between actual and estimated costs in any given year is necessary to ensure that the NDIA and the public have confidence in the sufficiency and predictability of funding.

Current NDIS funding arrangements have two in-built mechanisms for managing fluctuations in expenses — cost overrun and cash ceiling arrangements.

Cost overrun arrangements

Under the current funding arrangements, any 'cost overruns' are to be funded by the Australian Government. However, what defines a cost overrun (or the circumstances when it occurs) is not clear. The Heads of Agreement state that:

> The Commonwealth will fund 100 per cent of the risk of any increase in costs associated with higher participant numbers and/or higher average per person care and support costs, and 100 per cent of DisabilityCare Australia's cash flow risk, during the launch and transition period.

Full scheme arrangements for cost overruns are not yet finalised.

Are the current arrangements appropriate?

Good risk management requires that those who are best placed to manage the risk of fluctuations in expenses should have responsibility for doing so.

Under current funding arrangements, the Australian Government has responsibility for the risk of fluctuations — State and Territory Government contributions to the NDIS are fixed contributions (effectively capped), and the Australian Government has committed to contributing the 'remainder'. However, the Bilateral Agreements do not spell out how the remainder is calculated, nor is it publicly stated whether the calculation of 'the remainder' is based on the NDIA's projections of lifetime scheme costs, or adjusted as actual scheme costs evolve.

There are a number of factors that can contribute to cost overruns, including:

- changes to the boundaries of the NDIS (defined in the NDIS Rules and interpreted by the Federal Court)
- inaccurate or outdated actuarial estimates of total scheme costs
- underestimates of the number of participants in bilateral agreements
- higher average package costs than estimated
- how efficiently the NDIA administers the scheme

- cost shifting from State and Territory Governments to the NDIS that increases scheme costs.

Many of these factors are not in the control of the Australian Government.

While no single entity has control over all of these factors, the NDIA has access to the best information about the factors driving fluctuations in expenses, not the Australian Government. If this information was used to calculate increases to funding contributions to the NDIS, and there was a buffer to account for the risk that actual costs might deviate from expected costs, then cost overruns should not occur, or only when cost increases are sudden and difficult to predict.

FINDING 12.1

If funding contributions to the National Disability Insurance Scheme increase in line with projected scheme costs and there is an actuarially-assessed buffer for risk, then cost overruns in a mature scheme will only occur where cost increases are sudden and difficult to predict.

The contributions of the Australian Government should be explicitly tied to the long-term projections of scheme costs based on the provision of reasonable and necessary supports, rather than committing to 'the remainder'. Calculating funding contributions in this way will provide the NDIA with sufficient certainty and flexibility to efficiently manage the costs of the scheme over the long term, rather than relying on injections of cash from the Australian Government under the current cost overrun arrangements. Such arrangements would put it on a much firmer insurance-based footing, and clearly differentiate it from a welfare program.

That is not to say that any government should commit to unconditionally increasing funding for the scheme — as noted in chapter 1, the scheme is only uncapped to the extent that taxpayers are willing to pay for it. Transparency and independent oversight are necessary to provide a check and balance on required scheme funding. Performance reporting is further discussed in chapter 11.

Projections of long-term costs should be generated by the NDIA. This information, along with details of the underlying assumptions, should be shared with the DSS, who would continue to generate the information provided to the Department of Finance in preparing the budget forward estimates. The independent review of the Annual Financial Sustainability Report (which includes the NDIA's projections) required under the NDIS Act should continue (chapter 11).

In the case of a sudden, unforeseeable increase in scheme costs that was not factored into government funding contributions, the Australian Government is the appropriate government to make any required cash injection given its access to a more efficient tax base than State and Territory Governments. As such, the current transition arrangements where

the Australian Government funds 100 per cent of cost overruns should continue for the full scheme.

RECOMMENDATION 12.3

From full scheme, the Australian Government should explicitly factor projected increases in scheme costs, based on the provision of reasonable and necessary supports, into the calculation of its contributions to the National Disability Insurance Scheme.

If cost overruns occur from full scheme, they should be funded by the Australian Government.

Reserve arrangements

Reserves act as a way of increasing funding certainty and providing a buffer for the risk that costs exceed available funds in a given year. As the Commission said in 2011, there should be a long-term link between costs and available funds, with a sufficient buffer provided for risk:

> In effect, the process of managing costs and revenues is like a dance of a pair of ballroom dancers — they are not always in the same position, but the pattern of their movements are orderly and they always remain linked. (PC 2011, p. 647)

In 2011, the Commission recommended the NDIS be structured as a 'pay-as-you-go' scheme and be established with a large enough reserve fund to smooth out fluctuations and reduce uncertainty. The Commission noted that a reserve would act as a buffer against unpredictability, and avoid the Australian Government needing to inject additional funds from general revenue when claim costs were higher than expected in a given year (PC 2011, p. 449).

The Tasmanian Government pointed out that the transition funding arrangements provide the NDIA with a buffer:

> The ability for the NDIA to retain up to three months of reserves was agreed by governments as part of the funding mechanism for transition in recognition of the NDIA's need to have access to a buffer to fund a surge in claims during the rollout. (sub. PP247, p. 11)

As outlined above, during transition, the NDIA can access between one and three months' worth of contributions from package cost underspends. However, any cash reserves above this need to be returned to contributing governments in proportion to their contribution.

Participants generally supported giving the NDIA a pool of reserves

The NDIA supported establishing a reserve, but was cautious about losing access to its current cash buffer:

> Insurance companies and most other existing injury support schemes typically hold significant reserves on their balance sheet. The NDIA notes that any future contingency reserve could only be built from Full Scheme. This is in comparison to the Transition, where States and Territories pay the NDIA in arrears. The appropriate level of any future contingency reserve depends on the specific purposes identified for the reserve (related to operating 'like an insurance scheme').
>
> At the same time, the NDIA notes that it would be undesirable during the Transition to fund the creation of a contingency reserve through removal of the NDIA's current cash buffer because this would reduce operating flexibility, particularly as the NDIA strives to review the appropriateness of the NDIA participant and provider pathways. (sub. PP327, p. 66)

Bruce Bonyhady said:

> Currently, the NDIA has no capacity to deal with unexpected contingencies, other than seek government top-ups, and this is a weakness in the current governance and funding arrangements. (sub. 100, p. 10)

Other participants pointed to the potential benefits from the use of reserves:

> Victoria supports establishing a future contingency reserve to allow the NDIA to manage fluctuations in expenditure and access a level of reserves that better reflect the level of risk it needs to manage. (Victorian Government, sub. PP298, p. 10)
>
> It would seem appropriate that a reserve fund should be established as any enterprise seeks to do where future demands are uncertain. (Quality Living Options Bendigo Inc, sub. PP220, p. 3)

However, others were sceptical of the need for a reserve:

> Such a scheme should be funded like any other government program, through the budget process. Government budget processes are well developed to deal with unexpected expenditure demands, including any necessary decisions to limit future expenditures. (Richard Madden, sub. PP307, p. 8)
>
> Government funding is fungible, and given the NDIA has the financial backing of the Australian, State and Territory Governments, an alternative arrangement should be considered to make funding available for use in a manner consistent with the use of a contingency reserve, but without the need for a large pool of cash to be quarantined for that purpose. (ACT, sub. PP312, p. 14)

There are benefits from establishing a pool of reserves

Providing the NDIA with a pool of reserves has the advantage of providing certainty to participants and providers that the scheme will be enduring. This is an important departure from previous highly uncertain and heavily rationed disability arrangements:

> The need for a stable revenue source also suggests that a funding buffer is required, since there will be annual fluctuations on the cost side. In those periods, the NDIS would need to run down a funding 'buffer' to meet those needs, while it would need to build up the reserve level at other times. (PC 2011, p. 650)

A pool of reserves will also allow the NDIA the funding flexibility to take a long-term approach to participants needs to reduce their support requirements in the long term (including upfront investments to reduce future outlays and ultimately reduce scheme costs). While the NDIA could bring forward its existing allocation of funding to make these investments or manage fluctuations in expenses (either as part of the cost overrun arrangements or seeking additional money from the Australian Government) like any other government expenditure program, these arrangements do not provide the NDIA with certainty over access to those funds, even though this is critical to the application of insurance principles.

The need for a pool of reserves is not negated by the Australian Government being the 'funder of last resort'. Having reserves available provides transparent and tangible evidence of the commitment to fund disability services, now and into the future. It is a bulwark against the vagaries of annual budget cycles, and avoids potential shortfalls and rationing.

It is worth noting that providing the NDIA with a pool of reserves does not mean that the NDIA should be responsible for the day-to-day management and investment of those funds (PC 2011, p. 35). Other public insurance schemes, such as the Transport Accident Commission and NSW Lifetime Care and Support, outsource this function.

Reserves should be gradually built up over time

The NDIA's current cash ceiling arrangements, with access to three months of underspends, does not give the NDIA a means for building up a reserve fund, as there is a cap on accumulations. Other public insurance schemes, such as the TAC and NSW Lifetime Care and Support (now part of icare), gradually built up reserves over time (box 12.5).

The Commission considers contributions to the NDIS should similarly provide enough leeway for the NDIA to manage long-term costs (including making early investments). Insurance schemes typically adjust the premiums that they charge to reflect changes in cost forecasts over a set period of time, and the Commission recommended earlier that the calculation of Australian Government contributions should take into account changes in costs over the long term. Allowing some future funding to be brought forward into current years with reference to these projected long-term costs to create a buffer for risk is consistent with this recommendation, and consistent with the approach of other comparable insurance schemes.

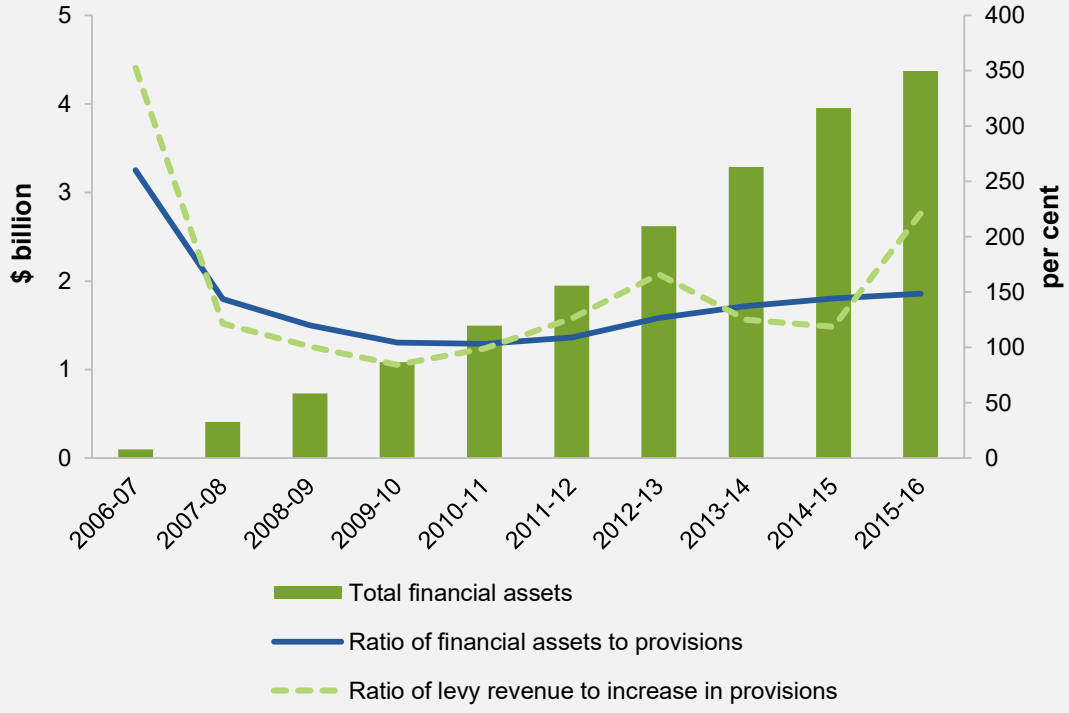
One way this could be achieved would be to create a buffer for risk by including a small margin in the contributions of the Australian Government that allows some future contributions to be brought forward to the current year. In 2011, the Commission recommended that the NDIS be funded by a formula that had a margin over and above yearly expenses to buffer against fluctuations in expenses to create a partial reserve fund (PC 2011, p. 35).

Box 12.5 NSW Lifetime Care and Support built reserves up gradually

The NSW Lifetime Care and Support Scheme (now part of icare) was established in 2006 by the NSW Government to provide individuals with no-fault insurance for catastrophic motor vehicle accidents in New South Wales.

NSW Lifetime Care and Support is funded through the Medical Care and Services Levy on Compulsory Third Party insurance which has funded annual claims and also built up a pool of reserves. The reserves held by NSW Lifetime Care and Support were not established by an initial capital injection, but have built up gradually over time through this levy. Reserves (after returns on investment) are now more than sufficient to cover the lifetime cost of all existing and new participants and the scheme's operating expenses in that year, plus a profit and risk margin.

Build-up of Lifetime Care and Support Reserves



Source: icare (2016) and LCAS (2007, 2008, 2009, 2010, 2011, 2012, 2013, 2014, 2015).

A gradual accumulation of funds is a more fiscally sustainable way of building up reserves than a large initial capital injection, and this is consistent with the approach used by the TAC and NSW Lifetime Care and Support. Further, when the NDIS is in a steady state, it is likely that entry of participants into the Scheme will be fairly constant. Hence a fairly constant trickle of reserve funds to meet participants' early investment needs is likely to be appropriate for a mature scheme.

While the Commission does not consider that there should be a hard cap on the level of reserves held by the NDIA, a target amount is appropriate. As the Commission recommended in 2011, the level of reserves should be determined by an actuarial and economic determination of optimal reserves (PC 2011, pp. 671–672). There is no urgency

to build substantial reserves now. But there is an imperative for governments to make an immediate commitment to establishing a pool of reserves. It is an essential feature of an insurance-based scheme.

RECOMMENDATION 12.4

Governments should commit now to providing a pool of reserves for the National Disability Insurance Agency. The pool should build up gradually over time, with the target amount based on an actuarial and economic analysis of the optimal level of reserves.

13 Data and evidence

Key points

- The National Disability Insurance Scheme (NDIS) requires good quality data and evidence to inform an insurance based approach to disability support, and to understand any emerging risks to the financial sustainability of the scheme. Providing funding for comprehensive, accessible data is a sound investment when considered in the light of its importance in informing policy for the $22 billion scheme.
- A process of continuous improvement is embedded into the National Disability Insurance Agency's (NDIA) data collection approach — the NDIA's framework for monitoring financial sustainability involves continuous monitoring and evaluation of participant outcomes and costs.
- The NDIA collects data on participants when they access the scheme, when plans are developed, at plan implementation and plan review. At full scheme, there will be data on about 475 000 scheme participants (and progressively data will be collected for many participants over their lifetime).
- A comprehensive data warehouse and reporting capability (including for tracking longitudinal outcomes) are required to support the actuarial and research functions of the NDIA. Currently, the NDIA do not have the required capability to collect all the necessary data for the scheme. It is important that capability constraints are effectively addressed and the data warehouse capability developed.
- Ideally the NDIS will fit seamlessly within the landscape of services delivered to all people with disability. Data on services provided to people with disability outside the NDIS will be critical for assessing the performance of the scheme, and for identifying potential service gaps.
- Data collected on services provided outside the NDIS are being scaled back at a time when it is most needed. Governments should commit to the ongoing funding of the Survey of Disability, Ageing and Carers, and an expanded Disability Services National Minimum Data Set to include supports to people with disability not in the NDIS.
- Linking NDIS data with other datasets has the potential to provide a more complete picture on people with disability. The use of 'flags' in data collections for NDIS participants and people with disability can help shed light on differences in how people with disability interact with mainstream services and on outcomes. Better linking of datasets can also improve data collection efficiency.
- It is imperative that wider access to the NDIA's longitudinal database is permitted to allow research to be undertaken (with appropriate safeguards and policies to protect privacy).
- The NDIA should make public the details of the data it holds, and consult with stakeholders on how best to provide access to this data.

The National Disability Insurance Scheme (NDIS) requires good quality data and evidence to inform an insurance based approach to disability support, and to understand emerging risks to the financial sustainability of the scheme. Providing funding for comprehensive, accessible data is a sound investment when considered in the light of its importance in informing policy for the $22 billion NDIS.

This chapter examines the role of data for the NDIS (section 13.1), and the importance of data collection in relation to disability services provided outside the NDIS (section 13.2). Sections 13.3 and 13.4 look at linking and sharing data and section 13.5 discusses best practice principles for handling data and proposes a way forward.

13.1 The pivotal role of data for the NDIS

Data and evidence are pivotal to any insurance scheme. The financial performance of insurers depends on the quality of their data and how well the data are integrated into day-to-day decision making.

Like other insurance schemes, the NDIS relies on data and analysis systems to monitor (in real time) cost pressures and identify and manage emerging risks to the financial sustainability of the scheme.

Practices of continuous improvement are integrated into the NDIS (figure 13.1). As the NDIA said:

> The first insurance principle is about embedding practices of continuous improvement into the NDIS. It involves comparing actuarial forecasts of cost and participant outcomes with the actual experience of individuals, in order to maximise lifetime opportunities and minimise the lifetime costs of those who are insured. (sub. 161, p. 24)

The NDIS Prudential governance framework also states that:

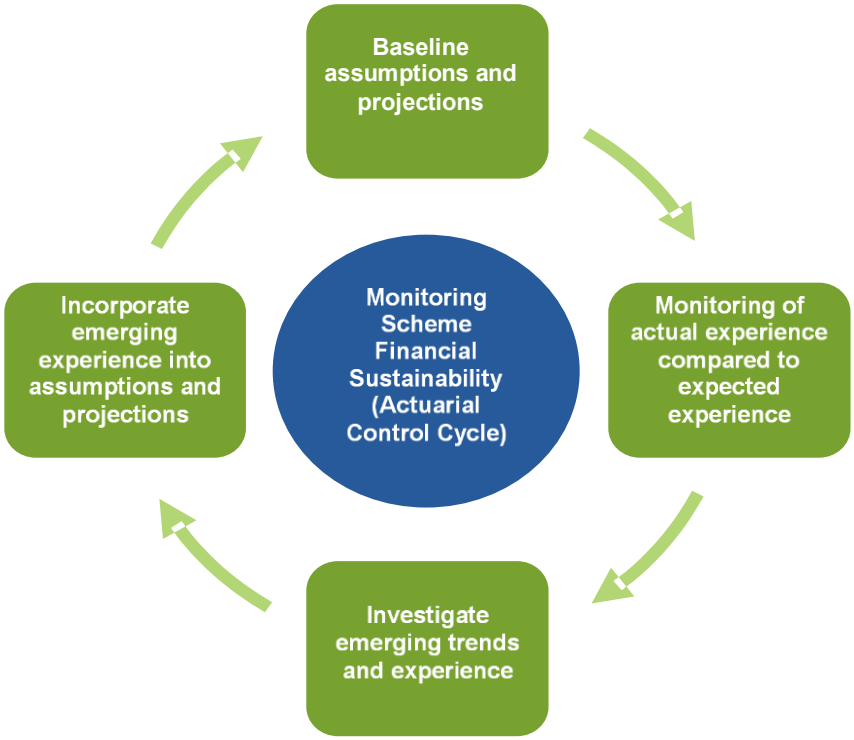
> The NDIA will have access to a person centred longitudinal database of all NDIS participants, and where necessary supplementary linked data sources, containing sufficient information to:
>
> - provide the NDIA operational staff with real-time comprehensive data and information on participant utilisation, cost of supports and participants outcomes; and
> - provide the necessary information for the Scheme Actuary to develop reports on quarterly experience, future expenditure and financial sustainability (NDIA 2016h, p. 23).

The NDIA's framework for monitoring financial sustainability (used by the Scheme Actuaries) includes an evaluation of participant outcomes and costs and involves collecting data on:

- the number of participants
- the characteristics of participants (to allow analysis of reference groups)
- the outcomes of participants

- the cost of supports of participants (sub. 161, p. 115).

Figure 13.1 **Financial sustainability monitoring framework**
Continuous monitoring and evaluation of outcomes and costs



Source: NDIA (sub. 161, p. 115).

This information is used by the NDIA to implement any changes that might be required to ensure that the scheme remains financially sustainable (figure 13.1). And, as discussed in chapter 11, it is also used for the NDIA performance reporting requirements, including the quarterly monitoring report and the Annual Financial Sustainability Report.

The NDIA collects data on participants when they access the scheme, when plans are developed, at plan implementation and plan review (figure 13.2). At full scheme, there will be data on about 475 000 scheme participants, including data on outcomes across eight key domains:

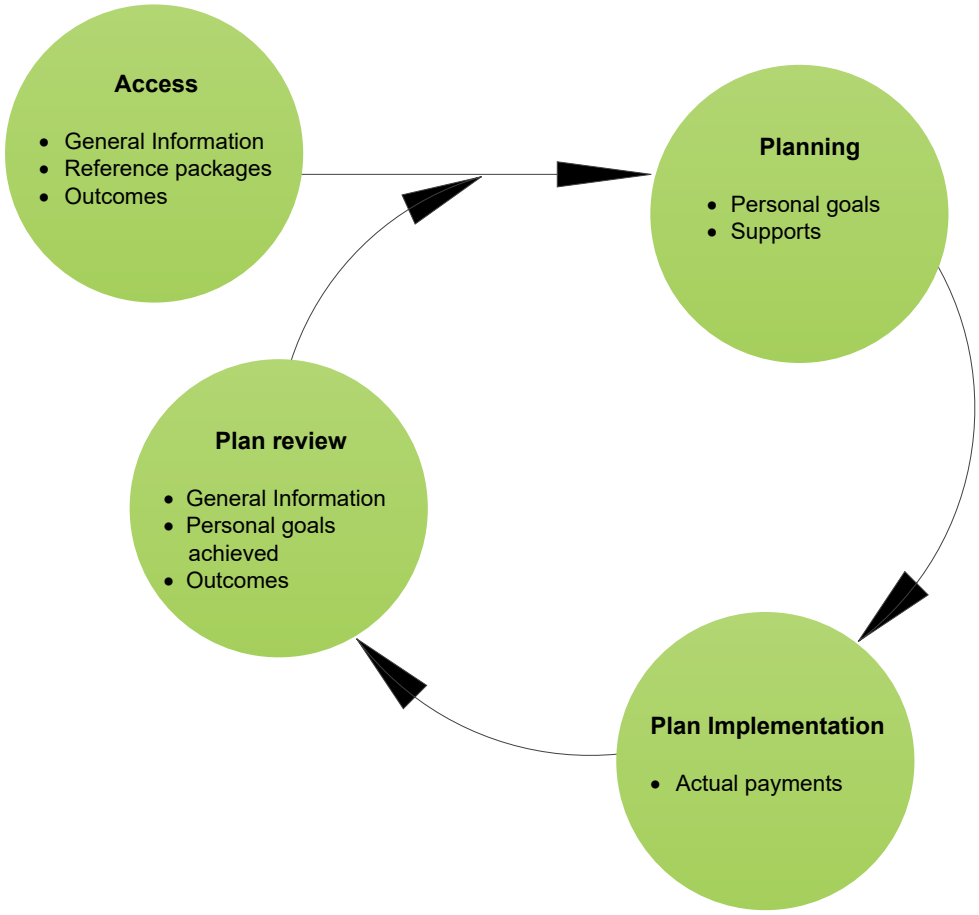
- choice and control
- daily activities
- relationships
- home
- health and wellbeing

- lifelong learning
- work
- social, community and civic participation (chapter 3, box 3.1).

A key advantage of a longitudinal database is that it can measure change over time. As most participants will receive individualised packages under the scheme over their lifetime, with time, NDIS data will be available for participants over their lifetime. Commenting on the NDIA's longitudinal dataset to support actuarial analysis of the scheme, Bruce Bonyhady said 'the NDIA is building the most comprehensive population-based longitudinal database on disability in the world' (sub. 100, p. 15).

The NDIS longitudinal dataset will take some time to build, but the NDIA are already using data from the trials and transition to track scheme performance (including participant outcomes) and identify emerging cost pressures to the scheme (chapter 2).

Figure 13.2 **Collecting data on participants**



Source: Based on NDIA (2016b, p. 10).

The critical role of data for the NDIS and the actuarial approach for measuring performance was commented on by a number of study participants. The Northern Territory Government, for example, said:

> Performance monitoring and reporting arrangements have the potential to affect the delivery and financial sustainability of the NDIS. Without robust and timely data (both qualitative and quantitative) the transition and outcomes of the Scheme are at risk. (sub. 205, p. 3)

The New South Wales Government said:

> A robust actuarial approach is required to measure scheme performance, including against agreed indicators and broader factors impacting on scheme outcomes. This will provide longitudinal data to refine reference packages as the scheme matures, and support market facilitation in areas where the supply of supports is limited. (sub. 60, p. 10)

And the Australian Institute of Health and Welfare commented on the potential benefits of the NDIS dataset:

> The establishment of the NDIS brings with it the opportunity to capture more comprehensive data, as well as opportunities to enhance data access in line with the Australian Government's public data agenda. Indeed, for the first time in Australia, data on scheme participants will enable a joined-up view of their disability support needs, the services provided in response to those needs, and the social and economic outcomes of those services. (sub. PP349, p. 5)

Building the evidence about what works and why

Building the evidence base about what works and does not work for different groups (or what yields the best outcomes at the lowest cost) is also critical. This information is important not only for the NDIA (to maximise the benefits and minimise the costs of the scheme), but also for people with disability and their carers and providers of disability services. Mind Australia, for example, said:

> At present, a lack of evidence on what works for whom and in what circumstances is lacking and needs to be developed as part of ensuring that planners can assist people to make purchasing decisions that are in their best interests, and which deliver sustainable outcomes desired by the scheme. (sub. 144, p. 8)

The Centre of Research Excellence in Disability Health also said:

> As the National Disability Insurance Scheme moves to full rollout there will be a comprehensive data base on all components of the scheme and user experiences such as service provision, service use, costs, and social, economic and health outcomes of the people with disabilities. It is critical to use this data to evaluate the outcomes of the Scheme and to identify how it can be improved.
>
> Importantly the NDIA data will be longitudinal and will enable the tracking of outcomes within and between individuals over time. (sub. 69, p. 2)

And the Victorian Government pointed to the importance of linking support plans with outcomes:

> Ensuring the sustainability of scheme costs will not only require careful management of access and scheme boundaries, consistent with the core NDIS objectives, but will also depend critically on the effectiveness of NDIA planning and assessment processes in delivering an insurance-based approach to investment to support people with disabilities.
>
> This requires an evidence base derived from longitudinal data that links individual support plans with client outcomes, and this will take time. (sub. 174, p. 4)

Facilitating innovation and undertaking research (such as controlled experiments) can help identify low cost choices among effective disability supports and interventions and shed light on what processes used by the NDIS are most effective (for example, planning approaches). One of the NDIA's insurance principles is investment in research and innovation — that is, to encourage and build the capacity and capability for innovation, outcomes analysis and evidence-based decisions on early interventions (chapter 1, box 1.1). The NDIA said it:

> … invests in research and innovation to support the long-term approach of the insurance approach. Investment in research is focused on supporting the NDIS make evidence-based decisions on early interventions to maximise lifetime value for participants. (sub. 161, p. 25)

The NDIA is currently focusing on identifying key transition points for specific cohorts and designing early interventions. The areas of focus include:

- the Early Childhood Early Intervention
- School Leaver Employment Supports
- an intervention initiative for the 7–14 years cohort (sub. 161, pp. 25–6).

The NDIA has also commissioned research on hearing, Autism Spectrum Disorder interventions, Foetal Alcohol Spectrum Disorder interventions and Assistance Animals as supports for people with disability (sub. 161, p. 26).

But it is still very early days in terms of building the evidence base. As the Department of Social Services (DSS) said:

> The insurance-basis of the NDIS is still maturing and it is too early to assess its long-term effectiveness in improving wellbeing for people with disabilities and managing costs in the Scheme. The evidence-base for lifetime cost estimation is increasing, and will need investment to be sufficiently robust and broad-based to inform individualised supports. The impact and use of technology by participants is also important to consider and incorporate into the evidence-base. While this will take time, the early and effective implementation of insurance-based principles is necessary to avoid unsustainable cost escalation. (sub. 146, p. 25)

Data gaps within the NDIS data collection

In this report, the Commission has identified a number of data gaps within the NDIS collection and made recommendations accordingly. For example, the NDIA does not collect

information on which participants have employment restrictions (chapter 3) or on which activity domains are relevant for individuals when they enter the scheme (chapter 4). The evidence base on the effectiveness of Information, Linkages and Capacity Building activities is also very thin (chapter 6), and there are gaps in the NDIA's performance reporting (chapter 11).

While more data would provide the benefit of a stronger evidence base, the benefit must be weighed against the costs of gathering the extra data.

- The collection of data imposes a burden on participants, providers and NDIA staff. A balance needs to be struck between the impost on people (and the possibility of a decline in data quality if too much is asked) and the potential benefit from the additional data.
- There are costs associated with establishing and supporting adequate information, communication and technology (ICT) and administrative systems.
- While the cost of storing data has fallen substantially in recent years, there is a cost to modifying programs to enable information to be recorded.

When deciding what data to collect, the scope to leverage off other data collections to lower the impost on participants, providers and NDIA staff must also be taken into account.

Does the NDIA have the capability to collect the required data?

The NDIS is a new scheme, and the capability to collect data is evolving. The NDIA identified the collection of data on participants as a 'major challenge'.

> Another major challenge is ensuring appropriate collection and access to quality data on participant needs, supports and outcomes. A comprehensive data warehouse and reporting capability, including for tracking longitudinal outcomes is required. Currently, the NDIA does not have the required capability and continued development in this area is critical. (sub. 161, p. 118)

Some examples of problems with the ICT system for the NDIS include that it:

- cannot transfer free text to the data warehouse, so details on individual circumstances that could impact on reasonable and necessary supports are not readily available
- does not transfer all required information on participant assessments to the data warehouse
  - for example, when assessing participants' level of function, the data warehouse is provided a standardised functionality score, but information on the screening tool used for the assessment is not transferred to the data warehouse. This compromises the ability of the NDIA to assess the appropriateness of screening tools being used or to assess how consistently a screening tool is operating in practice.

The plan was always for a staged development of ICT capacity for the NDIS. The Australian Government allocated $143 million over four years for the implementation of the system

(with the appropriation split between the NDIA, the DSS and the Department of Human Services) (DSS 2015a, p. 1 NDIA, sub 161, p. 14), with capacity building to focus on the following.

- In the first year: the ability to accept participants into the scheme, register providers and enable participants and providers to make claims.
- In the second year: improving participant and provider functionality, workflow management, business assurance and fraud prevention.
- In the third and fourth years: the e-MarketPlace and broadening communication options.
- The need for work supporting longitudinal data analysis, monitoring and facilitating an insurance approach was noted, but no time frame was specified (NDIA, sub. 161, pp. 14–15).

The NDIA has recognised that the remedial actions to address ICT failures 'have also put the development of other ICT initiatives under pressure' (sub. 161, p. 15). For example, the development of the e-MarketPlace was scheduled for 2017-18 (NDIA 2016i, pp. 31–32), but the NDIA recently indicated that the e-market program is in the design phase and that there is now no fixed time period for the launch (NDIA 2017d).

The Commission is concerned that, without ongoing improvements in this area, there is a risk that the necessary changes to the ICT system (to have a fully operational data warehouse that can support the actuarial and research functions of the Agency) will not be implemented fast enough.

While the scheme is still in the early stages of operation, it is important that the NDIA closely monitor the progress of resolving the system interface issues and the development of the data warehouse capability. In particular, ensuring that the actions are sufficiently resourced and prioritised, and where necessary, that remedial action is taken. The NDIA's annual report should include an item on the progress of the ICT system and if there are any problems that could disrupt the operation of the scheme or affect the assessment of scheme progress or financial sustainability.

Constraints on data collection

Because the NDIA needs to draw on evidence from outside the scheme, it faces the potential risk that external data collections may change. The NDIA will need to monitor the data being collected outside the scheme. Over time, it may be appropriate to revise the collection of data within the scheme if key external comparators cannot be identified.

13.2 Data on disability services outside the NDIS

Disability data collected outside the scheme should continue

Not all data relevant for assessing the effectiveness of the NDIS can, or should be, collected within the scheme. And, as a number of study participants noted, it is important to understand the wider environment in which the NDIS operates. The Australian Institute of Health and Welfare (AIHW), for example, said:

> … about 89% of all people with disability in Australia, and 36% of people with severe or profound disability aged under 65, won't be supported by the NDIS … As such, truly understanding the costs of, and pressures on, the NDIS, as well as the experiences of people with disability more broadly, will require understanding the wider environment in which the NDIS operates. (sub. PP349, p. 1)

Also:

> The ability to articulate a broader story — with the NDIS included in the context of the wider suite of supports and payments for people with disability — will be critical to governments' understanding, not only of the costs of, and pressure on, the NDIS, but also of the broader experiences of, and outcomes for, people with disability. (sub. PP349, p. i)

The two main existing datasets that collect information on supports for people with disability are:

- the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC)
- the Disability Service National Minimum Data Set (NMDS) — the main source of information on government provided or funded services for people with disability outside the NDIS (box 13.1).

The SDAC collects information on the level of support needs of people with disability and the level of natural supports available to them. Because the SDAC covers both NDIS and non-NDIS participants, it will continue to be a valuable data source post-NDIS rollout — it can also provide valuable information on the needs and level of ability of future NDIS participants.

Some of the benefits of the NDIS are expected to result from reduced demands on other government supports (chapter 3). As Anglicare Australia said, the impacts of the scheme will include the cost implications on other government programs.

> … it is incumbent on the Commission to recommend evaluation measures regarding the scheme's financial sustainability that take into account the costs avoided or passed on to other areas of government if the NDIS is not properly supported. (sub. 157, p. 21)

And the DSS said:

> Better cross-system reporting on disability could make system boundaries and responsibilities more transparent, as well as give a more coherent picture of improvements in services to people with disability. (sub. 146, p. 5)

Box 13.1 Two important data collections outside the NDIS

Survey of Disability, Ageing and Carers

The Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) provides a comprehensive snapshot of the social and economic participation, circumstances and limitations of people with disability and people over 65 years, and (informal) carers of these two groups.

The latest (2015) SDAC surveyed about 25 750 households (private dwellings and self-care retirement villages) and 1000 cared-accommodation establishments. The survey was the eighth iteration of a series of similar surveys that began in 1981.

Groups covered

The three groups of interest in SDAC are:

- people with disability: disability is defined as any limitation, restriction or impairment that restricts everyday activity and has lasted (or is likely to last) at least 6 months. Both NDIS and non-NDIS participants are included
- people over 65 years old: also recorded whether they have a disease or disorder likely to last longer than six months
- carers: classified as primary carer (those over 15 years old that provide the most support) or other carers (those that provide care, but not the most care, or are under 15 years old).

Goals

SDAC's main objectives are to:

- measure the prevalence of disability in Australia
- measure the need for support of older people and those with disability
- provide a demographic and socio-economic profile of people with disability, older people and carers compared with the general population
- information on carers and those cared for.

NDIS relevant information

SDAC allows valuable insights on the NDIS market by indicating the:

- level of unmet demand for disability services
- level and sustainability of informal caring arrangements
- social and economic circumstances and participation of people with disabilities and their carers.

(continued next page)

Box 13.1 (continued)

Disability Services National Minimum Data Set

The Disability Services National Minimum Data Set (NMDS) is an annual collection and collation of a standard set of data items on disability support services provided under the National Disability Agreement. The data are collected from service users by funded agencies, and is provided to jurisdictions, which in turn provide the data to the Australian Institute of Health and Welfare (AIHW) for national collation and reporting.

The services currently covered by the NMDS include:

- *accommodation support*: services that provide accommodation to people with disability, and services that provide support to enable a person with disability to remain in their existing accommodation or to move to more suitable or appropriate accommodation
- *community support*: services that provide the support needed for a person with disability to live in a non-institutional setting
- *community access*: services designed to provide opportunities for people with disability to gain and use their abilities to enjoy their full potential for social independence
- *respite*: services that provide a short-term and time-limited break for families and other voluntary caregivers of people with disability to help support and maintain the primary caregiving relationship, while providing a positive experience for the person with disability
- *open employment*: services that provide employment assistance to people with disability in obtaining and/or retaining paid employment in the open labour market
- *supported employment*: services that provide employment opportunities and assistance to people with disability to work in specialised and supported work environments
- *advocacy, information, alternative forms of communication*: advocacy; information/referral; combined information/advocacy; mutual support/self-help groups; and alternative formats of communication
- *other support*: research and evaluation; training and development; peak bodies; and 'other support services'.

Sources: ABS (2016a), AIHW (2017a, 2017b).

The AIHW identified a number of data gaps.

> While there is some information about the use of specialist services by people with disability (for example, those provided under the National Disability Agreement, now in transition to the NDIS), we know little about their access to, and use of, mainstream and other services. We also lack a strong evidence base supporting our understanding of the interactions between sectors. (sub. PP349, p. 2)

The AIHW also highlighted the importance of understanding the interaction with, and role of, other services in meeting the needs of people with disability, including:

- mainstream services, such as health, aged care and housing
- specialist supports provided outside the NDIS, such as mental health services

- other supports, such as those provided by informal carers and the community more generally (sub. PP349, p. 2).

Concerns raised about current disability data collections

A number of stakeholders raised concerns about the ongoing funding arrangements for SDAC. Richard Madden said:

> SDAC funding is not secure. The ABS conducts the survey each three years, but must rely on funding from stakeholders (Commonwealth Departments of Social Services and Health, and States and Territories). Funding also determines the sample size. (sub. 101, pp. 11)

The DSS also said that it:

> … notes that not all jurisdictions are contributing funding towards the 2018 Survey of Disability, Ageing and Carers (SDAC). (sub. PP318, p. 11)

Currently, the ABS conducts the SDAC every six years, with an additional survey every three years if funding is provided. In recent years, the survey has been conducted every three years, with half the cost of this second survey funded by the Australian Government Departments of Social Services and Health and the remaining funds provided by the States and Territories (with contributions based on population levels).

The Commission understands that the cost of the 2018 survey is about $19 million. While most jurisdictions have agreed to contribute funding, some are yet to commit. Without ongoing commitment of funds, there is uncertainty about the frequency of the survey and/or how representative the survey will be (as the sample size may be reduced).

The SDAC is important because it provides outcomes data on people with disability both inside and outside the NDIS (as well as for carers) and the extent of unmet need. The AIHW noted that 'the planned 2018 iteration will be well timed to capture relevant information towards the end of the NDIS roll-out period' (sub. PP349, p. 5).

Less frequent (every six years instead of every three) and/or less reliable data will mean less up-to-date data to inform the outcomes during the critical early years of the NDIS. As the AIHW put it:

> … there is a risk that the vital SDAC information may only be available each 6 years, which is too infrequent to inform the experiences and outcomes associated with such a major policy reform as the NDIS. (sub. PP349, p. 5)

RECOMMENDATION 13.1

Australian, State and Territory Governments should commit, by June 2018, to fund (on an ongoing basis) the Australian Bureau of Statistics Survey of Disability, Ageing and Carers, so it can be conducted every three years.

Concerns were also raised about other datasets being discontinued as supports are transitioned to the NDIS. The DSS, for example, said:

> One way to better understand how mainstream services and the NDIS are supporting people with disability is to ensure adequate data collection and reporting. As States wind down the provision of specialist disability services, there is a risk State provided data may decrease. The NDIS will provide a rich source of new data, but only for around one tenth of the total population of people with a disability. DSS considers that all governments need to commit to sustaining and enhancing data collection and reporting on people with disability access to services in cost effective ways. (sub. PP318, p. 11)

Addressing interface issues and data gaps

With the transition to the NDIS, many programs that provide support to people with disability are being changed or discontinued (chapter 6). In addition, some supports previously provided through specialist disability programs will be provided by other systems (for example, some supports for people with psychosocial conditions may be provided through health systems).

While there may be reporting on services provided for each of these programs, it is unlikely that a comprehensive picture of supports provided to people with disability will be available unless a unified reporting system is agreed to. To date, reporting on specialist disability programs has occurred under the National Disability Strategy and data collected through the NMDS.

Where governments provide or fund supports to people with disability, they are likely to collect information on the programs and the characteristics of clients. There would be a small additional cost for governments to collect information on disability and NDIS participation status as part of these data collections — and in many cases, disability status is already collected.

One of the main impediments to expanding the NMDS to collect information on a wider set of services provided to people with disability will be identifying the additional information to collect. This will take time, but should begin as soon as possible.

There are relevant working groups operating under the National Disability Agreement with the expertise to identify the range of services provided to people with disability (the Senior Officers Working Group) and the technical knowledge of the data (the Research and Data Working Group). Each working group comprises of subject matter experts from State, Territory and the Australian Governments. These groups should be authorised to begin planning changes to the NMDS.

Broadening the data collection under the NMDS will not only provide the NDIA with better information to manage scheme costs and outcomes, but also an evidence base for monitoring services provided to people with disability who are not eligible for the NDIS. This

information could also provide insights on any cost shifting from the NDIS onto State and Territory provided services.

RECOMMENDATION 13.2

The Australian, State and Territory Governments should agree to expand the data collection for the Disability Services National Minimum Data Set to include supports to people with disability that are provided or funded by governments outside the National Disability Insurance Scheme (NDIS).

The data collected should include services provided to NDIS participants, but not provided by the NDIS.

A decision on the data to be collected should be made by June 2018, with the broader data to be included in the 2018-19 Disability Services National Minimum Data Set.

13.3 Linking data

Linking datasets for improved collection efficiency and more insights

Data linkage is a process that allows information from datasets to be combined (while also allowing privacy to be preserved). Data linkage has the potential to fill current gaps in what we know about people with disability. As the AIHW said:

> … integrating data in this way can tell a much more powerful, person-centred story than is possible from individual datasets in isolation, and can help policy makers to improve their understanding of a range of issues. … Linkage can also be used to assess outcomes at different 'levels' or for different cohorts (for example, for Indigenous Australians). (sub. PP349, p. 2)

Examples include linking specialist disability services or payments data to national hospital, Medicare Benefits Schedule or Pharmaceutical Benefits Scheme and aged care data to shed light on how people with disability interact with health services.

Linked data will also be important for tracking outcomes for people who leave the scheme in the future. This would be most relevant for people who join the scheme through early intervention pathways and people who will exit to use the aged care system.

But there are also practical challenges with linking datasets, including gaining approval to link data so that researchers can analyse data and release results in a timely way (AIHW, sub. PP349, p. 3).

Current Australian Government policy is to optimise the social value from administrative data collections.

> The data held by the Australian Government is a strategic national resource that holds considerable value for growing the economy, improving service delivery and transforming policy outcomes for the Nation. … The Australian Government commits to optimise the use and reuse

> of public data; to release non sensitive data as open by default; and to collaborate with the private and research sectors to extend the value of public data for the benefit of the Australian public. (Turnbull 2015, p. 1)

But as the Commission's recent *Data Availability and Use* inquiry (PC 2017a, pp. 114–116) highlighted, there is considerable scope to use linked datasets better and more often in policy design and analysis. If the recommendations of that inquiry are adopted (the Australian Government is currently considering a response), the scope for linking administrative datasets will be enhanced.

Data linkage keys

A data linkage key is a way of identifying records from multiple datasets that relate to the same person or organisation. If a common unique identifier is used (such as a Medicare number or Australian Business Number), datasets can be linked using the identifier. In the absence of a common identifier, it will be necessary to create a linkage key from a range of identifying information (such as name, date of birth and address).

While the initial linkage will require access to identifying information, once the match is made, a key can be developed that matches the unique identifiers for the same individual across the datasets. That data linkage key can then be used to link datasets that do not contain identifying information (thus assisting in protecting privacy).

The Commission's *Data Availability and Use* inquiry recommended the retention of linkage keys (PC 2017a, p. 44). The retention of linkage keys will be critical for the NDIA obtaining information in a timely and cost effective manner.

The NDIA will need to regularly update information to assess the lifelong impacts of the scheme. Retaining data linkage keys will reduce the cost and effort that is required to link administrative datasets. It should also reduce the rate of failed matches between the datasets.

Retention of data linkage keys should also reduce the need to duplicate efforts to 'clean' datasets. Administrative datasets often have issues with data quality (such as misspelt entries, inconsistent dates or data recorded in the wrong units of measurement) and retaining data linkage keys can overcome the need to replicate data cleaning.

Linking to surveys

There are some recent examples of survey information being linked with administrative datasets (ABS 2011a, 2011b, 2017b) that could provide a template for linking NDIS data with relevant surveys (such as the SDAC and the General Social Survey).

The ability to link NDIS data with these surveys would be enhanced if the surveys included a 'flag' indicating if the respondent was a NDIS participant. The SDAC included a flag for NDIS participants in the 2015 version of the survey.

The AIHW is also working on including a NDIS participant flag in some of the Institute's surveys, including by States and Territories, for future implementation in the AIHW's Specialist Homelessness Services Collection (sub. PP349, p. 4). Commenting on a NDIS flag, the AIHW said:

> The AIHW is developing a flag for use in data collections to indicate whether a person is receiving support through the NDIS. This flag could be used to look at the use of mainstream and other services by NDIS participants. If used together with the standardised disability flag, it could potentially also be used to examine participation in the NDIS as well as to look at if there are differences in the use of mainstream services between NDIS participants and other people with disability. (sub. PP349, p. 4)

13.4 Sharing data

Access to the longitudinal dataset

A number of stakeholders argued that it is critical that researchers are able to access the NDIA's longitudinal dataset (box 13.2). As the Centre of Research Excellence in Disability and Health noted, the NDIA has limited capacity to conduct research, and:

> … it is important that this rich data is made available to external researchers from a broad range of disciplines (e.g. business and economics, epidemiology, statistics, social sciences, public policy) who can provide independent evaluation of outcomes. … The Agency has relatively limited internal capacity to conduct the broad range of research questions that need to be answered. This recommendation is in line with the Productivity Commission's recent Inquiry into Data Availability and Use. (sub. 69, p. 3)

The longitudinal dataset should allow researchers to assess the effectiveness of particular supports by linking information about supports with participant characteristics and outcomes.

Box 13.2 Participants support researchers having access to NDIA's data

Richard Madden:

> The NDIA currently receives information on each service for which it is billed by service providers, and has full information on the NDIS participant who has received the service. NDIA should work with stakeholders and the AIHW and ABS to design an appropriate minimum data set for participants and supports received, which can be extracted from its data holdings. … A de-identified data set on participants and supports received should be provided without charge to the AIHW in a timely fashion for statistical reporting. (sub. 101, pp. 12–13)

Bruce Bonyhady:

> The disability data that is being collected … should be made available for research, as a matter of high priority, subject to appropriate safeguards. As the Productivity Commission is currently conducting an Inquiry into Data Availability and Use which will report shortly, this Review should include recommendations on how best to ensure that the NDIA data will be made available for research to improve the lives of people with disability, their families and carers. (sub. 100, p. 15)

Australian Institute of Health and Welfare:

> … while it is entirely appropriate for the NDIA to monitor the progress and sustainability of the scheme, an independent agency (such as the AIHW) should be engaged to undertake reporting more broadly, perhaps against a disability reporting framework similar to that used in the health sector.
>
> … There is great potential benefit in making non-sensitive data 'open by default' by not restricting its use or redistribution; but how to make optimal use of this huge and increasingly unstructured source of information is a major challenge. While the need to manage 'big data' is clearly evident, the key issue for all data users is to ensure these data are used in the most effective manner; that is, 'smart data'. It also presents an opportunity to develop better ways to analyse and present data, and to partner with a wider range of collaborators. (sub. PP349, p. 6)

Benefits from data sharing

A key reason for allowing approved external researchers access to the longitudinal data is that it increases the opportunities for identifying best practice models and ways to improve the scheme. Such solutions are more likely to evolve if a community of researchers develops who are actively engaged in discussions about the merits and potential unintended impacts of alternative approaches. The size and capability of the research community interested in examining NDIS related issues is likely to be substantially larger if researchers have timely access to quality data.

The gold standard for evidence based policy are systematic reviews with decisions based on a literature that has built up on an issue, particularly with academic researchers reviewing their peer's research, and re-evaluating the issue from a slightly different perspective.

This dialectic approach has the scope to develop robust findings on an issue. Such an approach is common in medical research (and especially epidemiology). The NDIA does not have the resources to replicate such a process in house.

Existing legal and policy basis for the NDIA to share data

The NDIA is sharing data with other organisations. The NDIA provided the Commission with a set of de-identified unit record data to assist with this review. The State and Territory Governments are routinely given access to similar data (NDIS Act, s. 174). The Australian Government Actuary has also had access to the NDIA's data to undertake the role of reviewing actuary (as set out in the *National Disability Insurance Scheme Act 2013* (Cwlth) (NDIS Act)).

However, the NDIA does not currently have a public policy outlining when and how data can be shared. For the NDIA to share data, it needs:

- no legislative barrier to sharing data
  - there is no need for legislation to permit data sharing but where legislation does prescribe data protections (as is the case of the NDIS Act), there needs to be a clear legislative basis for doing so (box 13.3)
- established rules on data sharing
- the technical capacity to share data.

The Commission's recent *Data Availability and Use* (2017a) inquiry identified two other critical factors that can hamper the level of data sharing — organisation culture and agency practice.

FINDING 13.1

There are benefits from allowing researchers to have access to National Disability Insurance Scheme unit record data. Access could be provided by creating a de-identified longitudinal dataset and by allowing approved researchers access to bespoke and more detailed data sets on a case-by-case basis.

Box 13.3 The NDIA has legal permission to share data

The NDIS Act provides scope for unit record data to be shared with Australian, State and Territory government agencies, academic researchers, peak bodies and disability service providers.

Disclosure of protected information for research, actuarial analysis or policy development is permitted if the CEO of the Agency believes the information is reasonably necessary (s. 60).

The CEO can certify that information be disclosed for public interest reasons (s. 66).

The CEO may disclose information to the heads of a range of Australian, State and Territory government agencies for the purposes of the department or agency (s. 66).

Such disclosure of information needs to be consistent with rules established for the running of the Agency.

The Act also specifies that the NDIA should 'develop and enhance the disability sector, including by facilitating innovation, research and contemporary best practice in the sector' (s. 118).

Does the NDIA have rules and policies that permit data sharing?

Scheme Rules do not limit the ability to share data with other government agencies, peak bodies, providers or researchers who are interested in using the information to improve the scheme.

The *National Disability Insurance Scheme (Protection and Disclosure of Information) Rules 2013* (Cwlth) provide guidance to the CEO when considering disclosure of information for public interest purposes (Part 4) and sets out matters relating to the CEO's power to disclose information to Secretaries, chief executives and heads of Australian, State and Territory Government agencies (Part 5).

The two main areas of guidance for the CEO in considering public interest access is that those seeking access to the data have 'sufficient interest in the information' and that 'the information cannot reasonably be obtained from a source other than the agency' (*National Disability Insurance Scheme (Protection and Disclosure of Information) Rules 2013* (Cwlth), r. 4.3).

When releasing information to the heads of government agencies, the main guidance the Rules provide for the CEO is that a record should be kept of what data was supplied, who the data was supplied to and the requested purpose of the data (*National Disability Insurance Scheme (Protection and Disclosure of Information) Rules 2013* (Cwlth), r. 5.5).

The Commission understands that the NDIA does not have a policy on the release of public information, although progress on preparing such a policy is well advanced.

Does the NDIA have the technical capacity to share data?

There are two elements to the technical capacity of the NDIA to share data — the technical ability of the Agency staff and the technical capacity of the Agency's information and communication technology.

The NDIA has staff that are qualified and capable of warehousing, curating and transforming data. However, there are currently deficiencies in the NDIA's technical capacity to collect data.

13.5 A way forward

The Commission's recent inquiry on *Data Availability and Use* found that comprehensive reform of Australia's data infrastructure is needed to signal that permission is granted for active data sharing and release, and that data infrastructure and assets are a priority. To be effective, these reforms should be underpinned by:

- clear and consistent leadership to effect cultural change
- transparency and accountability for release and risk management
- reformed policies and legislation
- institutional change (PC 2017a, p. 35).

A culture of data availability and use

Leadership is important for establishing a data sharing culture. As the Commission's *Data Availability and Use* inquiry put it:

> New arrangements for data access will require, within Governments, strong and consistent leadership, from the Ministerial level as well as the upper echelons of the bureaucracy. (PC 2017a, p. 28)

The Tasmanian Government also noted:

> It takes clear, high-level direction and authorisation in order to get data-sharing initiatives up and running. (2016, p. 14)

Without a culture that grants active permission for the sharing and release of data, the benefits of data sharing and use will not be realised (and as noted above, the benefits of greater sharing and use of data about people with disability are likely to be significant). It is therefore critical that the NDIA has a data sharing culture if the benefits of the data held by the NDIA are to be realised.

The NDIA should actively promote data sharing within the Agency and with external bodies and researchers. Publishing data holdings, policies and processes (discussed later) can help signal that the NDIA is 'open for business' when it comes to data sharing and release. There are also a range of data communities of practice that the NDIA could participate in to develop expertise in data availability and use, including, for example, the Australian Government's Data Champions Network.

Data about people with disability can be highly sensitive, and there is likely to be community concern about how this data is used. Policies, processes and systems implemented to enable data sharing and release need to be designed to maintain trust, including via developing robust risk-management procedures.

One means of engendering trust is to have an independent process to review how data will be used. A standard means of reviewing the appropriateness of research on or about people

are ethics committees. Ethics committees are intended to ensure respect and protection of participants of the study, and to encourage ethical practices amongst researchers (NHMRC 2015, p. 6). Depending on the nature of the intended research using NDIS data, it may be appropriate for ethics committee approval to be obtained before data is accessed.

A comprehensive, longitudinal dataset

Data that is fit for purpose

As outlined above, the NDIA collects data for two purposes — to monitor and evaluate performance of the scheme and to inform policy.

Timely, standardised data collected at a sufficient level of disaggregation is also critical to enable broader use. The Commission's *Data Availability and Use* inquiry (PC 2017a, p. 345), set out four preconditions for releasing unit record level data. The data should be:

- machine readable
- readily linkable to other datasets
- understandable
- de-identified (unless the data is already publicly available).

One study participant, Richard Madden, suggested that the NDIA should provide the AIHW with data on participants:

> A de-identified data set on participants and supports received should be provided without charge to the AIHW in a timely fashion for statistical reporting (sub. 101, p. 13).

One benefit of providing the AIHW with data on disability is that it could be linked with other related data collections that the AIHW holds, particularly health data.

While linking disability and health data would not remove the need for the NDIA to collect outcomes information, it could significantly reduce the amount of information that it needs to collect, thus promoting cost savings to the NDIA and efficiencies across the health and disability systems.

Given that the AIHW already has expertise collecting, linking and reporting on health and disability data, and it has established and effective ICT systems, there are likely to be cost savings and efficiency benefits from the NDIA regularly providing such unit record data to the AIHW.

Managing the risk of sharing and releasing data

The Commission's *Data Availability and Use* inquiry found significant deficiencies in the way the public sector manages the risk of sharing and releasing data — including that data

is locked up and unable to be used due to concerns about the risk and sensitivity of that data, or it is shared (for genuine public interest purposes) but with poor controls on its use (PC 2017a, pp. 94–95).

The Commission proposed that data use should require rigorous assessment of *genuine* risk to inform the development of effective risk management strategies and controls by institutions that have the capability and resourcing to carry out this role effectively (PC 2017a, p. 181). A risk-based approach to data sharing and release allows the benefits of data use to be maximised, while the harms are minimised.

The five safes model is a best-practice framework for managing the risk of sharing and releasing data (box 13.4).

For the NDIA, a risk-based approach to sharing and releasing data means scaling releases of data depending on the risk of the release:

- public, or open data, should be sufficiently aggregated and confidentialised such that the data released is non-sensitive (that is, non-identifiable)
- a synthetic dataset is one way of making more disaggregated but non-sensitive data readily available to researchers
- data provided to trusted researchers in a secure environment can be more lightly de-identified
- data shared within the NDIA or with other government departments (chapter 11) may include identifiable details (if the purpose of use requires it — for instance, service delivery purposes) but secure access and storage procedures should be in place.

These initiatives require a certain amount of capability to be effectively undertaken. And the NDIA is a relatively new agency whose capability is still developing. While there will be benefits from the NDIA developing some in-house capability, there is also likely to be scope for the NDIA, particularly in the early years of its operation, to draw heavily on outside expertise from more mature organisations such as the AIHW and Data61.

Box 13.4 Five safes model

The traditional approach for managing risk of data sharing was to only release data that could not be used to identify people. This approach limits the type of analysis that can be undertaken (such as excluding analysis of disabilities where there are few sufferers, or not permitting analysis of exits from the NDIS). However, more recent approaches have been developed to allow researchers access to more identifying information, but which maintain the same level of privacy and data security, by using other levers. For example, in the NDIS context, virtual data laboratories could be used to ensure researchers can only extract results of their analysis when the data custodian considers that the results will not identify individual NDIS participants.

The five safes model focuses on five risk axes:

- *Safe people*: Can the researchers be trusted?
- *Safe projects*: Is the use of data appropriate? Does the researcher have ethics committee approval (where appropriate)?
- *Safe settings*: Does the access environment prevent unauthorised use?
- *Safe data*: Can the data disclose identity?
- *Safe outputs*: Are the statistical results non-disclosive?

In practice, the five safes model has been implemented using virtual laboratories or trusted access models which provide more risky data in a safer environment. Such facilities can be expensive to develop and require technical expertise and specialised information, communication and technology systems. While the NDIS may choose to develop its own capability, there is already an example that has been extensively used for health research in Australia — the Secure Unified Research Environment, provided through the Sax Institute (PC 2017a, p. 419). It provides a high security environment that facilitates the use of data from different custodians and also allows the collaboration of researchers working across multiple institutions, including overseas-based researchers.

Source: Adapted from Desai et al. (2016, pp. 3–5).

FINDING 13.2

The National Disability Insurance Agency should adopt a risk-based approach to sharing and release of data. A risk-based approach could include:

- open data that are able to be publicly released because they are non-sensitive
- a synthetic dataset that is more disaggregated but also non-sensitive, that is readily provided to researchers
- secure sharing of more sensitive data to researchers in an environment such as SURE
- better sharing of data with other relevant agencies such as the Australian, State and Territory Governments, with secure access and storage procedures put in place.

There are likely to be benefits, particularly in the early years of its operation, from drawing on the capability and expertise of more mature organisations such as the Australian Institute of Health and Welfare and Data61.

Best-practice policies, processes and systems

There is value in the NDIA making public details of the data it holds and how to access it. When developing policies and processes for seeking access to such data, the NDIA should consult with researchers, other data users, and relevant organisations that have expertise in data sharing (such as the DSS and the AIHW) and cover issues such as:

- what data will be of most value to researchers, including how to design a generic unit record file to reduce the cost to the NDIA of addressing bespoke data requests
- impediments researchers experience when trying to access administrative data, and practical ways to avoid them
- processes for seeking access to the data.

RECOMMENDATION 13.3

The National Disability Insurance Agency (NDIA) should engage with stakeholders on how data access will be operationalised. By July 2018, the NDIA should issue a statement outlining the organisation's goals for data sharing and an intended timeline for operationalising data sharing by the NDIA.

A Conduct of the study

The Commission received the terms of reference for this study on 20 January 2017. It subsequently released an issues paper on 22 February 2017 that invited public submissions and highlighted particular matters on which it sought information. A position paper was released on 14 June 2017, which sought further information and feedback.

An extension to the date for the final report from 20 September 2017 to 11 October 2017 was granted by the Treasurer. A copy of the extension letter is included with the terms of reference at the front of this report.

In total, the study received 372 submissions (table A.1). The study also received 185 brief submissions online, including those collected by the organisation Every Australian Counts. All public submissions are available on the study's website.

During the study, the Commission held consultations with people with disability, advocacy groups, peak bodies, service providers, disability care and support workers, and government departments and agencies (table A.2).

The Commission would like to thank all those who contributed to this study.

Data and information

The Commission would like to thank the National Disability Insurance Agency (NDIA) for providing unpublished data and information to the study, and for allocating a staff member to spend several days in the Commission's Canberra office to provide feedback on analysis conducted by the Commission. Any errors in the analysis of these data and information in this paper are attributable to the Commission.

There are two areas the Commission did not examine.

1. The construction of the NDIA's reference packages and how they are used to derive typical support packages. The Commission requested data on the nature of reference packages, which the Agency declined to provide on the grounds of the sensitive nature of the material. The NDIA instead provided a member of the actuarial team to discuss the mechanics of the reference packages with Commission staff.
2. The updates to the NDIA's Hourly Rate Model (formerly known as the 'Reasonable Cost Model' and 'Hourly Cost Model'). The model was requested by the Commission in August 2017, but was not provided the model until 11 September 2017. This was too late for the Commission to study the model and its assumptions in detail.

The Commission would also like to thank the Department of Social Services for providing unpublished data and information to the study.

This paper uses the National Centre for Vocational Education Research's data on vocational education outcomes (VOCSTATS). These data are collected by registered training organisations and state training authorities around Australia. The National Centre for Vocational Education Research is not responsible for errors in the extraction, analysis or interpretation of the data presented in this study.

Table A.1 **Public Submissions**[a]

Participants	*Submission number(s)*	
Ability First Australia	62	
Aboriginal Medical Services Alliance NT (AMSANT)	PP336	#
ACT Council of Social Service (ACTCOSS)	138	
ACT Disability, Aged and Carer Advocacy Service (ADACAS)	87, PP260	
ACT Government	156, PP312	#
Activ	PP302	
AEIOU Foundation	32, PP277	#
Aftercare	PP348	
Allianz Australia Insurance	42, PP265	
Allied Health Professions Australia (AHPA)	37	
Alzheimer's Australia	10, PP313	
Amaze	160, PP281	
Anglicare Australia	157, PP339	#
Anglicare NT	PP340	#
Anglicare Tasmania	145	#
Annecto	34	
APC Prosthetics	PP244	
Arts Access Australia	PP366	
Assistive Technology Suppliers Australasia (ATSA)	33	
Attendant Care Industry Association (ACIA)	141	
Australasian Podiatry Council (APodC)	52	
Australasian Sleep Association	PP214	
Australian Association of Social Workers (AASW)	124	
Australian Blindness Forum (ABF)	48, PP263	
Australian Federation of Disability Organisations (AFDO)	180, PP325	
Australian Institute of Health and Welfare (AIHW)	PP349	
Australian Lawyers Alliance (ALA)	54, PP257	
Australian Medical Association (AMA)	120	
Australian Orthotic Prosthetic Association (AOPA)	123, PP294	
Australian Physiotherapy Association (APA)	93	
Australian Psychological Society (APS)	19, PP229	
Australian Red Cross	PP258	
Australian Rehabilitation Providers Association (ARPA)	28	
Australian Services Union (ASU)	154	
Australian Services Union (ASU) and Disabled People's Organisations Australia (DPOA)	198	
Australian Unity	173, PP273	
Australians for Disability Justice (ADJ)	PP342	#
Autism Advisory and Support Service (AASS)	PP330	
Autism Aspergers Advocacy Australia	178	
Autism Association of Western Australia	PP219	

(continued next page)

Table A.1 (continued)

Participants	*Submission number(s)*	
Barnardos Australia	85	
Batt, Heather	PP368	
Becker, Bruce	PP353	*
Belconnen Community Service Board	39	
Better Caring	184, PP296	
Blind Citizens Australia (BCA)	130, PP351	
Bonyhady, Bruce	100, PP333	
Boyle, Michael	27	
Brain Injury SA	116	
Bravo Ability Service	96	#
Broken Rites	204	
Brotherhood of St Laurence	189	*
Burns, Kylie	PP315	#
Burrows, Matt	7	
Bus Association Victoria	1	
Business Council of Co-operatives and Mutuals (BCCM)	91, PP329	
Butterfly Foundation	78	#
Calvary Health Care Bethlehem	64	
Capricorn Community Development Association (CCDA)	142, PP300	
Carers Australia	195, PP224	
Carers Australia Victoria	131	
Catholic Social Services Australia (CSSA)	166, PP278	
Centacare Brisbane	44	
Centre for Disability Studies (CDS)	43, 49	#
Centre of Research Excellence in Disability and Health (CREDH)	69	
Cerebral Palsy Alliance	163	#
Cheesman, Bernadette	PP248	
Children and Young People with Disability Australia (CYDA)	188, PP358	
Cohealth	50, PP261	
Commonwealth Ombudsman	137	#
Communication Rights Australia, Disability Discrimination Legal Service and Villamanta Disability Rights Legal Service	88	
Community and Public Sector Union and Civil Services Association of WA (CPSU/CSA)	PP305	
Community and Public Sector Union (CPSU)	76, PP310	
Community Mental Health Australia (CMHA)	11, PP270	#
Community Services Industry Alliance (CSIA)	77, PP251	
Community Transport Organisation (CTO)	PP280	
Companion House	84	
Condren, James	66, PP208*	
Curley, Tricia	140	
Curlewis, Carmel	PP372	
DARE Disability Support	182	

(continued next page)

Table A.1 (continued)

Participants	*Submission number(s)*	
Deaf Australia	183	
Deafness Forum of Australia	127	
Department of Health (DoH)	175, PP360	
Department of Social Services (DSS)	146, PP318	
Dietitians Association of Australia (DAA)	119, PP292	
Diggins, Deb	PP364	
Disability Advocacy Network Australia (DANA)	PP371	
Disability Services Australia (DSA)	9, PP256	#*
Disability Services Commissioner	35	
Disabled People's Organisations Australia (DPOA)	165	
Down Syndrome Australia	121	
Dowse, Leanne; Paterson, Melinda; and Sprange, Mike	114	
DUO Services Australia	196	
EACH	PP276	
Early Childhood Intervention Australia (ECIA)	PP249	
Early Childhood Intervention Australia (ECIA) NSW/ACT	190	
Early Childhood Intervention Australia (ECIA) Victoria/Tasmania	129, PP301	
EarlyEd	PP290	
Ella Centre	PP250	#
Endeavour Foundation	202	
Epic Employment Service	70	
Espyconnect	PP267	*
Ethnic Communities' Council of Victoria (ECCV)	31	
Every Australian Counts	92	
Everyday Independence	133	
Family Advocacy	PP346	
Fanning, Vanessa	21	
Fear, Ross	103	
Financial Services Council (FSC)	98	#
First Peoples Disability Network	PP355	
Flourish Australia	74, PP246	
Freedom Key	125	#
Goldfields Individual and Family Support Association (GIFSA)	13	
Governments of Victoria, Queensland, South Australia, and the ACT	201	
Harrison, Jenny	PP236	
Health Services Union (HSU)	132, PP316	
Health Services Union (HSU), Australian Services Union (ASU) and United Voice	PP272	#
Homelife Association	59	
Hopkins Centre: Research for Rehabilitation and Resilience	105	
House with No Steps	104	
Inclusion Australia	185, PP357	
Inclusion Melbourne	PP207	

(continued next page)

Table A.1 (continued)

Participants	*Submission number(s)*	
Independent Schools Council of Australia (ISCA)	83	
Integra	99, PP268	#
Interaction Disability Services	PP213	
Interchange Inner East	PP271	
Jacqueline Pierce and Associates	147	
Jane, Belinda	80	
Jesuit Social Services	117	
JFA Purple Orange	186, PP350	
Jobsupport	191	
Kennedy, Richard	2	
Launch Housing	PP275	
Leadership Plus	128	
Legacy Australia	168, PP238	
Legal Aid NSW	PP245	
Lifestart Co-operative	97, PP322	
Lifestyle in Supported Accommodation (LISA)	3	
LINK Community Transport	194	
Livecare Australia	PP217	
Llewellyn, Gwynnyth	40	
Lutheran Community Care Queensland	197	
Macarthur Disability Services	57, PP288*	
Macular Disease Foundation Australia	75, PP243	
Madden, Richard	101, PP307	
Magarey, Kirsty	150	
Mallee Track Health and Community Service (MTHCS)	6, PP222	
Maloney, Liza	68	
Mamre Association	47	
Manning, Penny	36	
Martin, Sarah	41	*
Maurice Blackburn Lawyers	58, PP309	
McAuley Community Services for Women	PP211	
McDonnell, Cheryl	79	
Mental Health and NDIS Facebook Support Group	8	
Mental Health Australia	155, PP321	#
Mental Health Carers ARAFMI Illawarra	PP317	#
Mental Health Carers Australia	181, PP341	
Mental Health Coalition of South Australia (MHCSA)	PP308	
Mental Health Community Coalition of the ACT	135, PP286	
Mental Health Complaints Commissioner	164	
Mental Health of Young People with Developmental Disabilities	PP269	
Mental Illness Fellowship of Australia (MIFA)	122, PP338	
Mental Illness Fellowship of WA (MIFWA)	PP221	

(continued next page)

Table A.1 (continued)

Participants	*Submission number(s)*	
Menzel, Melisa	PP209	
Milner & Clyde	94	
Mind Australia	144	
MJD Foundation	PP233	
MND Australia	45, PP255	
Morton, James	110	
Multiple Sclerosis (MS) Australia	PP283	
Multiple Sclerosis Network of Care Australia	PP218	
Municipal Association of Victoria (MAV)	152, PP343	
Name withheld	4	
Name withheld	5	*
Name withheld	199	
Name withheld	PP215	
Name withheld	PP237	
Name withheld	PP287	
Name withheld	PP289	
Name withheld	PP365	
Nardy House	PP216	
National Disability and Carer Alliance	PP344	
National Disability Insurance Agency (NDIA)	161, PP32, PP367*, PP369*	
National Disability Services (NDS)	51, PP295	
National Mental Health Commission (NMHC)	153, PP319	
National Disability Insurance Scheme Independent Advisory Council (NDIS IAC)	149	
Neami National	63, PP347	
Nelson, Fergus	17	
Neurological Alliance Australia (NAA)	30	
New South Wales Government	60, PP230	
Noah's Ark	108, PP328	
Northern Territory Government	205, PP359	
NSW Council for Intellectual Disability (NSWCID)	193, PP234	
NSW Disability Network Forum	18	
NSW Disability Support Organisations	90	#
NSW Nurses and Midwives' Association	PP323	
Nulsen Disability Services	PP225	*
Occupational Therapy Australia (OTA)	15, PP285	
Office of the Public Advocate (OPA)	46, PP241	
Office of the Public Guardian (OPG)	143	
One Door Mental Health	179, PP266	
O'Rourke, Hon. Coralee	106	
Orygen	PP254	
Paraplegic and Quadriplegic Association of NSW (ParaQuad NSW)	PP239	

(continued next page)

Table A.1 (continued)

Participants	*Submission number(s)*	
Parkin, David	177, PP362	
Parkinson's Australia	PP232	
Peterson, Frank Lawrence	148	
Physical Disability Australia (PDA)	38, PP306	
Physical Disability Council of NSW (PDCN)	29	
Psychiatric Disability Services of Victoria (VICSERV)	169, PP284	
Plan Management Partners	126, PP324	
Positive Life NSW	PP356	
Potapczyk, Hannah	26	
Power Housing Australia	139	
Prader-Willi Syndrome Association of Australia (PWSAA)	112, PP228	
Public Health Association of Australia (PHAA)	134	
Public Service Research Group	56	
Quality Living Options Bendigo	PP220	
Queensland Advocacy Incorporated (QAI)	115, PP311	
Queensland Association of Special Education	PP297	
Queensland Government	PP345	
Queensland Nurses and Midwives' Union (QNMU)	PP240	
Queenslanders with Disability Network (QDN)	PP335	
Read, Suzanne	24	
Regional Development Australia Murraylands and Riverland (RDAMR)	12, PP231	
RehabCo	23	
Ross, Francis	PP331, PP363	*
Roundsquared	170	
Royal Australasian College of Physicians (RACP)	PP299	
Royal Australian College of General Practitioners (RACGP)	200, PP361	
The Royal Australian and New Zealand College of Psychiatrists (RANZCP)	158	
Royal Institute for Deaf and Blind Children (RIDBC)	95, PP259	
Royal Society for the Blind (RSB)	82	#
Ryan, Margaret	PP226	
SAL Consulting	PP304	
Scope Australia	72	
SDN Children's Services	73	
Self Advocacy Resource Unit (SARU)	PP279	
Sharing Places	53, PP291	
Sisters Inside Inc	16	
Smith-Merry, Jennifer	55	
Social Support & Precarious Workforce Research Discussion Group	71	
Sotica	67	#

(continued next page)

Table A.1 (continued)

Participants	*Submission number(s)*	
South Australian Government	203, PP354	
Speaking Up For You (SUFY)	PP242	
Speech Pathology Australia	136, PP303	
Spinal Cord Injuries Australia (SCIA)	61	
Summer Foundation	113, PP293	
Sylvanvale	192	
Syndromes Without A Name (SWAN) Australia	86, PP235	
Taggart, Michael	89	
Tandem	PP212	
Tasmanian Government	PP247	
The Able Movement	109	
The Australian Centre for Social Innovation (TACSI)	65	#
The Benevolent Society	PP334	
The Shepherd Centre	107	
Top End Association for Mental Health (TEAMhealth)	102	
Travellers Aid Australia (TAA)	20	
Ubercare Services	PP227	
United Voice	118	
VICSERV (Psychiatric Disability Services of Victoria)	169, PP284	
Victoria Legal Aid	PP314, PP367	
Victorian Aboriginal Community Controlled Health Organisation (VACCHO)	162, PP223	
Victorian Advocacy League for Individuals with Disability (VALID)	PP332	
Victorian Council of Social Service (VCOSS)	176, PP264	
Victorian Government	174, PP298	#
Victorian Healthcare Association	172, PP337	
Victorian Mental Illness Awareness Council (VMIAC)	167	
Vision Australia	PP210, PP252	
Volunteering Australia	PP274	
Wall, Elizabeth	PP352	
Western Australia Local Government Association (WALGA)	151, PP320	
Westhaven Association	81	
Wilson, Tony	14	
Windsor & Associates	171	
Woden Community Service	159	
Women with Disabilities Victoria	111, PP282	
Yanga, Anna	22	
YFS	25	*
Young People In Nursing Homes National Alliance (YPINH)	187, PP326	
Youngcare	PP253	
Youth Disability Advocacy Service (YDAS)	PP262	
Zemanek, Elizabeth	206	

a An asterisk (*) indicates that the submission contains confidential material NOT available to the public. A hash (#) indicates that the submission includes attachments.

Table A.2 **Stakeholder consultations**

Participants
ACL Disability Services & Gig Buddies Sydney
ACT Disability Aged and Carer Advocacy Service
Anglicare Australia
Anglicare NT
Anglicare SA
Anglicare Southern Queensland
APM (Advanced Personnel Management)
Australian Bureau of Statistics
Australian Council of Social Service
Australian National Audit Office
Australian Services Union and United Voice workers and organisers
Bonyhady, Bruce
CatholicCare Social Services
Catholic Social Services Australia
Centre for Disability Studies
Cerebral Palsy Alliance
Children and Young People with Disability Australia
Cohen, Dr Martin
Community Services Industry Alliance with NDS Queensland and local disability providers
Department of Employment
Department of Finance
Department of Health (Aged Care)
Department of Social Services
Disability Advocacy Network Australia
Disability Discrimination Commissioner (Alastair McEwin)
Disabled People's Organisations Australia
EPIC Assist
Fenton, Dr Marc
Firstchance
First Peoples Disability Network
Health and Community Services Union workers and organisers
House With No Steps
Integra
JFA Purple Orange
Karingal
Kevin Stone from Victorian Advocacy League for Individuals with Disability and five parents of participants
LeapFrog Ability
Lifestart
Marymead
McKinsey and Company
Mental Health Australia
Mental Health Coordinating Council of New South Wales

(continued next page)

Table A.2 (continued)

Participants
National Disability Insurance Agency
National Disability Insurance Agency Actuaries
National Disability Services
National Disability Services Queensland and the Community Services Industry Alliance
National Disability Services Western Australia
Neami National
New South Wales Government
Pegasus, Riding for the Disabled
People with Disability Australia
Physical Disability Council of New South Wales
Plan Management Partners
Queensland Alliance for Mental Health
Queensland Government
SalvoConnect
Samaritans New South Wales
The Treasury
Victorian Council of Social Service
Victorian Disability Forum
Victorian Government agencies
Victorian Government departments
Western Australian Association for Mental Health
Western Australian Government
Teleconference
ACT Community Services Directorate
ACT Chief Minister, Treasury and Economic Development Directorate
Australian Competition and Consumer Commission
Australian Federation of Disability Organisations
Australian Government Actuary
Australian Services Union
Carers Australia
Children and Young People with Disability Australia
Cross, Rebecca
Department of Health
Department of Prime Minister and Cabinet
Dyson, Maree
Gilchrist, David (University of Western Australia)
Hogan, Catherine
icare
Inclusion Melbourne
Jobsupport (Phil Tuckerman)

(continued next page)

Table A.2 (continued)

Teleconference
Knight, Penny (Curtin University)
Lifetime Care and Support Authority
Mental Health Australia
National Institute of Labour Studies, Flinders University
National Mental Health Commission
New South Wales Department of Family and Community Services
New Zealand Accident Compensation Corporation
Northern Territory Department of the Chief Minister
Northern Territory Department of Treasury and Finance
Northern Territory Department of Health
Queensland Department of Communities, Child Safety and Disability Services
South Australian Department for Communities and Social Inclusion
Tasmanian Department of Education
Tasmanian Department of Health and Human Services
Tasmanian Department of Premier and Cabinet
Tasmanian Department of Treasury and Finance
TelstraHealth
United Voice
Victorian Department of Health and Human Services
Victorian Department of Premier and Cabinet
Victorian Transport Accident Commission
Victorian Treasury
Western Australia Disability Services Commission
Young People in Nursing Homes

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—— 2011b, *Microdata: Personal Income of Migrants, Australia, 2009-10 and 2010-11*, Cat. no. 3418.0.55.001, Canberra.

—— 2013, *Australian and New Zealand Standard Classification of Occupations, 2013, Version 1.2*, Cat. no. 1220.0, Canberra.

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