Australian Government
Productivity Commission

Disability Care and Support

Productivity Commission Draft Report
Volume 1

February 2011

This is a draft report prepared for further public consultation and input.

The Commission will finalise its report after these processes have taken place.

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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) or by contacting Media and Publications on (03) 9653 2244 or email: maps@pc.gov.au

Opportunity for further comment

You are invited to examine this draft report and make written submissions to the Productivity Commission by 30 April 2011**.**

The final report will be prepared after submissions have been received and public hearings have been held, which will be forwarded to the Government by 31 July 2011.

Public hearing date and venues

Location	Date	Venue
Hobart	Monday 4 April 2011	Grand Ballroom 1 Hotel Grand Chancellor, 1 Davey Street
Melbourne	Tuesday 5 April 2011*	Bridge Room Amora Hotel 649 Bridge Road Richmond
Canberra	Friday 8 April 2011	Hearing Room, Level 2 Productivity Commission 15 Moore Street
Brisbane	Monday 11 April 2011*	Flinders Room Hotel Ibis 27-35 Turbot Street
Sydney	Wednesday 13 April 2011*	Fitzroy Room Adina Apartment Hotel 359 Crown Street Surry Hills
Adelaide	Monday 18 April 2011	Hindley 1 Hotel Grand Chancellor 65 Hindley Street
Perth	Wednesday 20 April 2011*	The Silver Room Novotel Hotel 221 Adelaide Terrace

An asterisk (*) indicates that the hearing may run for more than one day.

If you wish to attend, please register on the inquiry website http://www.pc.gov.au/projects/inquiry/disability-support or advise Roberta Bausch on (02) 6240 3221 or email disability-support@pc.gov.au. Please let us know if you have particular access or communication requirements.

Commissioners

For the purposes of this inquiry and draft report, in accordance with section 40 of the Productivity Commission Act 1998 the powers of the Productivity Commission have been exercised by:

Patricia Scott	Presiding Commissioner
John Walsh	Associate Commissioner

Terms of reference

I, Nick Sherry, pursuant to Parts 2 and 3 of the Productivity Commission Act 1998, hereby refer a national disability long-term care and support scheme in Australia to the Productivity Commission for inquiry and report by 31 July 2011. The Commission will begin the inquiry in April 2010.

Background

The Australian Government is committed to developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers.

The Commonwealth, along with the States and Territories, has a major investment in disability specific support. However, there remains a significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers. Demographic change and the anticipated decline in the availability of informal care are expected to place further pressure on the existing system over the coming decades.

While Australia's social security and universal health care systems provide an entitlement to services based on need, there is currently no equivalent entitlement to disability care and support services.

The Government is committed to finding the best solutions to improve care and support services for people with disability. An exploration of alternative approaches to funding and delivering disability services with a focus on early intervention and long-term care will be an important contribution to the National Disability Strategy.

Scope of the review

The Productivity Commission is requested to undertake an inquiry into a National Disability Long-term Care and Support Scheme. The inquiry should assess the costs, cost effectiveness, benefits, and feasibility of an approach which:

- provides long-term essential care and support for eligible people with a severe or profound disability, on an entitlement basis and taking account the desired outcomes for each person over a lifetime
- is intended to cover people with disability not acquired as part of the natural process of ageing
- calculates and manages the costs of long-term care and support for people with severe and profound disability
- replaces the existing system funding for the eligible population

- ensures a range of support options is available, including individualised approaches
- includes a coordinated package of care services which could include accommodation support, aids and equipment, respite, transport and a range of community participation and day programs available for a person's lifetime
- assists the person with disability to make decisions about their support
- provides support for people to participate in employment where possible.

In undertaking the inquiry, the Commission is to:

1. Examine a range of options and approaches, including international examples, for the provision of long-term care and support for people with severe or profound disability.

The Commission is to include an examination of a social insurance model on a no-fault basis, reflecting the shared risk of disability across the population. The Commission should also examine other options that provide incentives to focus investment on early intervention, as an adjunct to, or substitute for, an insurance model.

2. The Commission is to consider the following specific design issues of any proposed scheme:

- eligibility criteria for the scheme, including appropriate age limits, assessment and review processes
- coverage and entitlements (benefits)
- the choice of care providers including from the public, private and not-for-profit sectors
- contribution of, and impact on, informal care
- the implications for the health and aged care systems
- the interaction with, or inclusion of, employment services and income support
- where appropriate, the interaction with:
- national and state-based traumatic injury schemes, with particular consideration of the implications for existing compensation arrangements
- medical indemnity insurance schemes.

3. Consider governance and administrative arrangements for any proposed scheme including:

- the governance model for overseeing a scheme and prudential arrangements

- administrative arrangements, including consideration of national, state and/or regional administrative models
- implications for Commonwealth and State and Territory responsibilities
- the legislative basis for a scheme including consideration of head of power
- appeal and review processes for scheme claimants and participants.

4. Consider costs and financing of any proposed scheme, including:

- the costs in the transition phase and when fully operational, considering the likely demand for, and utilisation under different demographic and economic assumptions
- the likely offsets and/or cost pressures on government expenditure in other systems as a result of a scheme including income support, health, aged care, disability support system, judicial and crisis accommodation systems
- models for financing including: general revenue; hypothecated levy on personal taxation, a future fund approach with investment guidelines to generate income
- contributions of Commonwealth and State and Territory governments
- options for private contributions including copayments, fees or contributions to enhance services.

5. Consider implementation issues of any proposed scheme, including:

- changes that would be required to existing service systems
- workforce capacity
- lead times, implementation phasing and transition arrangements to introduce a scheme with consideration to service and workforce issues, fiscal outlook, and state and territory transitions.

The Government will establish an Independent Panel of persons with relevant expertise to act in an advisory capacity to the Productivity Commission and the Government, and report to Government throughout the inquiry.

The Commission is to seek public submissions and to consult as necessary with the Independent Panel, State and Territory governments, government agencies, the disability sector and other relevant experts and stakeholders.

Nick Sherry

Assistant Treasurer
[Received 17 February 2010]

Contents

The Commission's draft report is in two volumes. **This volume 1 contains the Overview, the draft recommendations and chapters 1 to 8**. Volume 2 contains chapters 9 to 17, Appendix A and the References. Appendices B to J will only be available on the Commission's web site (http://www.pc.gov.au). Below is the table of contents for both volumes.

Volume 1

Opportunity for further comment **III**

Terms of reference **V**

Abbreviations **XV**

Key points **2**

Overview **5**

Draft recommendations **45**

Information requests **67**

1 Introduction **1.1**

1.1 What has the Commission been asked to do? 1.1

1.2 Definitions and some key facts 1.2

1.3 Ways of thinking about disability 1.6

1.4 Rationales and objectives 1.10

1.5 Some design elements for a new scheme 1.12

1.6 Inquiry processes 1.15

1.7 Structure of the report 1.16

2 Why real change is needed **2.1**

2.1 Introduction 2.2

2.2 Disadvantage and disability 2.2

2.3 Insufficient support provision 2.7

2.4 Underfunding in the current system 2.17

2.5 Inefficiencies 2.24
2.6 Conclusions 2.35
3 Who is the NDIS for? 3.1
3.1 Introduction 3.2
3.2 A tiered approach to providing supports 3.2
3.3 Tier 1— minimising the impacts of disability 3.5
3.4 Tier 2 – ensuring appropriate support from any system 3.8
3.5 Tier 3 — individually tailored funded supports 3.9
3.6 Taking account of the broader context of service delivery 3.17
3.7 How many people are likely to receive individualised supports 3.30
3.8 Implementation issues 3.32
4 What individualised supports will the NDIS provide? 4.1
4.1 Introduction 4.1
4.2 Specialist disability supports 4.2
4.3 The role of 'mainstream' services 4.11
4.4 Income support 4.24
4.5 The basis for providing specialist disability supports 4.26
4.6 Means testing, front-end deductibles and co-payments 4.30
5 Assessing care and support needs 5.1
5.1 Introduction 5.2
5.2 What is being assessed? 5.3
5.3 What is the purpose of the assessment process? 5.7
5.4 Desirable features of assessment tools 5.11
5.5 The current suite of assessment tools 5.15
5.6 A single tool or a 'tool-box' 5.17
5.7 Who should conduct assessments? 5.18
5.8 When should assessements occur? 5.21
5.9 Should carers have their own assessment 5.23
5.10 How assessment might work in practice 5.25
5.11 Diligent use of the assessment tool 5.27

5.12 The transition to a fully-fledged assessment toolbox 5.28

6 Who has the decision-making power? 6.1

6.1 Person-centred approaches 6.2

6.2 What is 'self-directed funding'? 6.8

6.3 Reasons for self-directed funding 6.10

6.4 Impacts, benefits and costs 6.14

6.5 Design of self-directed funding 6.16

6.6 Exercising power at the family level 6.17

6.7 What services should be covered? 6.18

6.8 Employing people directly 6.29

6.9 Paying relatives for care 6.31

6.10 Take-up of self-directed funding and the need for support 6.33

6.11 What about the general risks of self-directed funding? 6.38

6.12 Implementing individualised funding 6.46

7 Governance of the NDIS 7.1

7.1 Introduction 7.2

7.2 Defining the scope of governance in the NDIS 7.2

7.3 The role of the NDIA and others within the NDIS 7.5

7.4 Why have just one agency? 7.16

7.5 Creating a National Disability Insurance Agency 7.21

7.6 Measures to encourage high performance 7.32

7.7 Managing the funding pool 7.37

7.8 Complaints and dispute resolution 7.39

7.9 Other functions 7.52

8 Delivering disability services 8.1

8.1 Disability support services 8.5

8.2 Navigating the disability system 8.9

8.3 Safeguarding quality 8.22

8.4 The implications of consumer choice for block funding, government-run services and rural areas 8.40

Volume 2

9 Disability within the Indigenous community **9.1**

9.1 A snapshot of Indigenous disability 9.2

9.2 Challenges to supporting Indigenous Australians with a disability 9.8

9.3 Indigenous disability and the NDIS 9.14

10 Collecting and using data under the NDIS **10.1**

10.1 Introduction 10.2

10.2 Deficiencies in the existing evidence base 10.3

10.3 Why an effective evidence base under the NDIS is needed? 10.6

10.4 Data systems 10.10

10.5 Research 10.15

10.6 Methods of analysis 10.19

10.7 Other features of the evidence base under the NDIS 10.28

10.8 Implementation 10.30

11 Early intervention **11.1**

11.1 Introduction 11.1

11.2 Nature and scope of early intervention 11.4

11.3 The benefits of early intervention 11.11

11.4 Targeting beneficial early interventions under the NDIS 11.20

11.5 Interventions outside the NDIS 11.24

12 Where should the money come from? Financing the NDIS **12.1**

12.1 The money can only come from several sources 12.2

12.2 Tax design criteria 12.7

12.3 Tax and revenue options 12.14

12.4 Ensuring sustainable returns 12.23

12.5 Fully funded, pay-as-you go or a hybrid? 12.31

12.6 Gross versus net taxation arrangements — and the implications for intergovernmental financial relations 12.35

12.7 Achieving a fair effort by all jurisdictions 12.43

13 Workforce issues **13.1**

13.1 A snapshot of the disability workforce 13.2

13.2 Are there, and will there be, labour shortages? 13.11

13.3 Attracting more workers to the disability services industry 13.16

13.4 Alternatives to increasing the formal workforce 13.29

13.5 Are labour supply concerns surmountable? 13.39

13.6 Qualifications, working knowledge and career paths 13.40

14 The costs of the scheme **14.1**

14.1 Introduction 14.2

14.2 Data 14.2

14.3 Estimated number of people in tier 3 14.4

14.4 Cost 14.12

14.5 Offsets 14.24

14.6 Scenarios 14.29

15 Insurance arrangements for injury **15.1**

15.1 Introduction 15.2

15.2 What is catastrophic injury? 15.5

15.3 Criteria to assess injury insurance arrangements 15.7

15.4 Certainty, timeliness and quality of lifetime care and support 15.9

15.5 Coverage of people acquiring a disability through a catastrophic injury 15.24

15.6 Impacts on recovery and health outcomes 15.28

15.7 People's freedom 15.31

15.8 The value of 'justice' 15.33

15.9 Providing incentives for people to avoid injuries 15.36

15.10 Efficiency and costs 15.42

15.11 The performance of common law systems of fault-based compensation 15.51

16 A national injury insurance scheme **16.1**
16.1 Introduction 16.1
16.2 Implementing a no-fault approach for lifetime care and support of all catastrophic injuries 16.3
16.3 The scope of the NIIS beyond 2020 16.35
16.4 Some other matters 16.40
17 Implementation **17.1**
17.1 Implementation in outline 17.1
17.2 Implementation of the NIIS 17.2
17.3 Implementation of the NDIS 17.4
17.4 Interaction between the two schemes 17.12
A Consultations **A.1**
A.1 Conduct of the inquiry A.1
A.2 Submissions received A.3
A.3 Visits and discussions A.17
A.4 Public hearings A.20
References **R.1**

Abbreviations

ACC	Accident Compensation Corporation (New Zealand)
AIHW	Australian Institute of Health and Welfare
BoD	Burden of Disease
COAG	Council of Australian Governments
CSTDA	Commonwealth/State Territory Disability Agreement
CTP	Compulsory Third Party Insurance
DALY	Disability Adjusted Life Year
DIG	Disability Investment Group
DSP	Disability Support Pension
EFT	Equivalent Full Time
FaHCSIA	Department of Families, Housing, Community Services and Indigenous Affairs
HACC	Home and Community Care Program
LTCSA	Lifetime Care and Support Authority (New South Wales)
LTCS	Lifetime Care and Support Scheme (New South Wales)
MAIB	Motor Accident Insurance Board (Tasmania)
MS	Multiple Sclerosis
NDA	National Disability Agreement
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NES	National Employment Standards
NHMRC	National Health and Medical Research Council
NHS	National Health Service (United Kingdom)
NIIS	National Injury Insurance Scheme
QALY	Quality of Life Year

SACS	Social and Community Services
SCS	Survey of the Community Sector
SDAC	Survey of Disability, Ageing and Carers
TAC	Transport Accident Commission (Victoria)
VET	Vocational Education and Training

OVERVIEW

Key points

- The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports.
- There should be a new national scheme — the National Disability Insurance Scheme (NDIS) — that provides insurance cover for all Australians in the event of significant disability. While Australians would pay more taxes (or governments would cut other spending), people would know that if they or their family acquired a significant disability, they would have a properly financed and cohesive system to support them.
- The NDIS would fund long-term high quality care and support (but not income replacement). Around 360 000 people would receive scheme funding.
- Beyond that main function (and the biggest source of its costs), the NDIS would have several other important roles, including mustering community resources, providing information to people, quality assurance, diffusion of best practice among providers, and breaking down stereotypes.
- The needs of people with a disability and their carers would be assessed rigorously by NDIS-appointed local assessors, with careful management to avoid assessment 'softness' or 'hardness'. Assessment would lead to individualised support packages. Strong governance would be necessary to contain costs and ensure efficiency.
- The agency overseeing the NDIS — the National Disability Insurance Agency — would be a federal agency created by, and reporting to, all Australian governments. It would have strong governance arrangements, with an independent board, an advisory council of key stakeholders, clear guidelines to ensure a sustainable scheme and with legislation that protected the scheme from political influences.
- Support packages would be portable across state and territory borders, as would assessments of need.
- People would have much more choice in the NDIS. Based on their needs assessment and their individualised support package, they would be able to:
  - choose their own service providers
  - ask a disability support organisation (an intermediary) to assemble the best package on their behalf
  - cash out their funding allocation and direct the funding to areas of need they think are most important. There would have to be some controls over the latter to ensure probity and good outcomes. People would need support to adopt this option and, given overseas experience, it would take some time for many to use it.
- The NDIS would cover the same range of supports currently provided by specialist providers, but would give people more opportunities to choose mainstream services and would encourage the development of innovative approaches to support.
- In 2009-10, the Australian Government provided funding to the disability sector of around $1.7 billion, while state and territory governments provided funding of around $4.5 billion — or a total of $6.2 billion.

(continued next page)

Key points (continued)

- The Commission's preliminary estimates suggest that the amount needed to provide people with the necessary supports would be an *additional* $6.3 billion, roughly equal to current funding. Accordingly, the real cost of the NDIS would be around $6.3 billion per annum. That could be funded through a combination of cuts in existing lower-priority expenditure and tax increases.
- Current funding for disability comes from two levels of governments, with an annual budget cycle — making it hard to give people with disabilities any certainty that they will get reasonable care and support over the long-run
  - currently, supports might be good one year, but insufficient the next.
- The Commission is proposing that the Australian Government take responsibility for funding the *entire* needs of the NDIS. This is because the Australian Government can raise taxes more sustainably and with fewer efficiency losses than state and territory governments.
- State and territory governments should offset the Australia-wide tax implications of the NDIS by either (a) reducing state and territory taxes by the amount of own-state revenue they currently provide to disability services or (b) by transferring that revenue to the Australian Government.
  - The Commission prefers option (a) because it leads to a more efficient way of financing the NDIS, with greater certainty of long-run funding, and with a no greater level of Australia-wide taxes than other options. Compared with most of the alternatives, it would also have a lower risk that jurisdictions would not meet their ongoing commitments.
- To finance the NDIS, the Australian Government should direct payments from consolidated revenue into a 'National Disability Insurance Premium Fund', using an agreed formula entrenched in legislation. A tax levy would be a second-best option.
- The scheme would commence in early 2014, commencing with a full scale rollout in a particular region in Australia. That would allow fine-tuning of the scheme, while providing high quality services to many thousands of people. In successive years, the scheme would:
  - extend to all Australia in 2015
  - progressively expand to cover all relevant people with a disability, commencing with all new cases of significant disability and some of the groups most disadvantaged by current arrangements.

A separate scheme is needed for people requiring lifetime care and support for catastrophic injuries — such as major brain or spinal cord injuries. Currently, many Australians get poor care and support when they experience such injuries because they cannot find an at-fault party to sue. A no-fault national injury insurance scheme (NIIS), comprising a federation of individual state and territory schemes, would provide fully-funded care and support for all cases of catastrophic injury. It would draw on the best schemes currently operating around Australia. State and territory governments would be the major driver of this national reform.

Overview

A preamble

The disability support 'system' overall is inequitable, underfunded, fragmented, and inefficient and gives people with a disability little choice. It provides no certainty that people will be able to access appropriate supports when needed. While some governments have performed much better than others, and there are pockets of success, overall no disability system in any jurisdiction is working well in all of the areas where change is required.

The central message of this draft report is that a *real* system for people with a disability is required — with much more and better-directed money, a national approach, and a shift in decision-making to people with a disability and their carers. This overview explains what is wrong with the current system and how to improve it. It shows how a new system would work for individuals with a disability and their families, and how it would provide benefits for the community as a whole.

Why is change needed?

There is general agreement by people with a disability, their families, service providers and governments that the existing 'system' of support services for those with high-level disabilities is not functioning well.

- There are not enough resources, and there are many gaps in certain kinds of services in all jurisdictions and most locations. Rationing is likely to get worse unless there is reform.
- Inadequate services can hit certain communities particularly hard — such as people in regional and remote areas, people from a non-English speaking background and Indigenous people.
- Rationing places an unreasonable burden on people with a disability and their families. It means lower levels of wellbeing and large forgone life chances. There are particularly big gaps in the availability of support at key transition points in people's lives. People wait years for specialist wheelchairs, need to stay with their parents over many decades instead of moving into independent

supported accommodation, and do not get timely or sufficient access to support. Carers have among the lowest level of wellbeing of any group of Australians.

- Under-servicing in one area — such as not enough access to respite and home modifications — results in costly additional servicing in another less appropriate area or at a later time (such as someone staying in hospital because their home has not been modified).
- People with similar levels of functionality get access to quite different levels of support, depending on their location, timing or the origin of the disability — what some call the 'lottery' of access to services. For instance, some jurisdictions have fault-based motor vehicle compensation arrangements (Queensland, ACT, Western Australia, and South Australia). In these jurisdictions, someone acquiring a catastrophic injury in a motor vehicle accident would have to identify an at-fault party to get adequate lifetime care and support. Other jurisdictions provide comprehensive coverage on a no-fault basis for such accidents.
- People with a disability have too little control over what happens to them and limited choice of service providers. The usual justification for paternalism — the complexity of services — has little application in a sector where one of the most important services is relatively straightforward personal support in which the empathy and responsiveness of the carer is the most important feature.
- Approaches to delivery of supports, therapeutic services and administrative processes are only weakly evidence-based, despite the billions of dollars given to such services each year.
- Funding for service providers is often uncertain and inadequate, and comes with unnecessary compliance burdens, stifling innovation and flexibility.
- The 'system' is hard to navigate (a 'confusopoly' in the words of one participant — box 1) and is not well integrated nationally. Even within a jurisdiction, people deal with a multitude of programs and agencies, few of which coordinate or share information. If people move across state boundaries, their entitlements can stop at the border.

The existing system is unsustainable. The high costs involved with crisis situations can impede funding for other support services. This is because when faced with budget constraints, systems have little choice but to give priority to families in crisis. This means that any growth in the number of crises can cause further rationing over time. Moreover, when this rationing affects the availability of early intervention and respite programs, it is likely to further increase the number of families falling into crisis (hence leading to an ongoing causal relationship between respite shortages and crises).

Box 1 **Some comments from participants in this inquiry**

The regularity with which I meet parents with murder suicide ideation as they have been unable to find adequate help for their child is both alarming, but also a marker of the failure of coordination of any service … I also note that murder suicide in these families is becoming a more recognised event, as recently occurred in Victoria. (personal submission, senior psychiatrist)

We have from our personal point of view been spending over a year to just try and get a high-low bed because my son is 113 centimetres tall at four, he weighs 25 kilos and he does not walk. He also has hypotonia, so has low tone, so he is very floppy. (Timothy Smith — Fortitude Parents Group, Sydney Hearings, Transcript, p. 716)

We saw our adult children reach their late twenties and thirties with no hope of achieving the independence that moving out of home brings. We saw ourselves caring until we die, with no hope of humanely and gradually transitioning our people into a new residential setting. (Ryde Area Supported Accommodation for Intellectually Disabled Inc., sub. 204, p. 1)

I am a mum of a young child … with multiple impairments – physical, sensory, intellectual – she is expected to be non-verbal for life … There is a myriad of paperwork to be completed, you must re-prove your child's disability to every agency that you encounter… there are wait lists for services, lack of physiotherapists, lack of funding. (Jennifer Kyriacou, sub. 9, p. 1)

Unnecessary paperwork and revision [is] required when care requirements are ongoing. (Debra Australia, sub. 554, p. 3)

… it took over 2 years from when it became pretty clear I needed a motorized wheelchair to when I finally got one, and then yet longer to get transport training. This held me back unnecessarily from gaining independence and impacted on my self-confidence. I missed out on many opportunities to take part in the community, including doing some valuable volunteering. (Samantha Peterson, sub. 581, p. 1)

When I was vertical I had a lot more respect. As soon as I parked my backside into a wheelchair, the way society treated me and the way that I was shunned and excluded just blew my mind. I had no idea what people in chairs had been facing all their lives … We only get four hours of help a week, and with those four hours there are very strict, rigid guidelines that we can use them for, so therefore they will say, "No, we can't do that to help you," "No, if it's classed as respite, we can only do" this, this and this … I got extremely depressed, and that was the only time that I thought to myself, "I'm living in Australia and yet I'm reduced to this." (Ms Shaunagh Stevens, Melbourne Hearings, Transcript, p. 180)

… you not only have to deal with disability, but the uncertainties of disjointed, complex and inadequate array of disability supports. (Ben Lawson, sub. 103, p. 2)

I find myself dealing with anxiety and loneliness and the possibility of when my parents grow older, that I will have no support and services available. (Gary Burge, sub. 2, p. 1)

(Continued next page)

Box 1 **Participants' comments** (continued)

Following our paediatricians pronouncement that she was indeed permanently intellectually disabled, we were very much left to navigate the maze of disability life by ourselves, unsupported, save for some family members and close friends, and the kindness and understanding of some of our daughter's initial therapists … The confusopoly added anxiety and pressure to an already extremely stressful situation. (Name withheld, sub. 482, p. 3)

The scheme needs to be national so that people with disability can take their funding with them when they move across state and territory boundaries. The money needs to be attached to the person (direct funding) and not to an organisation or program. Families at present are bound to stay in the same place as the funding they have received. If that place is the ACT then you can't move anywhere. (Sally Richards, sub. 26, p. 5)

Then "sliding doors and groundhog day" revisited with government changes to policy and funding arrangements which stopped funding to individuals on the basis of individual need and went back to block funding of organizations — leading again to disempowerment, no choice, a take or leave it attitude of service providers and retribution for leaving, or complaining, about a service that is unacceptable, inadequate or unsatisfactory. … All the power is vested in the service provider. (Felicity Maddison sub. 380, pp. 2–3)

This group [those with an acquired brain injury] rarely receives adequate funding to fully support their needs because of the high cost of those needs and as a result experience pain and discomfort, isolation, loneliness and despair. This limited funding also impacts on their capacity to receive appropriate allied health supports and the ability to access their local and broader community. (Inability Possability, sub. 514, p. 4)

I have seen grandparents weeping in despair at a public meeting about disability support, as they describe how badly they need help, and appropriate supported accommodation for their violently autistic grandson. (Name withheld, sub. 253, p. 4)

No one likes to see innocent kids suffer in any way and the pain we feel as parents having to watch this every day and to be helpless to change things, all we can do is scream out for assistance, and now is the time for some screaming (Name withheld, sub. 13, p. 5)

The way funding is allocated is a joke. Submissions are sent in and if you are about to die or divorce or have a breakdown, you might get considered. (Leonie Walker, sub. 12, p. 1)

Looking overall as a money matter, what strikes me is that money is being wasted here. By not spending the money on aids, you're probably creating disability for the future and also by not meeting properly the costs of disability, you're putting more stress on those carers and you're probably causing more suicide, divorce, separation, abandonment. As economists, this is an area crying out for an economic improvement. (Richard Cumpston, Canberra Hearings, Transcript, p. 370.)

People often experience these deficiencies over their whole lives. Disability exacerbates disadvantage. People with a disability and their carers often also experience low levels of income, educational attainment, employment, superannuation, health and wellbeing.

A new approach is needed

The flaws of the current system have driven strong demand for an entirely new approach and are its chief targets for change. The key test of a new scheme will be the extent to which it can address these existing deficiencies in an equitable, efficient, cost-effective and accountable way (while avoiding new pitfalls).

There are many possible models for a national disability scheme, varying in scope (relevant users, types and levels of support, generosity and duration), funding sources, decision-making arrangements and governance.

One option would be to substantially increase disability funding, but otherwise largely preserve the current arrangements. That would have beneficial effects, but it would fail to provide the certainty of support, early intervention and power over their lives that people are seeking. It would also not overcome the fragmentation and other inefficiencies identified above.

As such, the inquiry has focused on designing a coherent national system for disability support that is centred around removing the deficiencies of the current arrangements (table 1).

First, the Commission is proposing a National Disability Insurance Scheme (NDIS) to be overseen by a new organisation, the National Disability Insurance Agency. This would provide disability-related services and supports to the community at large, but with a particular emphasis on funded supports for people with significant disabilities and their carers.

Second, the Commission is proposing a National Injury Insurance Scheme (NIIS) to address catastrophic injuries from accidents, such as quadriplegia, acquired brain injuries, severe burns and multiple amputations. The scheme would comprise a coherent set of state-based, no-fault arrangements for providing lifetime care and support, building on existing schemes. It would have the same basic goals as the NDIS, but would be funded differently. Its role and links with the National Disability Insurance Agency and NDIS are discussed later.

Table 1 **Overcoming the problems of the present system**

Current problem:	*How the proposed arrangements would address the current problems*
Poor national insurance (people without a disability know they have no clear coverage if they acquire a disability)	Full coverage of all Australians of the costs of long-term disability care and support, so people without a disability could feel confident that they or their families would be supported in the event of a significant disability. Insurance has value for people even if they make no claims
Inequitable (eg what you receive in assistance depends on where you live)	A national scheme with national standards and entitlements that would cover people with disabilities from non-accidents with high needs For those with catastrophic injuries from accidents – new minimum national standards from wider accident schemes in all jurisdictions
Underfunded with long waiting lists	Funding would be doubled; and tied to the Australian Government's revenue-raising capacity (which is funded by more efficient and sustainable taxes)
Failures to intervene early (eg people stuck in hospital because of insufficient funds for minor home modifications)	The schemes, like all insurers, would aim to minimize long terms costs, so they would have a strong incentive to undertake early intervention where it is cost effective. The scheme would spend dollars to save more dollars and people would not have to wait for basic supports like wheelchairs and personal care
Fragmented	Universal schemes; strong regional management with local case managers to help people connect to services; disability support organisations to assist people with disabilities and their families to get the best outcomes; funds and assessments portable across borders and support providers
Lack of clear responsibilities	Assessments under the NDIS would identify and facilitate referrals to the right supports outside the NDIS
People with disabilities and their families are disempowered and have little choice	People would be able to choose their provider or providers. They could choose to have a disability support organisation manage their packages or to act in other ways on their behalf They would be able to manage their own funds if they wish and within rules
Economically unsustainable	Appropriate funding would stabilise the withdrawal of informal care under the present crisis-based system (which is leading to the costly withdrawal of informal supports by non-coping carers)
Inefficient with weak governance	The new scheme would be run to insurance principles by a commercial board with strong and constant monitoring by Treasury. Advice from a council of stakeholders (people with disabilities, carers and providers) People with disabilities and their families would have more control over the services they would receive. They would have a strong incentive to maximize outcomes. They would have a direct stake in cutting out waste and unnecessary services The scheme would have many safeguards to ensure costs did not get out of control Benchmarking against schemes overseas and between the NIIS and NDIS
People have no confidence about the future: what services will and will not be available	A scheme that would focus on long-term care and support needs People would have clear entitlements to their assessed needs Strong complaints, appeals and advocacy arrangements Strong reserves to buffer the insurance fund The scheme funds would not be tied to the annual budget cycle, but would have a mandated funding hypothecated to a separate fund
Poor information (a 'maze' for people with a disability); poor data collection for disability services to ensure efficient management	Information provision through web and other means by a single national organisation, disability support organisations to act on behalf of people, availability of objective information about supplier performance Coherent collection of data by scheme to manage costs and to assess outcomes
Poor evidence base	Research function and evidence-based practice

Who is the NDIS for?

The NDIS aims to achieve better outcomes for three different groups of 'customers'.

Tier 1: Everyone

In one sense, the NDIS is for all Australians, since it would provide insurance against the costs of support in the event that they, or a family member, acquire a disability. Insurance is valuable even if someone makes no claim. (Many people, for example, insure their houses against loss. Most never make a claim, nor do they expect to, but they willingly pay premiums each year to cover the risk.) The likelihood of someone acquiring a significant disability in any given year is low, but much higher than many other areas where people want insurance. For instance, Down syndrome (Trisomy 21) affects around one in every thousand live children born each year — and this is just one of many conditions leading to lifelong support needs for the person with a disability. Some people are uncomfortable with the word 'insurance', but the Commission's use of the word simply reflects the need to ensure that the community pools resources to provide reasonable long-term supports for people acquiring a disability.

An important role of the NDIS would also be to minimise the impacts of disability. This includes:

- promoting opportunities for people with a disability
- creating awareness by the general community of the issues that affect people with a disability
- drawing on its data and research capabilities to engage with other agencies to improve public health and safety.

In the awareness area, for example, the NDIS could recognise and encourage employment of people with a disability and try more generally to combat stereotypes that reduce opportunity. The potential benefits of a more inclusive society also extend to the wider community, including to employers. The costs associated with undertaking the three functions above would be very small and in some cases would come from existing resources.

Tier 2: People with, or affected by, a disability

Anyone with, or affected by, a disability could approach the scheme for information and referral services (as distinct from funded support). This would include

providing linkages with relevant services for which the NDIS was not directly responsible, such as mainstream services and community support groups. The scheme would also provide general information about the most effective care and support options. However, it will be critical to provide any referral and information services cost-effectively, with strict cost limits. As in tier 1, the population of potential 'customers' would be very high, but the overall costs would be small.

Tier 3: Access to publicly-funded, individualised supports

Tier 3 would be targeted at the much smaller group of people whose needs could not be met without taxpayer funding. Such a focus is consistent with the fact that risk-pooling through insurance tends to focus on higher-cost, less frequent events, like early death, serious injury and property loss. Many families and individuals have an ability to bear and finance some risks themselves, and this is often a more efficient and flexible way of addressing smaller and more common risks than formal risk pooling through insurance.

The NDIS would also not cover people whose needs would be best met by other systems. Accordingly, the NDIS would not cover people:

- acquiring catastrophic injuries, which would be covered by the NIIS
- with certain health conditions for which the publicly-funded healthcare system was best suited. For example, the care needs of people with terminal cancer would be best addressed in a palliative setting. People with bad backs and other musculoskeletal conditions would also typically receive assistance from the health system. The mental health system would assist the many people suffering psychological and psychiatric conditions, where these did not require regular daily supports. (However, the NDIS could play a role in the latter cases, sharing responsibilities for care and support with the mental health system.)
- whose needs would best be met in the aged care sector — such as people acquiring a disability after the pension age
- people *defined* as having disabilities, but for whom the NDIS is not needed. For example, a person whose periodic back pain sometimes prevents them from picking up an object from the floor without assistance, or a person with asthma who could not communicate while having an attack are all defined as having a disability using current disability classification systems. (The latter would be defined as having a severe disability.) These would not typically need (or want) funded support.

A person getting funded support from the NDIS would have a permanent disability, (or if not permanent, expected to require very costly disability supports) and would meet one of the following conditions:[1]

- have significant limitations in communication, mobility or self-care (3a in figure 1, and accounting for around 225 000 people)
- have an intellectual disability (3b) (around 50 000 people, not including some people with intellectual disability already covered above)
- be in an early intervention group (3c) (around 80 000 people). This would include two groups of people. One group would be those for whom there was a reasonable potential for cost-effective early therapeutic interventions that would improve their level of functioning (as in autism, acquired brain injury, cerebral palsy and sensory impairments). The other would be those with newly diagnosed degenerative diseases, such as Multiple Sclerosis and Parkinson's disease, for whom early preparation would enhance their lives. For instance, assisting in retaining bladder control can assist people with worsening Multiple Sclerosis
- have large identifiable benefits from support that would otherwise not be realised (3d). This category takes account of the difficulties of slotting everyone into the specific groups above. The National Disability Insurance Agency would apply this fourth criterion judiciously rather than routinely. It would be constrained by guidelines, and monitored for its effects on scheme costs. If the agency were to use this criterion loosely, it could pose a risk to the overall financial sustainability of the scheme.

The population estimates are indicative rather than precise because the survey data available are not designed for providing information on eligibility for supports, but for more general statistical purposes. The ultimate numbers that would actually use funded NDIS services would depend on who approached the scheme and the results of their assessments. The population of people accessing funded supports would be a fraction of those people who access (or are the targets of) tiers 1 and 2. But the overwhelming costs of the NDIS will relate to tier 3, and it is here where good governance will be critical to ensure both high quality supports and scheme sustainability.

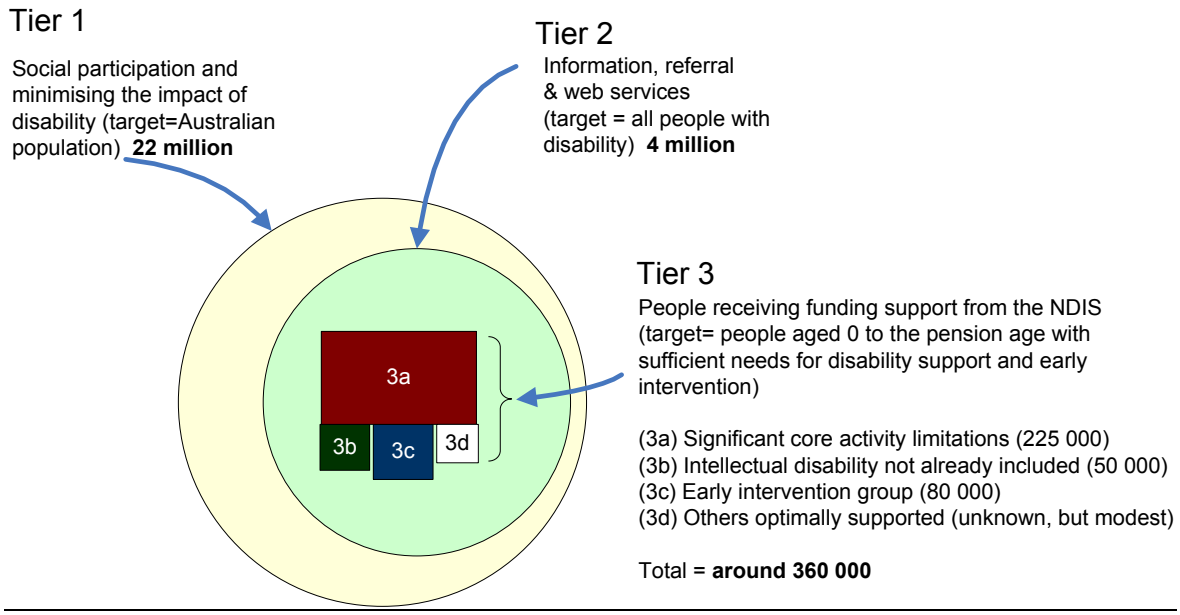
The NDIS would fund all people who met the criteria for tier 3 funding, and not just people who acquired a disability after the introduction of the scheme (as was the case with the NSW Lifetime Care and Support Scheme). Limiting the scheme to

[1] As is usual for most taxpayer-funded services in Australia, the NDIS would not provide individualised funding for people who are not permanent Australian residents.

new cases of disability would mean the persistence of sub-standard support for hundreds of thousands of people for decades.

Many people currently eligible for specialist disability services may be concerned about whether they would still be able to get funded services under the NDIS. The NDIS would have broader criteria for providing funded services than existing state and territory arrangements. Most people currently getting disability services would receive more support under the NDIS.

Figure 1 **The three tiers of the National Disability Insurance Scheme**
2009 population estimates



Aged care is a particularly important parallel support system

A large group of people with a disability get their support through the aged care system rather than the NDIS or NIIS. That system delivers and funds care and support services to people on the basis of age. While there are many similarities between the conventional disability system and aged care, there are also many differences, such as in philosophy, employment goals, the duration of care and support, and the areas of greatest competence (such as management of dementia). These differences suggest there are grounds for two distinct systems.

Moreover, there are differences in fair and efficient financing sources, which would be confused were the systems to be fully integrated. There are strong grounds for people who have accumulated significant lifetime assets prior to the pension age to contribute financially to their own *aged care*. This reflects that the likelihood of disability in old age is high, can be anticipated, and people can save to meet those

costs. Making people who acquired their disability when young pay for their care and support needs *before* the pension age would fail to meet the equity and insurance rationales for the NDIS and NIIS. Any such expectation would discourage employment and saving by young people with a disability.

While the aged and disability systems should not be combined, they nevertheless have to interact efficiently and meet people's reasonable preferences. The critical issue is to ensure that people would be able to use the support system that best met their needs, regardless of the funding source.

The Commission is proposing that, upon reaching the pension age (and at any time thereafter), the person with the disability could elect to stay with the NDIS or move to the aged care system. A younger age threshold would apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

- If a person elected to move to the aged care system, then they would be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches).
- If a person elected to stay with the NDIS care arrangements, their support arrangements would continue as before, including any arrangements with disability support organisations, their group accommodation, their case manager or their use of self-directed funding.
- *Either way*, after the pension age, the person with a disability would be subject to the co-contribution arrangements set out by the Commission in its parallel inquiry into aged care. Most people who acquired a disability before the pension age would not have enough income or assets to trigger any requirement for co-contributions *after* the pension age. However, some people who acquired a disability prior to the pension age may have built up sizeable assets and entitlements to retirement income. Most likely, these would be people who acquired their disability just a few years before the pension age, but it could include others. Like any other aged person, people in these circumstances would be expected to contribute to their care (whichever system provided that care). It would be inequitable if there were no such co-contribution requirement. Moreover, it would prevent people with assets or high incomes from attempting to enter the NDIS prior to the pension age to escape the co-contribution arrangements in the aged care system.
- If a person over the pension age required long-term aged residential care then they would move into the aged care system to receive that support.

The advantage of these flexible arrangements is that the NDIS would — from the perspective of any person — become a lifetime scheme if that is what he or she wanted.

While removing barriers to accessing the features and services of the two systems would overcome any major problems associated with a non-integrated system, it still leaves open the question of *public* funding arrangements. Overly elaborate arrangements for dividing the funding responsibilities are not justified since the Australian Government would be the sole source of new taxpayer-funded money for both the disability and aged care systems. To be workable, any division of funding responsibilities should be simple, easy to understand, and not represent a marked divergence from past responsibilities unless change was clearly warranted (the 'why rock the boat?' rule). There are several available options.

The first option is that regardless of when or how people acquired their disability, and irrespective of which system they elected to be in:

- the disability sector would fund the care and support needs of people with a disability up to the pension age, including for disability arising from age-related conditions like strokes and early onset dementia. (A younger age limit would apply to Indigenous people.)
- the aged care sector would fund the care and support needs of all people over the pension age. If a person elected to continue to use the NDIS care arrangements, the assessment tools from that system would be used to determine their funding, and the person would continue to receive supports through the NDIS. This would ensure that people who acquired a disability before the pension age would have the assurance that they would not get a different level of care and support.

The only exception to these arrangements would be people over the pension age who acquire catastrophic injuries, such as from a motor vehicle crash. The NIIS would fund people's support needs attributable to such accidents.

A second option would be for the NDIS to continue to fund people with an earlier acquired disability *after* the pension age, but with the aged care sector funding the *incremental* support costs associated with natural ageing.

Under either option, the source of the public funding component would remain invisible to the user. They would simply choose their preferred system.

The first funding arrangement is the simplest and is closest to the status quo of current responsibilities — and for that reason it is currently the Commission's preferred option. The Commission will look at this issue more closely after the draft report.

The assessment, funding and planning process

The NDIS would provide a number of supports and services, depending on a person's circumstances. The assessment and planning process would be a layered approach. It would:

- determine the tier of the NDIS that would be appropriate to each contact
- determine what supports outside the NDIS that people should be referred to, such as to a Job Network provider or mental health service. This would be mainly targeted at people in tier 2, but would also be relevant for people in tier 3 who needed supports both in and outside the NDIS
- for tier 3 contacts,
  - involve working with the person with a disability to develop a personal plan about what the person wants to achieve, including their employment and social participation goals
  - assess the nature, frequency and intensity of an individual's support needs, regardless of how these might be met. The assessment process would be person-centred and forward looking. It would consider the supports that would allow a person to fulfil a range of functions, rather than only respond to what an individual cannot do. However, the assessment would not be simply based on what people want, and it would be undertaken independently rather than through self-assessment alone
  - consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports'). For example, it would not be reasonable to expect an 85 year old carer to provide the bulk of the support to her son with a disability. But it would usually be appropriate to expect parents of a young child to provide support overnight and for a reasonable period during the week, as this is what parents usually do for their children. Where informal carers meet a large share of a person's support needs, they would receive their own assessment to establish the sustainability of that care and ways in which they could be supported
  - translate the assessment process's identified reasonable needs into a person's individualised support package to be funded by the NDIS, after taking account of natural supports. Most people would get an entitlement to particular supports (hours of respite and attendant care, aids and appliances, and so on), rather than a budget. However, people could elect to get an individualised budget under self-directed funding if they wanted to manage their budget directly and were able to do so (see later).

The NDIS would periodically reassess people's need for funded support as their circumstances changed, especially at key transition points, like leaving school, getting a job or moving out of home, or losing a natural support.

Assessments and information would be portable across the system — subject to protection of privacy — so that people would not have to repeat information for different providers or government agencies (such as repeated proofs that a child has a congenital intellectual disability). Support packages would also follow people across state and territory borders.

The assessment tool

Assessment tools are needed to calculate the level of needs and funding for a person covered by the scheme. Good tools should be valid (testing what they purport to), reliable (giving similar answers if people are re-tested or if people with similar characteristics are assessed), rigorous and cost-effective. The Commission proposes a coherent package of tools (a 'toolbox'), to be used across Australia, with different tools suited to particular needs for support (for example, aids and appliances compared with needs for job readiness training). The assessment tool/s would be developed within the widely accepted International Classification of Functioning, Disability and Health.

There is currently no ideal tool to use in the NDIS, but governments should not delay implementation of the scheme in the absence of 'perfect' tools. Accordingly, the NDIS would use the best available tools in its initial implementation phase, with the ongoing development of best practice approaches. Tools should be open source, rather than privately copyrighted.

Careful use of assessment tools is critical

Wide or vague assessment criteria for funded support, exaggerated claims for supports, or the increasingly generous use of assessment tools by assessors would risk diluting resourcing, be unfair, undermine community acceptance of adequate public funding and threaten scheme sustainability. There are several safeguards to prevent this.

- Assessments would be designed to be as objective as possible. The people making assessments would need to be independent from the client (unlike treating GPs), be properly trained in the use of the tools and be approved or appointed by the National Disability Insurance Agency for the purpose of conducting NDIS assessments. The agency would monitor assessors for their

appropriate use of the assessment tools. 'Hard' assessments would be unfair on the client. Assessment 'softness' could jeopardise the scheme.

- Assessments would concentrate on the reasonable and necessary supports people require. People would be asked what they had received under the old system. This would focus people on reasonable expectations about the packages they would receive (and in most cases, people would get more). That information would also be useful in modelling the impacts of the new system. An additional factor encouraging people to make reasonable claims is that many people would not want more supports than necessary — for example, more assistance with showers than they need.
- The assessments would not be 'rubber stamped'. Prior to making budgetary decisions, the National Disability Insurance Agency would confirm that the particular assessment followed the appropriate protocol, and was consistent with the 'benchmark' range of assessed needs for other people with similar characteristics. Deviations outside the norm would need to be justified. That means that the agency would detect and adjust excessively hard or soft assessments before people got their individual packages. The NDIS would initially be rolled out in a particular region in Australia — and this would help create sensible benchmarks and test assessment arrangements.
- The National Disability Insurance Agency would collect data to assess the reliability and validity of the assessment tools, and the tools would be developed over time. The assessment process would also be an important source of data for program planning, high level reporting, monitoring and judging the efficacy of interventions. It would also assist in forecasting the likely long-run liabilities for the scheme — a major focus for the management and sustainability of the NDIS.

Those safeguards aside, the goal of the NDIS would be to properly fund the reasonable assessed needs of people with a disability. This is an essential element of avoiding the uncertainty, chronic underfunding and unmet demand that has beset past allocation systems. Currently, the level of support is defined by annual government budgets that bear no consistent relationship to people's actual needs.

What disability supports can people get and on what terms?

What's in?

The current full range of disability supports would all be covered by the scheme (box 2) and the development of innovative supports would be encouraged. Supports would need to be reasonable and necessary. For instance, funded therapies would have to be in keeping with current clinical practice, evidence based practice and/or clinical guidelines.

There should be no means testing and limited use of 'excesses' and co-payments

The Commission proposes that there should be no income or asset tests for getting funded NDIS services. This is because the social gains from insurance also apply to higher income groups, and asset and means tests would discourage work and savings incentives for a group of people already facing weak incentives in these areas. (This is quite different from aged care for the reasons given earlier, and where a co-contribution based on a means test is justified.)

As in the Medicare safety net and most insurance products, there would *sometimes* be a requirement to pay a fixed upfront contribution (of say $500 per annum) to the NDIS, with free access to services after that point — so-called 'excesses'. These increase the likelihood that people would only make reasonable claims. However, there would be a waiver of any excess for families assessed as already contributing significantly towards the costs of their support through unpaid care. (In effect, they already 'pay' an excess in the form of unpaid support.)

The role of co-payments is a vexed one. Co-payments are charges made *each* time a person uses a service (compared with the one-off payment of an excess). They can discourage people from using low-value therapies, which is both fair and efficient. However, co-payments can also have unintended effects because sometimes people might be discouraged from using essential therapies — and end up using more publicly-funded services elsewhere (for example, through hospitalisation or greater long-term use of attendant care). Given this, the Commission proposes that the NDIS would fully fund the number of episodes of therapy appropriate to the person and which were supported by clinical evidence, with people choosing further episodes meeting their full costs.

Box 2 What supports would the NDIS provide?

Aids & appliances and home & vehicle modifications (including artificial limbs)

Personal care that supports an individual to take care of themselves in their home and community. This includes help with showering, bathing, dressing, grooming, personal hygiene including bowel and bladder care/toileting, assistance with eating and/or drinking, mobility and transfers; health maintenance, such as oral hygiene, medication use or regular and routine exercises and stretches. This would also include nursing care when this was an inextricable element of the care of the individual (for example, when meeting the care and support needs of a ventilated quadriplegic).

Community access supports to provide opportunities for people to enjoy their full potential for social independence. The intention is to allow people a lot of choice in this area. Supports would focus on learning and life skills development, including continuing education to develop skills and independence in a variety of life areas (for example, self-help, social skills and literacy and numeracy) and enjoyment, leisure and social interaction. The supports would:

- include facility and home-based activities, or those offered to the whole community
- include supervision and physical care
- range from long-term day support to time-limited supports.

Respite to provide a short-term and time-limited break for people with disabilities, families and other voluntary carers of people with a disability. These services are designed to assist in supporting and maintaining the primary care giving relationship, while providing a positive experience for the person with a disability and include:

- respite care provided in the individual's own home
- respite care provided in a community setting similar to a 'group home' structure
- host family respite that provides a network of 'host families' matched to the age, interests and background of the individual and their carer
- 'recreation/holiday programs' where the primary purpose is respite.

Specialist accommodation support, such as group homes and alternative family placement**.**

Domestic assistance to enable individuals to live in the community and live on their own, such as meal preparation and other domestic tasks; banking and shopping; assistance with selecting and planning activities and attending appointments.

Transport assistance to provide or coordinate individual or group transport services, including taxi subsidies.

Specialist employment services that provide or prepare people for jobs (including transition to work programs).

Therapies such as occupational and physiotherapy, counselling, and specialist behavioural interventions.

Case management, local coordination and development, which are broad services, including individual or family-focused case management and brokerage (disability support organisations), as well as coordination and development activity within a specified geographical area. They aim to maximise people's independence and participation in the community.

Crisis/emergency support, following, say, the death of a family member or carer, including emergency accommodation and respite services.

Guide dogs and assistance dogs, including the reasonable costs of being assessed for a dog, a dog, user training and veterinary costs.

What's outside the scheme?

Some services meet the needs of broader groups of people with a disability and Australians generally. These would continue to be provided outside the scheme (though the NDIS would provide referrals to them and, where needed, support the activity of people in them). Ultimately, there must be boundaries to the NDIS — it cannot take over responsibility for all services and supports that people with a disability use, or it would be too unwieldy and governments would be unlikely to implement it. The main complementary services are education, employment, health, housing, income support and public transport.

The Department of Education, Employment and Workplace Relations provides mainstream employment services through the Job Network, which are used by most jobseekers, including many with a disability. However, the NDIS would fund 'job readiness' programs (such as the 'Transition to Work' program in NSW) and specialised employment services.

State and territory departments of education (supported by Australian Government funding) are responsible for disability support in schools. That might involve structural modifications for buildings to ensure better accessibility, aids and appliances to increase educational opportunity, teacher aides, development of new curriculum materials, and teacher training (for example, in sign language). Many of these expenditures are hard to attribute to a specific individual, since they often meet the needs of many students with disability. As such, they should not form part of the scheme. (Similar arguments apply for post-school educational services.) However, the scheme would cover goods and services that would be needed regardless of whether a person was attending an educational institution or not, including personal attendant care, a hearing aid or a wheelchair.

Primary care and hospital (in-patient and outpatient) based services, medical services, and pharmaceutical products should remain a mainstream concern. As is the case with the community more generally, people will continue to access the existing health care system as the need arises. However, the scheme would have a role in reducing disability specific barriers, such as where a person has difficulty communicating their symptoms to a doctor (and has no guardian to perform that function) or where they need care that a familiar personal support worker is best placed to provide.

The boundaries between the mental health sector and the NDIS are blurred for the most severe and enduring mental illnesses. People with these illnesses will sometimes need daily supports that are akin to those of people with a disability generally. The Commission has included some provision for the daily support costs

(not clinical services) of people with severe mental illness in its preliminary cost estimates. However, the Commission is aware that the mental health system is under review and that this may affect the appropriate system for providing supports. The Commission is seeking feedback on where the boundaries should be drawn, and the implications for the NDIS's costs, eligibility conditions, service offerings and integration with the mental health sector.

The NDIS would cover provision of specialised accommodation services (such as group houses) — net of the standard contribution from a person's income for rent. When reasonable, it would also fund home modifications for privately-owned housing and the old stock of disability-unfriendly public housing, noting that such housing is often the key form of accommodation for people with a disability.

More broadly, shortages of public housing are often a major problem for people with a disability and can undermine the objective of independence. However, the shortages are common to many prospective clients of public housing. Given that, there are strong grounds for the resourcing and locational decisions for public housing to remain a mainstream policy concern. Moreover, were the NDIS to fund any gaps in housing for people with a disability, state and territory governments might withdraw funding for public housing for people with a disability ('cost shifting' to the NDIS). The Commission has raised the possibility of an entirely new model for housing for people with long-term disability, based on 'cashing out' the costs of public housing and specialised accommodation. People could then decide where they might live and what type of dwelling they might like. They (and their families) would be able to add their own finances to any housing decision. This model would require cooperation with state and territory governments.

Income support measures — in or out?

The Disability Support Pension should be outside the NDIS. It is an income support payment, like unemployment benefits. It covered 793 000 people in June 2010, well beyond the numbers eligible for funded support under the NDIS (around 360 000). It includes people whose incapacity for work is due to illness or injury and people without a lifelong disability, who do not need the individualised supports that the NDIS would provide.

There are grounds for (further) reform of the Disability Support Pension, given that its design can significantly undermine the NDIS's goals of better economic, employment and independence outcomes for people with a disability. Some people have disabilities so severe that they could not realistically ever work — and the Disability Support Pension would continue to be the major source of long-term income support for them. However, some people using the Disability Support

Pension have the potential for employment — with the associated gains of higher income, social connectedness, health benefits and the contribution they could make to the Australian community.

Reforms would aim to encourage the view that the norm for many people should not be the long-term use of the Disability Support Pension (unlike the current 'until death or aged pension us do part'). Those changes would be mainly orientated to people with typically non-permanent conditions, like anxiety and depression, and at people who could have much higher hopes for employment participation (for example, those with sensory impairments or mild intellectual disabilities). Some policy measures could include additional payments for people to work, targeted rehabilitation, employer support, measures to encourage people to get even a small foothold into work (even if just a few hours a week), and temporary rather than effectively permanent entry to the Disability Support Pension for those with reasonable prospects of employment (with periodic re-assessments). There may be other ways of providing people with a disability better opportunities for employment.

Reduction in Disability Support Pension numbers would also provide a financial offset for the NDIS, noting that the present value of 30 years of one person's entitlement to the Disability Support Pension is around $500 000 and that the budgetary costs of the Disability Support Pension were around $12 billion in 2009-10. But the prime motivation would be to improve people's genuine participation in society, their wellbeing and to raise their lifetime income — consistent with the goals of the NDIS.

Other payments sometimes classified as income support — Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance, and the Child Disability Assistance Payment — are really payments for support of people with a disability, since they encourage the provision of informal care or address people's mobility needs. These payments apply to a broader population than that covered by the NDIS (particularly care for the aged). One option would be to add the value of any relevant payments to the individual support packages of people with a disability who qualify for funded supports under the NDIS. (People outside the NDIS would continue with the current arrangements.) The person with a disability or their guardian would manage the funds. That way, people would have the maximum flexibility and sometimes people with a disability might decide to choose alternative carer options. However, this is a complex area, and the Commission seeks feedback about this option. Either way, NDIS assessments should take account of any of these payments — with information sharing with Centrelink.

Giving people power and choice

There is a strong rationale for people with a disability to have much more power over what and how support services are delivered. The Commission proposes a 'consumer choice' model, in which people with a disability (or their guardians) would:

(a) after consultation and assessment, the NDIA would provide people with a package of supports (not a budget amount), and people would be able to choose their service providers, possibly with the support of intermediaries (disability support organisations). People could switch disability support organisations and service providers if they did not meet their needs well. They might choose one service provider for one support need and another service provider for another need. They might ask a disability support organisation to bring together the package of supports and the best service providers on their behalf. A disability support organisation or service provider would only act for a person with a disability where that person had chosen to assign them that responsibility. The point is that the person with a disability would ultimately be in charge. This type of consumer choice would probably be the most common way in which people would exercise power (at least initially).

(b) have the choice (subject to some conditions — see below) to cash out their support package and manage it at *the detailed level*, allocating it to specific supports they assemble themselves (so-called 'self-directed funding'). Under self-directed funding, people could employ the support workers they want (and when), and choose to trade off some services against another. For example, the Commission knows of one case where a person with an intellectual disability used some of her funding to go to a movie weekly as her form of community access (replacing much more expensive and less enjoyable specialist day services). Self-directed funding is already partly implemented in Australia, and common in the United Kingdom and the United States. There is widespread and compelling evidence that it leads to good outcomes (in life satisfaction, confidence in their care, feelings of control, health, employment, a variety of other wellbeing dimensions, and potentially all at lower cost). There would be no obligation for people to use self-directed funding, and many would find it too bothersome or complicated, or would be happy to choose the disability support organisations and service providers and let them bundle supports for them. Moreover, the experience in the United Kingdom suggests that take-up may be initially slow. In England, just over 10 per cent of people aged less than 65 years completely manage their own budget. The share has been growing rapidly and some local councils have much higher rates than this. Under the NDIS, the pace of adoption of self-directed funding can be expected to grow as people gain

confidence in the new system, as the market evolves, and as the system provides more support for exercising choice (for example through DSOs).

The difference between the two ways of achieving choice is that the first is like consumers finding a restaurant. They do not cook the food, but they do get to choose the restaurant that suits their preferences. They will not go back if the food or service is poor. The second is like a person cooking the meal. He or she would have the freedom to choose the exact recipe, cooking methods, utensils, and when to cook, but it would involve a lot of work and they could make mistakes.

Model (a) is relatively easy to implement, but self-directed funding (model b) involves some complexities. To use self-directed funding:

- People would be told their individual budget — an outcome of the National Disability Insurance Agency assessment process — and would be told what parts of that budget could be 'cashed out' to use flexibly. (For example, they could not cash out essential therapies.)
- People would create a personal plan and develop a concrete funding proposal, which if accepted by the National Disability Insurance Agency, would be the basis for spending the money. They would have a lot of choice. As shown to be effective overseas, people could hire the workers they want, including neighbours and friends, rather than going through specialist disability agencies. The agency would run a trial to assess the risks and benefits from paying family members for some of their care and support. This has been a successful innovation overseas, particularly in the United States, but would need to be tested carefully, given its evident risks.
- The National Disability Insurance Agency would help by providing videos, written material and other guidance, as occurs in Victoria already.
- Disability support organisations (or indeed service providers) would help people (if they wanted) to handle the administrative and accountability requirements of self-directed funding (keeping receipt records, and dealing with workers' compensation, tax withholding, superannuation obligations and police checks) for a fee. Such agencies might also develop short training sessions in people skills and confidence to self-direct, especially as so many people with a disability have been used to a system in which they only had a passive role.
- There would need to be some accountability measures (though the overseas evidence suggests the incidence of abuse of self-directed funding is low). The National Disability Insurance Agency would not allow some people to self-direct if it gauged that the risks were too high, for example, past fraud. People could spend within the bounds of their plans, but would have to spend on and attend agreed therapies. They typically would not be able to shift money earmarked to

essential long-term assets (like a wheelchair or home modification) to current consumption, and there would be some blanket prohibitions, such as gambling with the funds.

- The National Disability Insurance Agency and its local case managers would monitor the use of self-directed funding. (The Victorian Government requires that the funds be placed in a separate bank account that can be monitored by the relevant department.) Self-directed funding would be formally evaluated three years after the commencement of the NDIS.

Financing the NDIS

While private voluntary insurance policies can provide useful cover for income loss for people experiencing disability, they are not suited to universal coverage of the population against the potential costs of long-term care and support associated with disability. The private insurance market does not operate well in this area, the costs would be prohibitive and many people would not get full coverage. This suggests some sort of compulsory insurance contribution — effectively a claim on general revenue or tax.

The financing mechanism must give people with a disability much greater certainty about getting reasonable supports over their lifetime. Current funding for disability comes from two levels of government subject to an annual budget cycle — making it hard to give people with disabilities any certainty that they will get reasonable care and support over the long-run.

That lack of certainty, combined with the need for stable revenue to underpin a proper governance arrangement for the NDIS (see below), means that revenue for the NDIS should not be subject to the annual budgetary review process. Whatever financing model is chosen it must dedicate the funds exclusively to long-term disability support ('hypothecation').

There are several options, but some are not likely to be appropriate. Savings-type models — like compulsory additions to superannuation levies or mandatory savings accounts — are ill-suited to disability support because disability can occur at any age (as compared with the need for aged care or retirement income), and fail to pool risks appropriately. The general design of so-called 'social insurance' schemes, in which employees and employers make compulsory contributions, are usually centred around income replacement related to people's previous wages, rather than focused on financing long-term care and support.

In that context, the Commission has concentrated on two models, based on hypothecation from new or higher taxes, or from general revenue using a specific *legislated* formula. Most tax bases are ill-suited to hypothecation because they are either too small relative to the demands of the NDIS or involve significant inefficiencies. The Commission has ruled out all state and territory government taxes. At the Australian Government level, only taxes on consumption or personal income would be suitable. Given the difficulty of changing GST arrangements, the only realistic tax base for a new hypothecated tax would be personal income. Were the Australian Government to introduce a new disability insurance levy, it should be implemented by adding an increment to existing marginal tax rates, rather than involving different income thresholds or new complex tax schedules.

However, better still, the Commission favours an arrangement in which — according to a legislated formula — the Australian Government directs payments from consolidated revenue into a National Disability Insurance Premium Fund. This approach means that the Australian Government could use whatever is the most efficient tax financing arrangement at the time, or partly fund the NDIS from savings in spending elsewhere. (In the latter vein, it should be noted that were governments to be starting with a blank slate in determining its funding priorities, there would be a strong rationale for provision of disability services to be one of its highest spending priorities.)

The Commission has not nominated a specific source of additional tax revenue or cuts in expenditure elsewhere. The reality is that the Australian Government will come under increasing fiscal pressure as a result of an ageing population (as shown by successive Intergenerational Reports), and the arrangements for financing the NDIS would need to be considered against that background.

This arrangement would not be reliant on the vagaries of Commonwealth, and state and territory budgets. Because the scheme would commence in stages (see later), not all the money would have to be funded by the government up front. The Commission considers that the funding of the scheme is manageable, taking into account a wealthy and growing economy, and the fact that Australian taxpayers only need to finance the additional amount of resources needed to fund a proper disability system.

Payments into the premium fund would meet immediate costs and would build up reserves to spread the costs of the scheme over time and for prudential reasons. The revenue formula may need to be periodically adjusted if the reserve position deteriorated, but only if the cost increases did not reflect poor cost management. The quid pro quo of revenue certainty would have to be strong cost management in the NDIS (see later) and tightly defined and appropriate assessment arrangements.

How much would be needed?

In 2009-10, the Australian Government provided funding to the disability sector of around $1.7 billion, while state and territory governments provided funding of around $4.5 billion — or a total of $6.2 billion. The Commission's preliminary estimate is that the amount needed to provide people with the necessary supports would be an *additional* $6.3 billion, roughly doubling existing funding.

Accordingly, the real (or net) cost of the NDIS would be around $6.3 billion a year. That could be funded through a combination of cuts in existing lower-priority expenditure and more taxes. (Of course, given the inevitable delay in implementing the NDIS, there would be a modest increase in these cost estimates.)

To put that level of funding in perspective, even if it were entirely funded through higher taxes, it would represent less than a 2 per cent increase in total tax revenue from all levels of government. It would amount to around an annual $280 premium per Australian for comprehensive insurance coverage of a person's long-term care and support needs if he or she acquired a permanent disability.

Given its capacity for raising efficient and sustainable taxes, the Australian Government should take responsibility for meeting the entire funding needs of the NDIS. State and territory governments should offset the Australia-wide fiscal implications of the transfer of responsibility by either:

(a) reducing state and territory taxes by the amount of own-state revenue they used to provide to disability services *or*

(b) transferring that revenue to the Australian Government.

An intergovernmental agreement would spell out the obligations of all jurisdictions.

The Commission prefers option (a) because it leads to a more efficient way of financing the NDIS, with greater certainty of long run funding, and with no greater a level of Australia-wide taxes than other options. It would also be easier to police and, compared with most of the alternatives, have a lower risk that jurisdictions would not meet their ongoing commitments.

All jurisdictions would be able to point to a much better system for disability care and support (in which they would play a major role — see later) and state tax reform for their citizens.

How should the NDIS be structured and governed?

The NDIS would be a much more devolved model than the current provider-centred approach. Under the consumer choice model described earlier, people with a disability could choose the disability support organisations and service providers that would provide the supports detailed in the person's support package. Alternatively, if they were able and wanted to, they could cash out their package and manage their funds themselves within clear guidelines and with monitoring. Either way, the NDIS would effectively involve hundreds of thousands of people who would largely be in control of their individual support packages, rather than just a few governments or suppliers. Indeed, from day to day, a person with a disability and their family would mostly have direct contact with the service providers *they have chosen*, just like most consumers. Much of the complex business of managing the NDIS by the scheme agency would (and should) be invisible to them. In the main, people's contact with the National Disability Insurance Agency would be through a local case manager.

But what happens behind the scenes will be critical to the success of the NDIS. It would use a corporate model of governance, as in other insurance arrangements in the private and public sectors. Government accident insurance schemes, like the Victorian Transport Accident Commission, NSW Lifetime Care and Support Authority and the New Zealand Accident Compensation Corporation, use a corporate insurance model.

The Commission proposes that Australian Government would establish a new statutory authority to administer the scheme — the National Disability Insurance Agency. The agency would have responsibility for supervising key aspects of the scheme. It would provide information to people generally ('tier 1' users); undertake research to identify best practice interventions; oversee assessment and the ongoing development of assessment tools, and would authorise individuals' assessment results (and funding proposals for those managing their own funds). It would provide support to people through local case managers and to providers by supporting workforce development and facilitating the sharing of best practice innovations. It would determine efficient prices.

A critical part of its function would be strict management of the NDIS, supported by systematic national data collection for actuarial analysis. As discussed earlier, effective ongoing commercial management is essential to avoid a blowout in assessment outcomes (and the funding associated with them) and to ensure appropriate service utilisation and costs. Poor management is the largest risk to the scheme's sustainability, and thereby the largest risk to long-run reasonable support of people with a disability and their families.

The National Disability Insurance Agency would be free to subcontract functions to third parties — for example, research — but the goal would be to run an efficient organisation.

Some of the most critical aspects of the NDIS would lie outside the National Disability Insurance Agency (figures 2 and 3). These would include:

- funds management, which would be integrated with existing Australian Government arrangements for investing in long-term assets. The agency would still have a role, setting broad guidelines for acceptable levels of risk and return on the scheme's investment funds
- mainstream services and specialised service providers — the agencies that deliver the main supports people with a disability want
- Disability support organisations. Among other things, these would offer to provide people with:

    (a) brokering services, such as information about the service providers that might be suited to the specific individual and arranging supports on their behalf (based on the person's personal plan, support package and stated preferences)

    (b) initial information about the scheme, the assessment process and their rights and responsibilities (funded by the NDIS)

    (c) personal planning

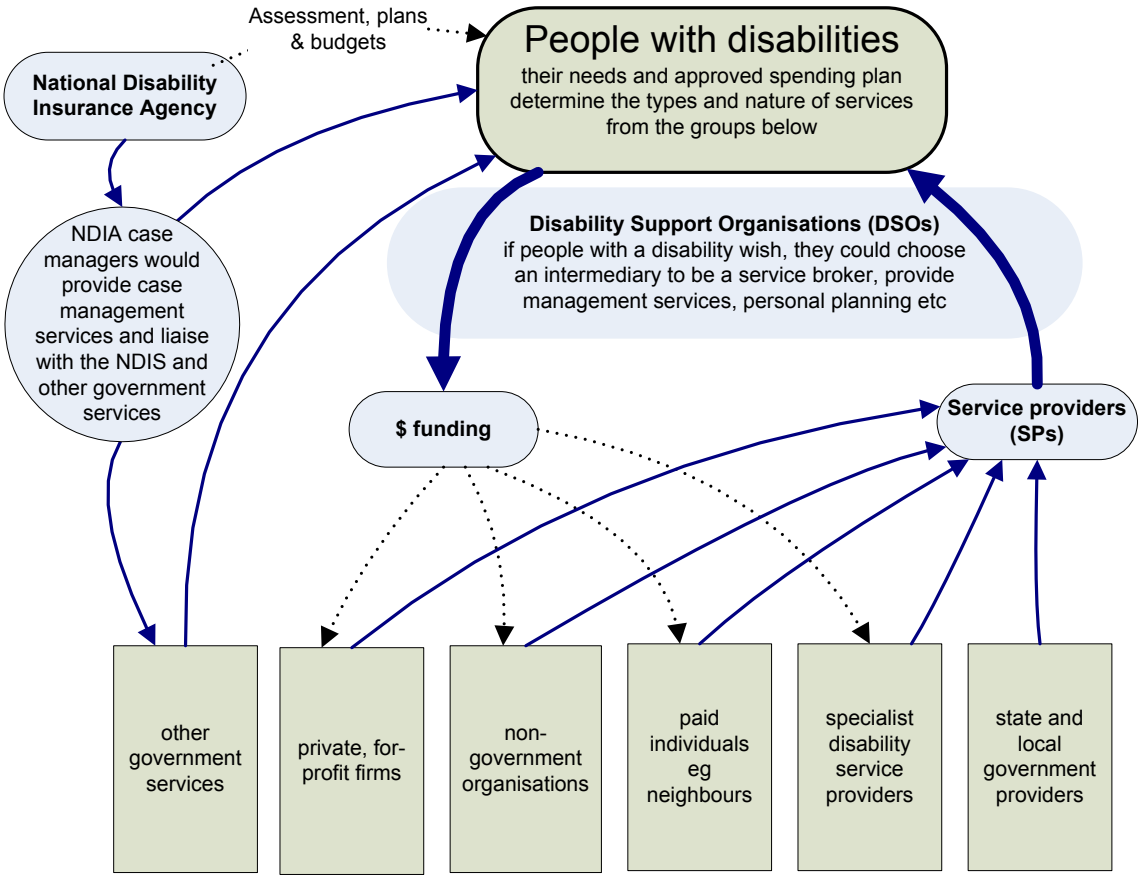
    (d) the skills and confidence to practically exercise choice

    (e) advocacy services

    (f) management services (such as dealing with the administrative aspects of self-directed funding, were a person to go down that route).

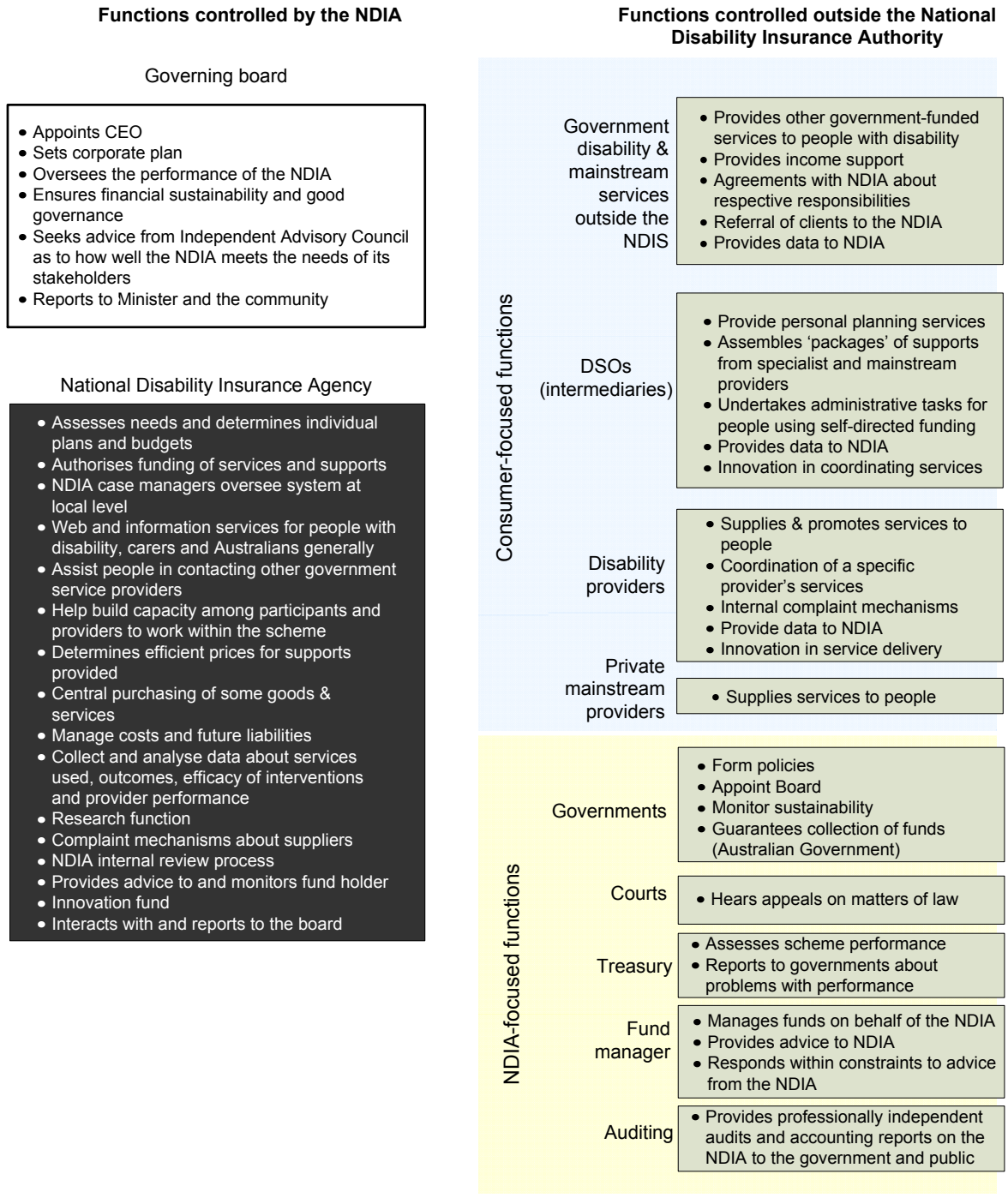
The functions of disability support organisations and service providers could overlap, but should not be exactly the same. Service providers could *act* as disability support organisations for the services from (b) to (f), but could not undertake (a). (Otherwise, this would be a bit like allowing a mortgage broker to be a division of a bank providing mortgages.) The services provided by disability support organisations would initially be subsidised by the NDIS (to develop the market), but ultimately would be reflected in service charges to people with a disability who choose to use them.

Figure 2 **From a consumer's perspective, the NDIS will give them the means to choose supports that will best meet their needs**



People with disabilities and service providers would need to be able to complain to, and contest the decisions of, the National Disability Insurance Agency. The agency would have an internal complaints office that would hear complaints about its conduct or disputes about its decisions. This would operate separately from the other parts of the agency. The office would be headed by an independent statutory officer, who would be responsible for reviewing complaints and appeals made by people with disabilities and support providers. The legislation for the National Disability Insurance Agency would create this role and specify that the officer appointed would be independent, would act fairly and impartially, basing their decisions on the available evidence, and could not be directed in their decision-making. People could appeal to courts on the National Disability Insurance Agency's decisions, but only on matters of law and not on merit grounds. Otherwise, the cost of the scheme would be higher and there would be increased financial risks.

Figure 3 **Who does what in the NDIS?**



The NDIS would not represent an Australian Government takeover of disability services. Rather, the goal would be to create a new federal social and economic institution that would be independent from all governments in operational matters. In consultation with state and territory governments, the Australian Government would draft legislation setting up the National Disability Insurance Agency and defining its functions. (At the practical level, the Australian Government would

have carriage of the legislation through the Australian Parliament and Senate.) As founders of the scheme, all Australian governments would oversee the appointment of a skills-based board. The scheme would particularly benefit from having some board members who have experience with long-term care or insurance schemes, since this is how the NDIS should be structured. Governments could sack the board, if it failed to perform. All jurisdictions would also be involved in appointments to a disability advisory council to advise the board on the scope and activities of the NDIS from the perspectives of people with disabilities, carers, suppliers of equipment and services, and state and territory service providers. The agency would provide reports about its financial and other performance to all governments.

What about accident insurance arrangements?

The Commission is proposing a separate 'federation' of accident insurance schemes for catastrophic injury (the National Injury Insurance Scheme or NIIS), drawing on the best arrangements already in place around Australia, and extending their scope. Catastrophic injuries mainly comprise major acquired brain injuries, spinal cord injuries, burns and multiple amputations. In the medical area, catastrophic injury would cover a wider set of disabilities, such as some instances of severe cerebral palsy. In many instances, people need lifelong supports.

Currently, there is a range of state and territory arrangements for insuring people for disability arising from accidents, including workers' compensation schemes throughout Australia, hybrid no-fault third-party motor vehicle insurance arrangements in some states (NT, Victoria, Tasmania and NSW), limited provision for people suffering disability as a result of crime (a major and rising source of catastrophic injury) and fault-based medical indemnity and public liability insurance.

There is little rationale for the striking differences in state and territory arrangements for dealing with catastrophic injury. Only no-fault accident schemes meet people's lifetime care and support costs efficiently. The major flaw in the remaining fault-based arrangements is that people who cannot identify an at-fault party in a catastrophic accident get inadequate supports. Even when an at-fault party *can* be identified, the processes for securing compensation for support through litigation are drawn out and costly in fault-based regimes. (It can sometimes take more than 20 years.) Nor is there evidence that the common law right to sue for compensation for care costs increases incentives for prudent behaviour by drivers, doctors and other parties. The Commission has investigated this issue in the past and has suggested significant reforms.

The Commission again proposes far-reaching changes.

The creation of a national injury scheme would avoid many of the deficiencies of common law compensation systems and improve outcomes for people with catastrophic injuries. It would comprise a system of premium-funded, nationally-consistent minimum care and support arrangements for people suffering catastrophic injuries.

Ultimately, the NIIS would cover all causes of catastrophic injuries, including those related to motor vehicle accidents, medical treatment, criminal injury and general accidents occurring within the community or at home.

While existing workcover schemes would stay in place, there are strong grounds for state and territory governments to transfer the care and support of catastrophic workplace claims to the NIIS through a contractual arrangement with their respective workers' compensation schemes. This reflects the fact that the incidence of catastrophic injuries under workcover schemes is low and that their systems are not well geared to provide coordinated lifetime care for such cases. Notably, Victoria has already transferred such cases to its motor vehicle scheme. (Existing no-fault workcover arrangements would cover the costs of care and support for non-catastrophic workplace injuries.)

Existing revenue sources (mainly premium income from mandatory insurance policies) should be retained in the NIIS. The costs of introducing full no-fault coverage of lifetime care depend on the source of the injury and the jurisdiction. In all cases, a significant source of revenue would be savings in legal costs (which account for a significant component of premiums in fault-based systems). In NSW, the additional cost to compulsory third party (CTP) motor vehicle premiums to finance no-fault insurance was nearly zero.

The Commission has sought feedback on the best way of financing any additional costs associated with no-fault coverage for catastrophic medical accidents.

For other sources of catastrophic injury, new sources of income would be needed to finance no-fault insurance. The KPMG-Econtech review of the efficiency of state and territory taxes (for the Henry Tax Review) found that municipal rates and land taxes were efficient — and these would be the best tax base for the states and territories for collecting the revenue required for these other sources of catastrophic injury. The impost would be small. Moreover, in the case of lifetime care and support costs for catastrophic injuries formerly covered by public liability insurance, there would be an offset through reduced premiums for such insurance.

Overall, a ballpark estimate is that the net annual costs of a comprehensive no-fault scheme covering all catastrophic injuries could be around $30 per Australian.

It would take some time to introduce no-fault arrangements for all catastrophic injuries, but fast progress could be made in some areas.

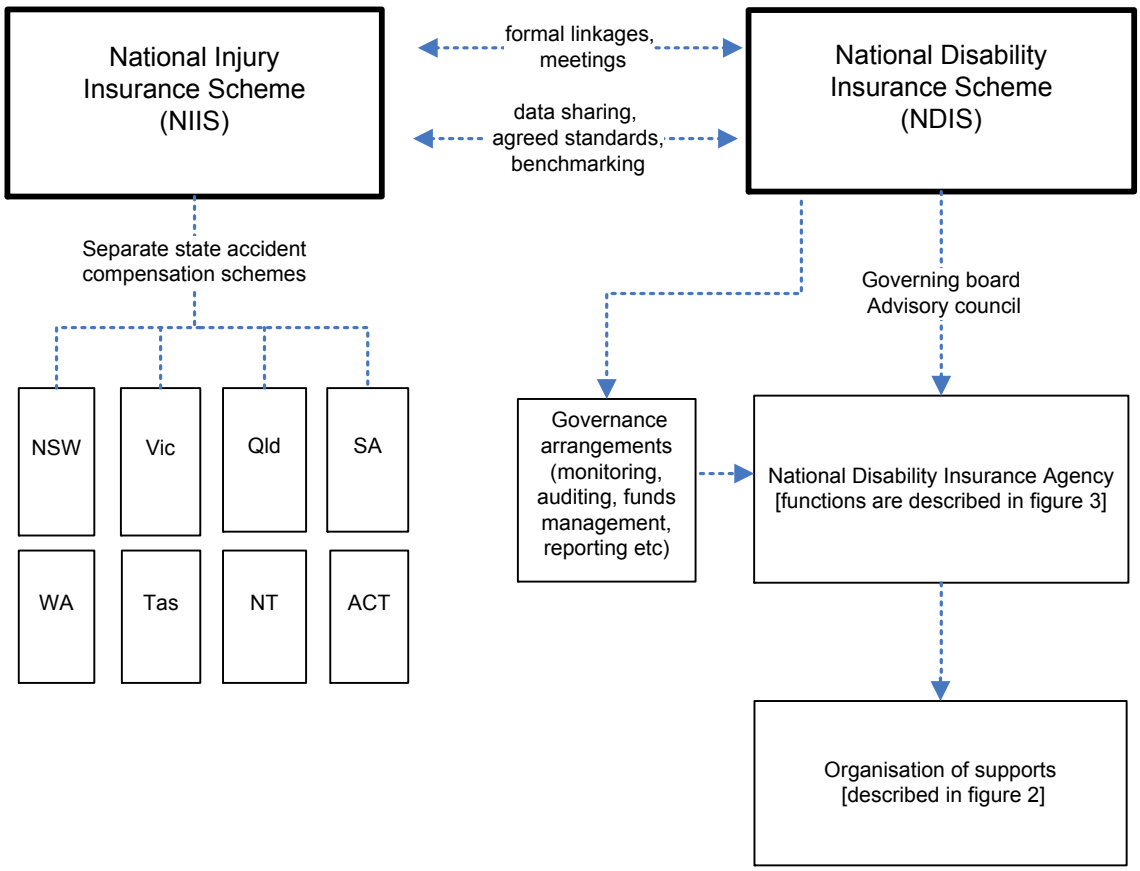
- State and territory governments would set up no-fault catastrophic injury schemes for motor vehicle and medical injuries (by the end of 2013) — and these would be the starting point for an NIIS that covered all sources of catastrophic injury several years later.
- The NIIS would be structured as a federation of separate, state-based injury insurance schemes. The purpose of federation membership should be to ensure consistency in assessments and to provide certainty around a benchmark minimum standard of care. Benchmarking would need to be transparent and agreed. Jurisdictions would learn from existing no-fault schemes — making progress quicker. New schemes would include well-developed and coherent models for rehabilitation and care, funds management, cost control — emphasising management of long-run expected liabilities — and, information collection and analysis (just as in the NDIS).
- Smaller states could choose to sub-contract scheme management to another state (or to a private sector insurer operating across jurisdictions or to the NDIS) to reduce the fixed costs of establishing their own schemes.
- The NIIS should eventually provide coverage for care and support for all significant severities of accidental injury, except where the only care needed can be provided by the health sector.
- Over time, there is a logic in extending coverage of the NIIS to provide no-fault cover for economic loss and general damages. However, that would be a more radical shift. Its practicability would have to be carefully tested. The Commission proposes a review of the NIIS in 2020, of which a part would examine this issue.

The National Disability Insurance Agency itself would play an important role in the NIIS (figure 4). It could act as a host for cooperation, assist in and publish benchmarking information for both schemes, and encourage diffusion of best practice.

Other than in its role as one stakeholder in the National Disability Insurance Agency, the Australian Government would be a less important party in the NIIS than state and territory governments. The Australian Government may also need to contribute to premiums in the Northern Territory, where the injury risks are higher. (This reflects the same equalisation principles underpinning the Commonwealth

Grants Commission's distribution of the GST.) Moreover, the Australian Government would push the establishment of the NIIS as a quid pro quo of its very large additional revenue contributions to the NDIS.

Figure 4 **Links between the NIIS and the NDIS**



Why two schemes?

The Commission has deliberately recommended two schemes, rather than a single disability scheme. This reflects the distinctive characteristics of the catastrophic injury schemes. The NIIS would:

- be focused on a relatively small group of people subject to very particular and individualised intensive management. When the NIIS is fully operational, the caseload would be around 20 000 people, or about 5 per cent of the caseload of the NDIS
- have a much greater interaction with the health system
- draw on its revenue sources to cover the expected lifetime liabilities of new cases (it would primarily be 'a fully funded' scheme)

- have as one of its goals, the reduction of local risks that can contribute to accidents. For example, local government can affect public safety through local initiatives, and accident schemes can use premiums to deter high-risk behaviour. One of the reasons for using sources of funding (premiums and, where necessary local government rates) different from the National Disability Insurance Agency is that these send price signals that encourage greater incentives for safety.

Moreover, it is a practical reality that there is already a nucleus of existing, well-functioning schemes, like those run by the Tasmanian Motor Accident Insurance Board, the Transport Accident Commission and the NSW Lifetime Care and Support Authority. There would be significant legislative change required to wrap up such accident schemes into a giant NDIS, and the resulting 'neatness' may not be worth the gains. That said, this issue should be revisited at the time of the proposed review of the NIIS in 2020.

Workforce issues

The expansion in the system associated with the NDIS would increase the demand for disability support staff. Moreover, workforce pressures are likely to rise as the aged care system expands (and as economy-wide labour force growth subsides with population ageing), further increasing the demand for workers. The capacity to provide expanded services will depend on attracting new employees and enabling workers in the system who want to work longer, or more flexible hours, to do so.

The long-run response to shortages will be wage increases following competition between suppliers for labour (the current low wage levels are a major deterrent to staff working in the industry). The scope for wage increases associated with excess demand also has a bearing on the implementation speed of the NDIS. Were governments to increase funding to disability services suddenly and dramatically, the immediate effect would likely be significant wage increases, without the desired expansion of supply. The phased implementation of the scheme proposed below would allow for both wage increases and a sustained increase in the workforce.

Apart from wage increases, other options for alleviating workforce shortages are:

- initiatives by service providers to adapt the work environment to increase workforce retention (such as shorter shifts, longer breaks between shifts, and greater certainty about shift arrangements)
- pursuing productivity increases by, for example, using bed turners, electronic alarms, and other equipment that can reduce the need for personal care

- supporting the current informal workforce, including using self-directed funding to allow the payment of friends, neighbours and, if justified by the trial results, relatives for some personal care and support
- an advertising campaign for new staff (apparently a successful initiative in New South Wales)
- using immigration of appropriate workers, but only if acute and persistent shortages are present. Ideally, wage increases would elicit a sufficient supply response within Australia.

The Commission is sceptical of imposing any additional *requirements* for credentials and training of the disability services workforce. In particular, there should be no minimum training requirement to work as a personal support worker. These support workers are the most important group in that workforce, and the essential skills they bring — empathy, a capacity for listening and social skills — are intangible and not easily created through training. Moreover, the most important 'training' of workers is often by the person with a disability and their families. (It should also be emphasised that the overwhelming current source of care is unpaid and usually untrained family carers, who are usually preferred by people with a disability.)

That said, formal and on-the-job training will often be an appropriate market strategy by providers hoping to attract customers and new workers. Training would also have to emphasise the need to respect the rights and wishes of people with disabilities. The NDIS should also undertake research to examine how training affects outcomes for people and ensures safety for workers.

Overall, the creation of the NDIS (and the NIIS) would have significant positive impacts on the disability workforce. The new system will translate to greater pay, more jobs, better working conditions, the capacity for innovative practice, enough resources to do the job properly, recognition of the critical role of workers, more choice of employers, and greater satisfaction from working in a system that achieves better outcomes for the people they support. These outcomes will be critical to attracting the workforce needed to underpin the expansion of the NDIS.

Reform of service delivery

The NDIS would have significant implications for service delivery. Under a consumer choice model in the NDIS, it would mean that:

- service providers and (the newly created) disability support organisations would need to adapt to a new way of thinking and supporting people with a disability

- block funding to service providers would phase out. Providers would compete for custom, as people with a disability, or their agents, could 'shop' around for the service providers that best met their support needs, subject to the resources specified in people's support packages. Providers would need to deal with competitive risks in the way most businesses do. The National Disability Insurance Agency would reimburse service providers or disability support organisations for those parts of a person's support package that they supplied. The agency would set efficient prices for such reimbursement to ensure the long-run viability of efficient providers, which would include adequate returns for capital investments. (Only people using self-directed funding would pay providers directly.) Ultimately, the pricing role of the agency would diminish as the market developed, and this could allow disability services to even more closely resemble the economy-wide service sector. However, block funding may persist in exceptional circumstances, such as pilots of innovative services, in some rural areas where markets might not support the provision of any service, or where there is a need to build longer term capacity, such as Indigenous-specific services
- people with a disability would more often use mainstream services, placing additional pressures for high quality performance by specialist agencies.

There would be significant IT infrastructure needs associated with an integrated disability system, in particular for obtaining access to clients' assessments or other information relevant to their support needs, for financial management, and for collecting data and passing it to the NDIS. (Notably, the Australian Government employment department had to oversee the creation and deployment of sophisticated IT system with the creation of the Job Network. The lessons learned from that exercise will be important for the National Disability Insurance Agency.) Moreover, the Australian Government is currently considering the adoption of standard business reporting for the not-for-profit sector to reduce regulatory burdens for that sector. This should make reporting of any required financial information to the National Disability Insurance Agency easier and less costly.

There are significant opportunities for service providers under the NDIS.

- The amount of funding to disability would be much greater, and there would be strong incentives for innovative practice (with providers as well as people with a disability 'unshackled' from block funding).
- The Commission proposes that the National Disability Insurance Agency include an innovation fund that providers would use for developing and/or trialling novel approaches to disability services.

- There would be arrangements that encourage the diffusion of best practice throughout the disability sector.

These aspects of the NDIS are components of a broader approach by the National Disability Insurance Agency to develop and implement a quality framework for service providers. Another essential component of this framework would be the development of complete, nationally consistent standards that would apply to all funded specialist service providers and disability support organisations. These would provide greater national consistency in service quality and facilitate equivalent treatment of service providers across jurisdictions. These standards should be complete rather than augmented on a state-by-state basis — essentially replacing state and territory equivalents for the purposes of the NDIS. A period of mutual recognition of state and national accreditation would be required to minimise the transitional impact on service providers.

Wherever possible, standards should be set in terms of directly observed consumer outcomes, with a focus on those most vulnerable or at risk of harm. This would be best achieved through periodic independent audits (potentially triggered by complaints) and consumer surveys and surveillance by local case managers (*not* by service providers themselves). Evidence of non-compliance would follow the typical enforcement 'pyramid' with advice for minor matters, but intensive investigation by the National Disability Insurance Agency, sanctions and potentially loss of certification (and therefore access to funding) for serious non-compliance. The approach should focus on effective safeguarding and raising the actual quality of supports, rather than 'paperwork' initiatives, which would do little to ensure quality assurance but would impose compliance burdens on specialist disability service providers.

In addition, some performance information about service providers would be made available to consumers, such as auditors' reports, the number of substantiated complaints, and the results of consumer satisfaction surveys. That information, with the brokering and information services of disability support organisations, will mean that the choices made by people with a disability will be more informed.

There has been a trend over the last 30 years towards provision of services by not-for-profit organisations, but government-run services still play a role, as do some for-profit agencies. As a funding and purchasing agency, the National Disability Insurance Agency would give no preferences to suppliers based on their ownership. Under a consumer choice model (supported by disability support organisations), the degree to which these different suppliers flourish or decline in importance would depend on their performance.

That said, in some cases, non-government organisations and private operators may be unwilling or unable to operate (though presumably they would often do so if prices were set sufficiently high). In any such instance, state and territory government agencies may be the only tenable service provider ('providers of last resort'). This may occur for clients with highly complex needs or challenging behaviours, as well as in remote settings.

An Indigenous strategy

Indigenous disability rates are around double those of non-Indigenous Australians. Disability often coincides with other major problems with housing, health, substance abuse, poverty and community breakdown. Indigenous Australians also face significant barriers to accessing disability support services. This occurs due to insufficient services in metropolitan and regional areas (with typically only visiting services in remote areas), social marginalisation, cultural attitudes towards disability and culturally inappropriate services.

These barriers to service delivery suggest that the service delivery model underpinning the proposed NDIS may not, on its own, deliver adequate care and support to Indigenous people with a disability. While Indigenous Australians would have access to individual support packages on the same basis as non-Indigenous Australians, it may also be necessary to block fund some service providers in order to overcome the additional barriers that Indigenous Australians face. In addition, Indigenous people often do not make claims for support. These distinctive aspects suggest that disability support for some Indigenous communities will probably need to take a different form.

Several other strategies may be useful in helping to overcome the barriers to service delivery, including:

- fostering and building capacity in community-based operations, in consultation with local communities, and through the engagement of local staff. Larger experienced service providers would provide support. This strategy would apply across all parts of Australia —urban, regional and remote communities. But the strategy would need to recognise the particular challenges of adequate support in remote locations where even mainstream services are often absent
- employing Indigenous staff and providing appropriate training
- developing the cultural competency of non-Indigenous staff.

But ultimately, Indigenous disadvantage and the disability that is one component of it, reflect a complex set of linked factors that require a whole of government

approach and community involvement. The Commission is considering these issues further.

Implementation of the NDIS

People want more supports urgently. But the reality is that more haste in structuring and commencing the NDIS could mean less speed and effectiveness. A full-scale 'well-oiled' system cannot be put in place in a year or two, but requires careful planning and the development of new systems. Implementation of the NDIS will have to confront the difficulties of reform in a system involving multiple jurisdictions and overlapping responsibilities. This means that present arrangements for state, territory and local government disability services will have to remain for a while and, after the introduction of the NDIS, coexist for some time. In the interim, the Australian Government should supplement funding under the National Disability Agreement to reduce some of the worst rationing.

In the period up to the full operation of the NDIS, there would need to be

- discussions between state and territory governments and the Australian Government about the legislation that would establish the National Disability Insurance Agency, set the boundaries for the NDIS, and finance the scheme. In consultations with all state and territory governments, the Australian Government would draft legislation
- finalisation of an intergovernmental agreement setting out the financing obligations of the Australian Government and the reciprocal introduction of tax reform by state and territory governments
- appointment of a board (by all Australian governments)
- work undertaken on the detailed features of an effective and efficient organisation (IT, data systems, information dissemination strategies, research functions), and more broadly for an effective scheme (workforce strategies, arrangements to encourage the formation of disability support organisations, and systems for managing self-directed funding and providing development support for service providers).

To oversee this process, the Australian and state and territory governments would form a joint taskforce. It would be headed by a person with insurance or disability experience who has driven change successfully in a large organisation, appointed with the agreement of all jurisdictions. The taskforce would report back regularly to Heads of Treasuries meetings and COAG on milestones reached in the planning for the commencement of NDIS by January 2014.

The costs of setting up the NDIS, while significant, would be reduced by learning from the existing no-fault accident insurance schemes around Australia. And, in the past, large structural changes have been achieved in several years, for example, as with the introduction of Centrelink. The Job Network — a sweeping change in employment services — took two years to implement. Medibank was implemented in one year after the passage of its enabling legislation.

The NDIS would begin at a manageable size. A workable way of proceeding must recognise that there would have to be enough people initially in the scheme for the National Disability Insurance Agency to learn about how the scheme works (and how to adapt it).

The scheme would commence in early 2014 in a particular region in Australia, providing high quality services to many thousands of people. This regional arrangement would incorporate all of the functions and structures of the NDIS, and offer supports to the full range of eligible people with a disability in that region. This would allow fine-tuning to test and refine the new scheme structures with a population that is not overwhelming. It would also help build a robust and sophisticated resource allocation process that would serve people's needs appropriately, while reducing the risks of cost blowouts. In successive years, the scheme would be scaled up.

In the second year, the scheme would be extended to all of Australia. However, from a practical perspective, the scheme could not immediately support the entire eligible population across all regions in just its second year of operation. This reflects the large scale of the scheme, and the fact that it will take time to:

- grow a high quality workforce
- develop capabilities in the National Disability Insurance Agency and specialist providers
- make assessments of around 400 000 people's reasonable needs.

Accordingly, the Commission proposes that over the period from 2015 to 2018, the scheme would progressively expand to cover all relevant people with a disability. In its first stages, the NDIS would cover all new cases of significant disability and some of the groups most disadvantaged by current arrangements, such as:

- children aged under five years who have substantial core activity limitations
- select groups for whom involvement in pilot early intervention programs looks promising
- people who are now cared for by ageing carers
- people who have been inappropriately placed in nursing homes.

Draft recommendations

Chapter 3 Who is the NDIS for?

DRAFT RECOMMENDATION 3.1

The National Disability Insurance Scheme (NDIS) should have three main functions:

- ***to cost-effectively minimise the impacts of disability, maximise the social and economic participation of people with a disability, and create community awareness of the issues that affect people with disabilities. These measures should be targeted at all Australians***
- ***to provide information and referral services, which should be targeted at people with, or affected by, a disability***
- ***to provide individually tailored, taxpayer-funded support, which should be targeted at the subset of people with disabilities who are assessed as needing such support.***

DRAFT RECOMMENDATION 3.2

Individuals receiving individually tailored, funded supports should be Australian residents, have a permanent disability, (or if not a permanent disability, be expected to require very costly disability supports) and would meet one of the following conditions:

- ***have significant difficulties with mobility, self-care and/or communication***
- ***have an intellectual disability***
- ***be in an early intervention group, comprising:***
  - ***those for whom there was a reasonable potential for cost-effective early therapeutic interventions (as in autism and acquired brain injury)***
  - ***those with newly diagnosed degenerative diseases for whom early preparation would enhance their lives (as in multiple sclerosis)***
- ***have large identifiable benefits from support that would otherwise not be realised, and that are not covered by the groups above. Guidelines should be developed to inform the scope of this criterion.***

DRAFT RECOMMENDATION 3.3

The NDIS should provide advice to people about those instances where support would be more appropriately provided through non-NDIS services. Support should be provided outside the NDIS for people whose:

- ***disability arose from a workplace accident or catastrophic injury covered by insurance premiums***
- ***support needs would be more appropriately met by the health and/or palliative care systems, comprising:***
  - ***those who would benefit from largely medically oriented interventions (including less restrictive musculoskeletal and affective disorders, and many chronic conditions)***
  - ***many people with terminal illnesses***
- ***support needs would be more appropriately met by the aged care system***
- ***needs were only in relation to mainstream employment, public housing or educational assistance.***

DRAFT RECOMMENDATION 3.4

The NDIS should put in place memoranda of understanding with the health, mental health, aged and palliative care sectors to ensure that individuals do not fall between the cracks of the respective schemes and have effective protocols for timely and smooth referrals.

DRAFT RECOMMENDATION 3.5

Whatever the actual funding divisions between the NDIS and aged care that are put in place, people should have the option of migrating to the support system that best meets their needs, carrying with them their funding entitlement.

Upon reaching the pension age (and at any time thereafter), the person with the disability should be given the option of continuing to use NDIS-provided and managed supports or moving to the aged care system. If a person chose to:

- ***move to the aged care system, then they should be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches)***
- ***stay with NDIS care arrangements, their support arrangements should continue as before, including any arrangements with disability support organisations, their group accommodation, their case manager or their use of self-directed funding.***

Either way, after the pension age, the person with a disability should be subject to the co-contribution arrangements set out by the Commission in its parallel inquiry into aged care.

If a person over the pension age required long-term aged residential care then they should move into the aged care system to receive that support.

In implementing this recommendation, a younger age threshold than the pension age should apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

DRAFT RECOMMENDATION 3.6

Following the transition spelt out in draft recommendation 17.1, the NDIS should fund all people who meet the criteria for individually tailored supports, and not just people who acquire a disability after the introduction of the scheme.

DRAFT RECOMMENDATION 3.7

The supports to which an individual would be entitled should be determined by an independent, forward-looking assessment process, rather than people's current service use.

Chapter 4 What individualised supports will the NDIS fund?

DRAFT RECOMMENDATION 4.1

The NDIS should cover the current full range of disability supports. The supports would need to be 'reasonable and necessary'. The NDIS should also support the development by the market of innovative support measures (using the approaches set out in draft recommendation 8.3).

DRAFT RECOMMENDATION 4.2

There should be no income or asset tests for obtaining funded NDIS services.

DRAFT RECOMMENDATION 4.3

There should sometimes be a requirement to pay a modest fixed upfront contribution to the NDIS, with free access to services after that point. The NDIS should waive the amount where families have already contributed significantly towards the costs of support through unpaid care.

DRAFT RECOMMENDATION 4.4

People should pay the full costs of services (primarily therapies) for which clinical evidence of benefits are insufficient or inconclusive if they wish to consume those services.

DRAFT RECOMMENDATION 4.5

Services that meet the needs of much wider populations, including people with disabilities not covered by the NDIS, should lie outside the scheme:

- ***health, public housing, public transport and mainstream education and employment services, should remain outside the NDIS, with the NDIS providing referrals to them***
  - ***but specialised employment services, disability-specific school to work programs, taxi subsidies, and specialised accommodation services should be funded and overseen by the NDIS.***

DRAFT RECOMMENDATION 4.6

The Disability Support Pension (DSP) should not be funded or overseen by the NDIS. The Australian Government should reform the DSP to ensure that it does not undermine the NDIS goals of better economic, employment and independence outcomes for people with disabilities. Reforms should aim to:

- ***encourage the view that the norm should not be life long use of the DSP, among:***
  - ***people with non-permanent conditions***
  - ***people with permanent conditions who could have much higher hopes for employment participation***
- ***provide incentives for people to work (even if only for a few hours per week) and for targeted rehabilitation for those with reasonable prospects of employment.***

These reforms should not be limited to new entrants into the DSP.

Chapter 5 Assessing care and support needs

DRAFT RECOMMENDATION 5.1

Working within the International Classification of Functioning, Disability and Health (ICF), the assessment process should identify the supports required to address an individual's reasonable and necessary care and support needs across a broad range of life activities, and should take account of an individual's aspirations and the outcomes they want to achieve.

DRAFT RECOMMENDATION 5.2

The assessment process should be a valuable intervention in its own right, rather than just an entry point to supports. The process should:

- ***draw on multiple sources of information, including:***
  - ***information provided by the individual with a disability, including their aspirations and requirements for supports***
  - ***information provided by unpaid carers***
  - ***current medical information on the person with a disability***
- ***assess the nature, frequency and intensity of an individual's support needs. The process should be person-centred and forward looking and consider the supports that would allow a person to achieve their potential in social and economic participation, rather than only respond to what an individual cannot do***
- ***determine what supports outside the NDIS people should be referred to, including referrals to Job Network providers and mental health services***
- ***consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports')***
- ***translate the reasonable needs determined by the assessment process into a person's individualised support package funded by the NDIS, after taking account of natural supports***
- ***provide efficiently collected data for program planning, high level reporting, monitoring and judging the efficacy of interventions.***

DRAFT RECOMMENDATION 5.3

Any tools employed by the scheme should exhibit validity and reliability when used for assessing the support needs of potential NDIS users. The preferred assessment tools should be relatively easy to administer and exhibit low susceptibility to gaming. The toolbox should be employed nationally to ensure equitable access to nationally funded support services (and allow portability of funding across state and territory borders when people move).

DRAFT RECOMMENDATION 5.4

Trained assessors should undertake assessments. To promote independent outcomes, assessors should not have a longstanding connection to the person. Assessors' performance should be continually monitored and assessed to ensure comparability of outcomes and to avoid 'sympathetic bracket creep'.

DRAFT RECOMMENDATION 5.5

The NDIS should periodically reassess people's need for funded support, with a focus on key transition points in their lives.

DRAFT RECOMMENDATION 5.6

Where an informal carer provides a substantial share of the care package, they should receive their own assessment. This should seek to identify their views on the sustainability of arrangements and the ways in which they could be supported in their role, including through the initiatives recommended in draft recommendation 13.3.

DRAFT RECOMMENDATION 5.7

The NDIS should establish a coherent package of tools (a 'toolbox'), which assessors would employ across a range of disabilities and support needs (attendant care, aids and equipment, home modifications).

DRAFT RECOMMENDATION 5.8

The assessment tools should be subject to ongoing monitoring, as well as a regular cycle of evaluation against best practices, including the ICF framework, and, if necessary, recalibration. The scheme should have systematic internal mechanisms to ensure that anomalies can be analysed and addressed.

DRAFT RECOMMENDATION 5.9

The NDIS should use the best available tools in its initial implementation phase, with the on-going development of best-practice tools.

Chapter 6 Who has the decision-making power?

DRAFT RECOMMENDATION 6.1

Governments should give people with disabilities eligible for benefits under the NDIS, or their nominated proxies, various options for exercising choice, including the power to:

- ***choose directly the service provider/s that best meet their needs***
- ***choose disability support organisations that would act as intermediaries on their behalf when obtaining services from service providers, and/or***
- ***'cash out' all or some of their individual budgets if they wish, with the NDIA making direct payments to their bank accounts, and allowing people to purchase directly the detailed package of supports that best meets their preferences ('self-directed funding'), subject to the constraints set out in draft recommendations 6.2, 6.7 and 6.8.***
  - ***The specific arrangements for self-directed funding should be underpinned by the principle that, subject to the assessed individual budget and appropriate accountability requirements, the arrangements should maximise the capacity for a person to choose the services that meet their needs best and that promote their participation in the community and in employment.***

DRAFT RECOMMENDATION 6.2

Self-directed funding should include the following key stages.

- ***It would be informed by any prior planning and aspirations expressed by the person during the assessment phase (draft recommendation 5.2).***
- ***The individual budget for self-directed funding would be based on the formal individual assessment of the person's needs and would include the cashed out value of all goods and services covered by the NDIS, except those where specialist knowledge is required for informed choices.***

- ***The person with a disability — and/or their support network or chosen disability support organisation — would create a personal plan and a concrete funding proposal to the NDIA that outlines the person's goals and the type of support that is necessary and reasonable to achieve these within the allocated budget.***
- ***The resulting funding proposal would require approval by the National Disability Insurance Agency (NDIA).***

There should be a capacity for a person to:

- ***obtain quick approvals for changes to a funding proposal***
- ***add their own private funds to a funding proposal***
- ***allocate the individual budget to any mix of preferred specialist and mainstream goods and services, subject to the requirements that:***
  - ***the person spend the budget in areas related to his or her disability needs and consistent with the funding proposal***
  - ***the scope to cash out funds set aside for large non-recurrent spending items should be limited to the (rare) circumstances where the NDIA has approved this as an appropriate decision.***

DRAFT RECOMMENDATION 6.3

The NDIA should pay annual allocations of self-directed funding in monthly instalments paid in advance, with the capacity for the person to 'bank' up to 10 per cent of the annual allocation to the subsequent year.

DRAFT RECOMMENDATION 6.4

There should be a capacity for people to recruit and employ their own support workers, subject to the proviso that these should not be close family members, other than when:

- ***care is intermittent and provided by a non-resident family member***
- ***exceptional circumstances are present and after approval by the NDIA***
- ***the person is in the family employment trial spelt out in draft recommendation 6.5.***

DRAFT RECOMMENDATION 6.5

There should be a trial of the employment of family members under self-directed funding to assess its risks, advantages, disadvantages and optimal design, with its wider adoption if the evaluation proves positive. The trial should use an appropriately rigorous scientific approach, drawing on the evaluations used in the United States 'Cash and Counseling' programs. For the trial:

- ***the NDIA should determine that there are few risks from hiring relatives for each family in the trial***
- ***the individual budget should be discounted by 20 per cent***
- ***support should be initially limited in duration to six months, with continuation of any arrangement for a given family based on the benefits and costs to that family***
- ***risks should be carefully managed to ensure appropriate use of funds and to safeguard people with disabilities and carers (draft recommendation 6.8).***

DRAFT RECOMMENDATION 6.6

The NDIA should:

- ***inform people with disabilities and their proxies of the various options for self-directed funding***
- ***provide support for people using self-directed funding, including easy-to-understand guidance about the practical use of self-directed funding, including standard simple-to-follow forms for funding proposals, hiring employees and for acquittal of funds***
- ***promote the use of self-directed funding, with examples of innovative arrangements***
- ***provide training to local case managers and front-line staff about self-directed funding***
- ***encourage the formation of disability support organisations to support people in the practical use of self-directed funding.***

DRAFT RECOMMENDATION 6.7

Before offering self-directed funding to a person, the NDIA should:

- ***meet with the person with a disability and their carers, and take account of their experience and skill sets***

- ***use that and any information provided during the assessment phase to determine whether the person and/or their support network are likely to be able to:***
  - ***make reasonably informed choices of services***
  - ***manage the administrative and financial aspects of funding if they wish to oversee these aspects by themselves.***

DRAFT RECOMMENDATION 6.8

In offering self-directed funding, the NDIA should ensure that:

- ***it reduces the risks of neglect or mistreatment of people with a disability by support workers or other service providers hired by users in the informal sector, by:***
  - ***ensuring easy and cheap access to police checks***
  - ***giving users the capacity to complain to the NDIA about inappropriate behaviour of providers, and to have these investigated***
  - ***monitoring by local case managers***
- ***it reduces the risks to support workers employed under self-directed funding by requiring that they are covered by workers' compensation arrangements and have an avenue for lodging complaints***
- ***it adopts a risk-management approach for receipting and other accountability requirements, which:***
  - ***requires less accountability for people with low risks or who have demonstrated a capacity to manage their funds well***
  - ***takes into account the compliance costs of excessive accountability measures***
  - ***allows a small component of the individual budget to be free of any receipting requirements.***

DRAFT RECOMMENDATION 6.9

The NDIA should undertake ongoing monitoring of self-directed funding arrangements, with a quarterly report to the board of the NDIA on issues arising from self-directed funding. There should be a full evaluation three years after their commencement to assess any desired changes in their design.

DRAFT RECOMMENDATION 6.10

The Australian Government should amend the Income Tax Assessment Act 1936 and the Social Security Act 1991 so that the following are not treated as income for assessment of taxes or eligibility for income support or other welfare benefits:

- ***self-directed funding paid by the NDIA and, in the interim, by state and territory governments***
- ***early compassionate release of eligible superannuation amounts for disability expenditures which meet the criteria set down by the Superannuation Industry (Supervision) Act 1993.***

Chapter 7 Governance of the NDIS

DRAFT RECOMMENDATION 7.1

The Australian Government should establish a new independent Commonwealth statutory authority, the National Disability Insurance Agency (NDIA), to administer the National Disability Insurance Scheme.

The NDIA should be subject to the requirements of the Commonwealth Authorities and Companies Act 1997 (CAC Act), not the Financial Management and Accountability Act 1997.

DRAFT RECOMMENDATION 7.2

An independent board should oversee the NDIA. The board should comprise people chosen for their commercial and strategic skills and expertise in insurance, finance and management.

- ***As specified in the CAC Act, the board should not be constituted to be representative of particular interest groups, including governments, disability client or service provider groups.***

The Australian Government and the state and territory governments should together establish an appointment panel comprising people with skills and experience in these areas, including people with a clear interest in disability policy issues.

- ***The panel should nominate candidates for each board vacancy against tightly specified selection criteria set down in the Act governing the NDIA. Appointments should be based on the majority decision of governments.***

The Australian Government, with the agreement of the majority of state and territory governments, should have the power to remove the chair or dissolve the board as a whole.

The board would have the sole power to appoint the CEO and to sack him or her if necessary, without authorisation from governments.

DRAFT RECOMMENDATION 7.3

The Australian Government, together with state and territory governments, should establish an advisory council. The council should provide the board of the NDIA with ongoing advice on its activities and effectiveness in meeting its objectives, from the perspectives of people with disabilities, carers, suppliers of equipment and services and state and territory service providers and administrators.

- ***The council should comprise representatives of each of these groups.***

DRAFT RECOMMENDATION 7.4

The arrangements between the NDIA and governments should be at arm's length, and subject to strict transparency arrangements.

The federal Treasurer should have responsibility for the NDIA.

DRAFT RECOMMENDATION 7.5

The Australian Government, with the agreement of state and territory governments, should provide the NDIA with its own legislation that specifies its objectives and functions, and its governance arrangements.

- ***Financial sustainability should be a specific obligation of the board, the management and the minister, and this obligation should be enshrined in legislation. It should specifically guide any external review body (draft recommendation 7.8).***
- ***An entitlement to reasonable support should be enshrined in legislation, together with details about people's eligibility for services and the range of services to be offered.***

Future changes to the legislative framework should be undertaken only by explicit changes to the Act itself, made transparently, and subject to the usual processes of community and Parliamentary scrutiny, and in consultation with all state and territory governments.

- ***Such proposed legislative changes should be accompanied by an independent assessment of the impact of the changes on the sustainability of the scheme.***

DRAFT RECOMMENDATION 7.6

An independent actuarial report on the NDIA's management of the NDIS should be prepared quarterly and annually, and provided to the board, the regulator, the federal Treasurer, and to all state and territory governments. It should assess risks, particularly in regards to the capacity of the expected funding stream to meet expected liabilities within its funding framework, the source of the risks and the adequacy of strategies to address those risks.

DRAFT RECOMMENDATION 7.7

A specialist unit should be established within the federal Treasury to monitor the performance of the NDIA against a range of cost and performance indicators, and report its findings annually to its minister, state and territory governments and the public.

DRAFT RECOMMENDATION 7.8

The NDIA should be independently reviewed, initially after its first three years of operation, and every five years thereafter, with the outcomes publicly and promptly released.

DRAFT RECOMMENDATION 7.9

The NDIA should be subject to benchmarking with other comparable corporate entities to assess its relative efficiency in its various functions, with the federal Treasury initiating benchmarking studies.

DRAFT RECOMMENDATION 7.10

The NDIA should establish two service charters that specify respectively the appropriate conduct of the (i) NDIA and (ii) specialist service providers and disability support organisations.

DRAFT RECOMMENDATION 7.11

The wording of the NDIA Act should limit the capacity of merits review processes to widen eligibility or entitlement. It should require that any claims by NDIA clients would need to:

- ***meet a 'reasonable person' test***
- ***balance the benefits to the person with a disability against the costs to the scheme, including any adverse implications for the long run sustainability of the scheme from the review outcome***

- ***take into account the obligation of people with disabilities or their families to avoid decisions that unreasonably impose costs on the scheme.***

DRAFT RECOMMENDATION 7.12

The NDIA should include an internal complaints office that would:

- ***be separate from the other parts of the NDIA dealing with clients and service providers***
- ***hear complaints about breaches of the service charters (draft recommendation 7.10)***
- ***reassess contested NDIA decisions on a merit basis.***

The office would be headed by an independent statutory officer who would review appeals made by people with disabilities and support providers against the decisions of the NDIA.

- ***The NDIA legislation should create this role and specify that the officer would be independent, would act fairly and impartially, basing their decisions on the available evidence, and could not be directed in their decision-making.***
- ***A person or support provider should only be able to appeal the decisions of the office on matters of law, rather than on merit, to the courts.***

The NDIA should publish the number, types and outcomes of complaints and appeals (subject to privacy protections).

DRAFT RECOMMENDATION 7.13

If the proposal in draft recommendation 7.12 for appeal processes supported by an independent statutory officer are not adopted, then the Australian Government should create a specialist arm of the Administrative Appeals Tribunal to hear appeals on merit about the NDIA's decisions subject to the constraints of draft recommendation 7.11. The Australian Government should set aside significant additional resources to fund this specialist arm and should include a larger reserve for the NDIS, calculated to take account of the higher risks of this approach.

Chapter 8 Delivering disability services

DRAFT RECOMMENDATION 8.1

The NDIA should support consumer decision-making by providing:

- ***a centralised internet database of service providers that indicates the ranges of products and services, price, availability and links to measures of performance and quality***
- ***well resourced and effective provision of advice and information to clients, as well as monitoring of their wellbeing. These services should be graduated in terms of the needs of the client and concentrated at key points, such as when entering the disability system or important transition periods.***

DRAFT RECOMMENDATION 8.2

The Australian Government should fund and develop a national system for a shared electronic record of the relevant details of NDIA clients, including assessed need, service entitlements, use and cost of specialist disability services, outcomes and other key data items with privacy safeguards.

DRAFT RECOMMENDATION 8.3

The NDIA should develop and implement a quality framework for disability providers, which would include:

- ***the development of complete, nationally consistent standards that would apply to all funded specialist service providers and disability support organisations. The NDIA should monitor compliance with these standards and other regulations through a range of instruments, including graduated and rolling audits of service providers, community visitors, senior practitioners, independent consumer surveys, complaints, surveillance by case managers and interrogation of the electronic disability record***
- ***arrangements that encourage the diffusion of best practice throughout the disability sector***
- ***providing consumers with information about the quality and performance of service providers on the national internet database of service providers***
- ***establishing an innovation fund that providers would use for developing and/or trialling novel approaches to disability services.***

Chapter 9 Disability within the Indigenous community

DRAFT RECOMMENDATION 9.1

The Australian Government and state and territory governments should consider the feasibility of overcoming the barriers to service delivery in the NDIS for Indigenous people with a disability by:

- ***fostering smaller community-based operations that consult with local communities and engage local staff, with support from larger experienced service providers***
- ***employing Indigenous staff***
- ***developing the cultural competency of non-Indigenous staff.***

In its initiatives for delivering disability supports to Indigenous people, the NDIS should be mindful of the wider positive measures addressing Indigenous disadvantage being adopted throughout Australia.

Chapter 10 Collecting and using data under the NDIS

DRAFT RECOMMENDATION 10.1

Prior to the implementation of the NDIS, the NDIA should design and establish extensive and robust data systems, underpinned by the associated information technology and administrative systems. The systems should be used to develop a central database that would:

- ***guide financial management of the scheme, and in particular, to continuously manage risks to scheme sustainability and to pinpoint areas of inefficiency***
- ***inform decisions about disability services and interventions***
- ***enable performance monitoring of service providers***
- ***monitor and evaluate outcomes***

Disability support organisations and service providers would be required to provide timely relevant data to the NDIA.

DRAFT RECOMMENDATION 10.2

The NDIA should establish an independent research capacity under the NDIS. It should determine how research is undertaken and the research agenda, following public consultation.

DRAFT RECOMMENDATION 10.3

The NDIA should make relevant data, research and analysis publicly available, subject to confidentiality, privacy and ethical safeguards.

DRAFT RECOMMENDATION 10.4

In implementing draft recommendation 10.1, the NDIA should determine after consultation with relevant stakeholders, including the Australian Privacy Commissioner:

- ***the key actuarial information needed to underpin sound scheme management***
- ***data standards, definitions, terminology and collection processes***
- ***data reporting standards, taking into account the Australian Government's initiatives for standard business reporting***
- ***arrangements for achieving inter-connectedness of information technology systems among the NDIA, other relevant government agencies and service providers***
- ***rules for accessing data, including confidentiality and privacy safeguards***
- ***arrangements for integrating data and associated information technology and administrative systems with eHealth initiatives.***

The NDIA should then establish data collection and associated IT and administrative systems that link all agencies and service providers within the disability system.

Chapter 11 Early intervention

DRAFT RECOMMENDATION 11.1

Early intervention approaches used by the NDIA should draw on evidence of their impacts and be based on an assessment of the likelihood of cost-effectiveness. NDIS funding for early intervention should be additional to that allocated to clients for their ongoing care and support and should not be able to be cashed out under self-directed care packages.

DRAFT RECOMMENDATION 11.2

The NDIA should build an evidence base on early intervention. It should commence this task by identifying, in consultation with stakeholders, existing or potentially promising approaches for further research.

Chapter 12 Where should the money come from? Financing the NDIS

DRAFT RECOMMENDATION 12.1

The costs of supporting people with a disability from year to year should be met from claims on general government revenue (a 'pay as you go' scheme):

- ***but would be subject to the strong disciplines for certainty of funding specified in draft recommendation 12.2***
- ***supplemented by payments to create reserve funds.***

However, the scheme should be managed and reported as if it were a 'fully-funded' scheme in which each year's funding is considered in the context of the scheme's expected future liabilities.

DRAFT RECOMMENDATION 12.2

The Australian Government should direct payments from consolidated revenue into a National Disability Insurance Premium Fund, using an agreed formula entrenched in legislation that:

- ***provides stable revenue to meet the independent actuarially-assessed reasonable needs of the NDIS***
- ***includes funding for adequate reserves.***

If that preferred option is not adopted, the Australian Government should:

- ***legislate for a levy on personal income (the National Disability Insurance Premium), with an increment added to the existing marginal income tax rates, and hypothecated to the full revenue needs of the NDIS***
- ***set a tax rate for the premium that takes sufficient account of the pressures of demographic change on the tax base and that creates a sufficient reserve for prudential reasons.***

DRAFT RECOMMENDATION 12.3

The Australian Government and state and territory governments should sign an intergovernmental agreement specifying that:

- ***the Australian Government should:***
  - ***collect all of the revenue required to fund the NDIS through the National Disability Insurance Premium Fund***
  - ***make no further special purpose payments to state and territory governments for disability supports.***
- ***state and territory governments should offset the Australia-wide fiscal implications of the transfer of responsibility by either:***

(a) reducing state and territory taxes by the amount of own-state revenue they used to provide to disability services or

(b) transferring that revenue to the Australian Government.

The Commission sees particular merit in option (a).

Any NDIS funding arrangements should ensure that state and territory governments that provide less own-state funding for disability supports than the average should not be rewarded for doing so.

Chapter 13 Workforce issues

DRAFT RECOMMENDATION 13.1

The Australian Government should attract further support workers into the disability sector:

- *by marketing the role and value of disability workers as part of the media campaign launching the creation of the NDIS*
- *by providing subsidies to training of disability workers*
- *through immigration of support workers, but only in the event that acute and persistent shortages occur, and drawing on the lessons from the Canadian Live-In Caregiver program and other similar programs.*

DRAFT RECOMMENDATION 13.2

Australian governments should ensure that, across all jurisdictions, police check arrangements for paid workers providing services to people with a disability:

- *apply only in cases where both the person with a disability is vulnerable AND the risks associated with delivery of services are sufficiently high*
- *not include disclosure of crimes covered by spent convictions legislation*
- *cover people for a given period, rather than for a particular job.*

DRAFT RECOMMENDATION 13.3

In order to promote training and counselling for carers, the NDIS should:

- *assess carer needs as well as those of people with disabilities (draft recommendation 5.6) and, where needed, use the assessment results to:*
  - *refer people to the 'Carer Support Centres' recommended in the Commission's parallel inquiry into aged care and to the National Carers Counselling Program*

  - ***include the capacity for accessing counselling and support services for carers as part of the individual support packages provided to people with a disability***
- ***assess the best training and counselling options for carers of people with disabilities as part of the NDIS research and data collection function.***

DRAFT RECOMMENDATION 13.4

The Australian Government should amend s. 65(1) of the Fair Work Act 2009 to permit parents to request flexible leave from their employer if their child is over 18 years old, but subject to an NDIS assessment indicating that parents are providing a sufficiently high level of care.

After monitoring the impacts of this legislative change, the Australian Government should assess whether it should make further changes to the Act to include employees caring for people other than children.

Chapter 16 A national injury insurance scheme (NIIS)

DRAFT RECOMMENDATION 16.1

State and territory governments should establish a national framework in which state and territory schemes would operate — the National Injury Insurance Scheme. The NIIS would provide fully-funded care and support for all catastrophic injuries on a no-fault basis. The scheme would cover catastrophic injuries from motor vehicle, medical, criminal and general accidents. Common law rights to sue for long-term care and support should be removed.

DRAFT RECOMMENDATION 16.2

State and territory governments should fund catastrophic injury schemes from a variety of sources:

- ***compulsory third party premiums for transport accidents***
- ***municipal rates and land tax for catastrophic injuries arising for victims of crime and from other accidents (excluding catastrophic medical accidents)***

Once the NIIS is fully established, the Australian Government should examine the scope to finance catastrophic medical accidents from re-weighting government subsidies and doctors' premium contributions.

[The Commission is seeking feedback on interim financing arrangements for catastrophic medical accidents — see 'Information Requests' at the end of the recommendations section.]

DRAFT RECOMMENDATION 16.3

The NIIS should be structured as a federation of separate state catastrophic injury schemes, which would include:

- ***consistent eligibility criteria and assessment tools, and a minimum benchmarked level of support***
- ***consistent scheme reporting, including actuarial valuations and other benchmarks of scheme performance***
- ***shared data, cooperative trials and research studies***
- ***elimination of any unwarranted variations in existing no-fault schemes.***

State and territory governments should agree to a small full-time secretariat to further the objectives outlined above. The NIIS and the NDIA should work closely together.

DRAFT RECOMMENDATION 16.4

State and territory governments should consider transferring the care and support of catastrophic workplace claims to the NIIS through a contractual arrangement with their respective workers' compensation schemes, drawing on the successful experiences of Victoria's Worksafe arrangements with the Transport Accident Commission.

DRAFT RECOMMENDATION 16.5

The initial priority for the NIIS should be the creation of no-fault accident insurance schemes covering catastrophic injuries arising from motor vehicle and medical accidents in all jurisdictions, with schemes in place by 2013. Other forms of catastrophic injury should be covered by at least 2015.

An independent review in 2020 should examine the advantages and disadvantages of:

- ***widening coverage to replace other heads of damage for personal injury compensation, including for pecuniary and economic loss, and general damages***
- ***widening coverage to the care and support needs of non-catastrophic, but still significant, accidental injuries, except where:***
  - ***the only care needed can be provided by the health sector***
  - ***the injuries arose in workplaces covered by existing workplace insurance arrangements***
- ***merging the NIIS and the NDIS.***

Chapter 17 Implementation

DRAFT RECOMMENDATION 17.1

In the second half of 2011 or early 2012, the Australian Government and the state and territory governments should, under the auspices of COAG, agree to a memorandum of understanding that sets out an in-principle agreement:

- ***that the NDIS should commence in stages from January 2014, be rolled out nationally in 2015 and be fully operational by 2018***
- ***to follow the reform timetable for the NIIS specified in draft recommendation 16.5.***

DRAFT RECOMMENDATION 17.2

The Australian Government and the state and territory governments, under the auspices of COAG, should create:

- ***a full-time high level taskforce from all jurisdictions to commence work on the detailed implementation of the NDIS***
  - ***to be headed by a person with insurance or disability experience who has driven change successfully in a large organisation, appointed with the agreement of all jurisdictions***
  - ***with a draft intergovernmental agreement to be prepared for final consideration and agreement by COAG in February 2013***
- ***a full-time high level taskforce from all jurisdictions to commence work on the implementation of the NIIS by the states and territories.***

DRAFT RECOMMENDATION 17.3

In the period leading up until the full introduction of the NDIS, the Australian Government should supplement funding under the National Disability Agreement to reduce some of the worst rationing of support services.

DRAFT RECOMMENDATION 17.4

In 2020, there should be an independent public inquiry into the operation of the NDIS and its effectiveness in meeting the needs of people with disabilities. The review should also encompass the review of the NIIS as set out in draft recommendation 16.5.

Information requests

Chapter 3

While the Commission has proposed a simple approach for the separate funding responsibilities of the aged care and disability sectors (draft recommendation 3.5), the Commission seeks feedback on other possible funding approaches.

The Commission seeks feedback on where the boundaries between the mental health sector and the NDIS might lie. In particular, the Commission would appreciate feedback on which system would be best placed to meet the daily support needs (not clinical needs) of individuals with a disability arising from long lasting mental health conditions (such as schizophrenia), including:

- *which services would be provided by the NDIS and not the mental health sector and how these could be clearly identified*
- *the magnitude of the budget that would be required*
- *how to guard against cost shifting*
- *how the NDIS would practically integrate any role in ongoing non-acute services with the wider mental health sector, including any shared responsibilities of case managers in the two systems.*

Chapter 4

The Commission considers that the NDIS should fund artificial limbs and seeks feedback on the desirability and practicality of this option. What items should be included if in the NDIS?

The Commission seeks feedback on the arrangements that should apply in relation to higher electricity costs that are unavoidable and arise for some people with disabilities.

The Commission seeks feedback on how to ensure that funding support given for taxis under the NDIS is kept within reasonable bounds.

The Commission seeks feedback about whether Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance, and the Child Disability Assistance Payment should fall within the scope of the NDIS.

The Commission considers that needs assessments should take account of the extent of natural supports, and that the NDIS should waive the front-end deductible where the value of this support exceeds some government determined level. The Commission would welcome feedback on what that level should be.

Chapter 5

The Commission seeks feedback on whether these tools, or any other assessment tools, would be appropriate for assessing the care and support needs of individuals having regard for:

- *the role of the assessment process in the context of an NDIS*
- *the desirable traits as outlined in section 5.4.*

Chapter 8

The Commission seeks further feedback on the effectiveness of monitoring instruments and any others that could potentially be used to assist oversight of the disability sector.

Chapter 9

The Commission seeks further feedback on the merits of the NDIA funding prevention and early intervention measures specifically targeting Indigenous communities, and how this could work in practice.

Chapter 16

The Commission seeks feedback on a workable funding arrangement for catastrophic injuries resulting from water, air and railway modes of transport.

The Commission seeks feedback on practical interim funding arrangements for funding catastrophic medical accidents covered under the NIIS.

The Commission seeks feedback on an appropriate criterion for determining coverage of medical accidents under the NIIS.

The Commission seeks feedback on the benefits and risks of requiring nationally consistent disclosure to an appropriately charged body responsible for monitoring and publicly reporting trends in legal fees and charges paid by plaintiffs in personal injury cases.

1 Introduction

1.1 What has the Commission been asked to do?

In late 2009, the Australian Government announced that the Productivity Commission would commence a public inquiry into a long-term disability care and support scheme in April 2010. It said:

> This inquiry is an opportunity to rethink how we support people with disabilities so that they can engage with their community, get a job where possible, and live a happy and meaningful life (Sherry, Rudd, Macklin and Shorten 2009).

The announcement followed a succession of reports that found that the current system to support people with disability and their families is deeply flawed and will increasingly be unable to meet people's needs. Recent examples include the 'Way Forward' report by the Disability Investment Group (DIG 2009a) and the 'Shut Out' consultation report by the National People with Disabilities and Carer Council (2009). Such reports reflected continuing concerns about systemic and long-standing inadequacies in disability care and support across Australia, and the consequent impact on people with disabilities and their carers.

In its preamble to the terms of reference, the Australian Government said that it 'is committed to developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers'. It noted that:

> … there remains a significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers. Demographic change and the anticipated decline in the availability of informal care are expected to place further pressure on the existing system over the coming decades.

It added that:

> While Australia's social security and universal health care systems provide an entitlement to services based on need, there is currently no equivalent entitlement to disability care and support services. … exploration of alternative approaches to funding and delivering disability services with a focus on early intervention and long-term care will be an important contribution to the National Disability Strategy. (terms of reference)

The Australian Government asked the Commission to consider how a national disability scheme could be designed, administered, financed and implemented. The Commission was asked to examine the feasibility, costs and benefits of replacing the current system of disability services with a new national disability care and support scheme that:

- provides long-term essential care and support
- manages the costs of long-term care
- replaces the existing funding for those people covered by the scheme
- takes account of the desired and potential outcomes for each person over a lifetime, with a focus on early intervention
- provides for a range of coordinated support options — accommodation, aids and appliances, transport, respite, day programs and community participation
- assists the person with the disability to make decisions about their support
- provides for people to participate in education, training and employment where possible.

This includes consideration of a variety of options, including a no-fault social insurance model and approaches used in other countries. The Commission was also asked to assess how these models would interact with Australia's health, aged care, informal care, income support and injury insurance systems.

1.2 Definitions and some key facts

There is no single definition of disability. Modern definitions of disability, including those drawn from the United Nations Convention on the Rights of Persons with Disabilities (adopted by the UN in 2006 and ratified by Australia in 2008), define disability as the interaction of long-term physical, mental, intellectual or sensory impairments, and attitudinal or environmental barriers that 'hinder ... full and effective participation in society on an equal basis with others'. The World Health Organisation (2009) similarly characterises disability according to the interaction between a person's body and features of the society in which they live.

This inquiry covers many issues that affect all people with disability. However, the terms of reference indicates that the scheme is intended to cover a subset of those affected by disability.

First, the terms of reference specify that the scheme should cover disability present at birth, or acquired through an accident or health condition, but not due to the

natural process of ageing. This means that the size of the relevant group is much smaller than all those with a disability. And, the numbers in this smaller group are projected to grow more slowly than those whose disability is ageing related. However, while this inquiry mainly considers people with disabilities aged under 65 years, population ageing will significantly raise the overall number of people with severe or profound disability, placing even more pressure on services, including for people who are not old. It will also affect the availability of unpaid carers.

Box 1.1 Some definitions

According to the Australian Institute of Health and Welfare, and as used in the Australian Bureau of Statistics (ABS) *Survey of Disability, Ageing and Carers*, 'disability' is defined as a limitation, restriction or impairment that has lasted, or is likely to last, for at least six months and restricts everyday activities. According to this definition, in 2009, just under one in five Australians reported having a disability.

The severity of people's disability varies significantly. At the more severe end of the spectrum people are classified by the ABS as having either:

- a profound core activity limitation, where an individual is unable to do, or always needs help with, a core activity; core activities are self-care, mobility and communication, and include washing, toileting, dressing and eating
- a severe core activity limitation, where an individual sometimes needs help with a core activity or task, and/or has difficulty understanding or being understood by family or friends and/or can communicate more easily using sign language or other non-spoken forms of communication.

While the above categories can be useful, as can the broader International Classification of Functioning, the appropriate definition of disability should take account of the policy context in which government is applying it and of the practical ease of identifying disability. For example, under the ABS's approach, many intellectual disabilities might not be categorised as severe or profound (reflecting the omission of learning as a 'core activity limitation'). However, in the Commission's view (chapter 3), there are strong grounds for a disability scheme to provide funded supports to such people. Similarly, some people suffering from short-lived but terminal diseases might well have severe disabilities, but governments might better support them through the health and palliative care systems.

Second, the scheme is not intended to provide funding packages to all people with a disability, many of whom would need no or few supports, or who would get supports more appropriately from other government services. These matters are discussed in chapter 3.

Some key facts about disability

There are various measures of the number of people with the most significant needs (box 1.2). For example, among those aged under 65 years, there are around 680 000 people with a profound or severe core activity limitation (SDAC 2009), around 310 000 who have at least daily care needs (with mobility, self care and/or communication) (SDAC 2009), and about 172 000 (SCRGSP 2011) who currently use specialist disability services (excluding Australian Government employment services).

The estimates in box 1.2 are of the total number of people with severe or profound core activity limitation at a point in time ('prevalence'). Each year, there are also *new* cases of disability ('incidence'). Of the 680 000 people with severe or profound core activity limitation, about 80 000 were new cases and about 600 000 were people who acquired a disability at an earlier time. While new cases add to the numbers of people with disability, deaths and reductions in disability reduce the numbers. In many instances, people will experience temporary disability (as potentially in cases of depression, anxiety and attention deficit hyperactivity disorder), and will not necessarily require long-term care.

The health conditions of people under the age of 65 years who have a profound core activity limitation include mental and behavioural disorders (including autism, Aspergers and some intellectual disability), nervous system disorders (including multiple sclerosis, congenital malformations, deformations and chromosomal abnormalities and other health conditions (including respiratory, and circulatory conditions and cancers) (table 1.1).

Table 1.1 **Health conditions of people who have a profound core activity limitation**

People under 65 years of age

Condition	*Percentage*
Diseases of the nervous system	14
Mental and behavioural disorders	40
Congenital malformations, deformations and chromosomal abnormalities	6
Diseases of the eye and adnexa; and ear and mastoid process	3
Diseases of the circulatory system, respiratory system, digestive system; endocrine, nutritional and metabolic disorders; neoplasms	14
Injury, poisoning and certain other consequences of external causes	4
Diseases of the musculoskeletal system and connective tissue	14
Other	5
Total	100

Source: SDAC (2009).

Box 1.2 How many people have significant needs?

While they share similar conceptual underpinnings, measures of significant disability vary markedly, depending on the data source and survey methods:

- Using the ABS Survey of Disability, Ageing and Carers, 2009 (SDAC 2009), around 263 000 people aged under 65 years had a profound core activity limitation in 2009 and 417 000 had a severe core activity limitation — or 680 000 in total.
- The ABS 2006 Census of Population identified a smaller group of people with a severe or profound core activity limitation (around 400 000 aged under 65 years in 2006), but this estimate is generally regarded as a less reliable measure than SDAC.
- Within the group of people classified as having a severe/profound core activity limitation there is a large spectrum of need for assistance. As an example, the 2009 SDAC indicates that approximately 310 000 people under the age of 65 years required at least daily assistance with one or more core activities (self care, mobility and communication). Within this 310 000:
  - about 23 per cent indicated that they needed assistance more than six times a day with at least one core activity
  - a further 24 per cent indicated that they needed assistance three to five times a day with at least one core activity
  - a further 17 per cent indicated that they needed assistance twice a day with at least one core activity
  - and a further 36 per cent indicated that they needed assistance once a day with at least one core activity.
- Usage of disability services provides other indicators of the numbers of people with the greatest need for support:
  - There were just over 265 000 people using specialist disability services under the National Disability Agreement (NDA) in 2008-09 (SCRGSP 2011). Of this 265 000, approximately 94 000 only used employment services. The NDA is directed at those whose disability was acquired before the age of 65 years.
- Around 200 000 people aged under 65 years used Home and Community Care (HACC) in 2008-09 for services such as nursing care, allied health, and the provision of aids and equipment that were not available under the NDA. People often use both NDA and HACC services, so the total number of users of NDA and HACC is not the sum of HACC and NDA services (approximately 20 per cent of people using NDA specialist services — excluding employment services — also access HACC services). Further, several people used very little HACC services (approximately one hour of care a fortnight).

1.3 Ways of thinking about disability

Several participants drew attention to the (now very commonly expressed) social model of disability, which takes the view that 'disability' arises socially, rather than medically. In this case, disability reflects social barriers, such as prejudice, out-of-date practices, and poorly designed infrastructure. In other words, while a person may have an impairment, their disability comes from the way society treats them, or fails to support them. For example, the capacity for mobility of a person in a wheelchair is limited if buildings and transport are not easily accessible. Society could allow a much fuller participation by a person with a mobility impairment by changing the environment. The extent to which it does not do so to may be seen as disabling.

Reflecting this view, the term 'disabled people' is widely used in official and other publications in the United Kingdom, while the term 'people with disability' is avoided (Glasby and Littlechild, 2009, p. 3). However, in Australia, the opposite is true. This appears to reflect the notion that all people have a complex set of traits (their preferences, jobs, hobbies, personalities) and that an impairment is just one aspect of their lives. For that reason, many people do not want to be defined exclusively by their impairment *or* the way society adapts to or exacerbates it. Accordingly, in this report, we use the term 'people with disability', which is customary in the Australian context.

Terminology aside, the key insight from the social model is that disability will sometimes arise from society's responses as well as from impairments themselves. Many submissions to the inquiry argued that this provides a strong policy basis for achieving the highest practical degree of social participation for people with disabilities and for giving them much greater capacity to exert power. (The importance of person-centred approaches to care and support is discussed in chapter 6.)

Nevertheless, while society can facilitate participation in the way it responds, there are limits in the extent to which it can achieve the full participation of every person, regardless of their traits. Society could not realistically be seen to have the capacity to eliminate the obstacles to participation faced by a person with extreme intellectual or behavioural disabilities. Accordingly, a more scientific approach to disability would see it as both a social and medical phenomenon, but for which an important social objective must be to facilitate participation in the various aspects of community life where practicable.

Moreover, societies have scarce resources, which means that there must be tradeoffs between what can ideally, and what can actually, be achieved for any person. There

are costs associated with making social changes to improve the lives of people with significant disabilities and, given resource constraints, these costs have to weighed up against other social objectives of a society.

Accordingly, as in many other areas of social policy — public housing, income support, health care and education — there are reasonable limits to what government or society can do to address inequality. However, it is widely accepted in Australia that governments and society must increase resourcing for disability and that they should address discrimination where it arises (for example, turning down a person for a job because of a disability not related to their work competence).

The United Nations Convention on the Rights of Persons with Disabilities

These issues are also the concern of the United Nations Convention on the Rights of Persons with Disabilities (box 1.3). Many submissions to this inquiry pointed to the importance of any new scheme adhering to the principles and obligations contained in that Convention, which Australia has ratified.

One participant observed that 'ratification carries with it much more than mouthing the sentiments and writing the high sounding statement into a glossy document':

> As noted by the UN Convention handbook for parliamentarians, '...establishing a right is not the same as ensuring that the right is realised', and neither is it the same as States providing, ... 'appropriate enabling environments so that persons with a disability can fully enjoy their rights on an equal basis with others'. … … simply being a party to a convention is no guarantee the intent of the convention will be realised. … if the report is to ensure the UN Convention is written into the NDS then the NDS must also ensure that an entitlement to service is ratified. (Jackson, sub. 30, p. 11)

In a similar vein, the National Disability and Carer Alliance said that, while ratification was 'an historic and significant moment', it was:

> … simply a first step on a long journey to ensure the rights enshrined in the convention are not only protected but, more importantly, able to be fully realised. While it is clearly not the only factor to be considered, it is important to acknowledge that rights can remain elusive if adequate resources are not provided. (sub. 413, p. 2)

Similarly, Catholic Social Services Victoria said that the United Nations Convention urges Governments to be proactive in identifying need and establishing more effective social support systems (sub. 453, p. 6).

Box 1.3 The United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities and its Optional Protocol entered into force on 3 May 2008 (with Australia ratifying shortly afterwards).

Guiding principles of the convention

There are eight guiding principles that underlie the convention:

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- non-discrimination
- full and effective participation and inclusion in society
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- equality of opportunity
- accessibility
- equality between men and women
- respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The convention states that persons with disabilities enjoy the same human rights as everyone. Without being exhaustive, these rights include equality before the law without discrimination, the right to live in the community, and the right to education and work.

The convention entails certain obligations on parties ratifying it, such as adopting legislation and administrative measures to promote the human rights of persons with disabilities, eliminating discrimination in workplaces and society; providing information to people with disabilities, undertaking disability-relevant R&D and appropriate consultation with people with disabilities in developing and implementing legislation and policies and in decision-making processes that concern them.

The goal of achieving equal rights is tempered by two considerations: a resource constraint ("With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its *available* resources") and their progressive, rather than immediate, realisation.

In September 2009, Australia ratified an optional protocol to the convention which provides for a complaints handling process for people considering that their rights have been violated.

Source: United Nations (http://www.un.org/disabilities).

A commonly-held view was expressed by the Association for Children with a Disability NSW, which said that the current disability system is in violation of the United Nations Convention, 'if not in letter, then certainly in spirit':

> We believe a National Disability Insurance Scheme will go a long way in addressing this. Our children are our future – including disabled ones! (sub. 297, p. 13)

Clarifying 'supports' versus 'services'

Different terms are used to describe the services and supports that are provided to people with a disability. In some instances, the terminology differentiates between services and supports.

For instance, sometimes the term 'services' is used to denote therapeutic services only (such as health care, physiotherapy and other interventions of this kind). Such services often do not involve much choice by the person with a disability. Some see these services as things that are 'done to people'.

In contrast, the term 'supports' is often used to describe measures that, combined with the person's own goals and motivation, makes it possible to live as full a life as possible. Supports are not 'done to people', but with them.

The underlying distinction between the idea of 'doing to people' and 'doing with people' is critical to an appropriate disability care and support scheme (and is a major reason for providing people with disabilities much more choice in a new system). However, while that distinction is a critical one, using the terms 'services' versus 'supports' to differentiate between the two approaches runs up against the common use of the word 'services', which does not usually carry any sense that people getting them lack power.

Accordingly, in this report, the Commission uses both terms, with the term 'services' used most commonly when referring to agencies that provide specialist services, such as attendant care or respite services, or when referring to mainstream services, like going to a movie. That usage is common to other reports on the disability sector, such as the annual review of government services (SCRGSP 2011) and the various reports by the Australian Institute of Health and Welfare. It is also common for providers of supports to be referred to as specialist service providers (for example, in the National Disability Agreement between the Australian Government and State and Territory Governments). Many submissions to this inquiry used the term 'services'.

However, the Commission draws particular attention to the distinction between disability support agencies (DSOs) and specialist service providers. The former are intended to provide support to people in using services — brokering, managing administration, mentoring and planning — and the term 'support' provides a useful way of distinguishing their role from that of traditional service providers.

1.4 Rationales and objectives

Various forms of care and support for people with a disability have long been a feature of the Australian social support system. Governments seek to enhance the quality of life and increase the economic and social participation of people with disabilities and their families, and to enhance and protect their rights. Those goals are reflected in a range of social, economic, regulatory and spending measures. These include equal opportunity regulation, building and other accessibility regulations, community education and — the key issue for this inquiry — the provision of care and support for people with disabilities and their families. This inquiry reflects the Australian Government's intention, as stated in the terms of reference, to explore better ways of meeting that goal, including perhaps through the creation of a new long-term disability care and support scheme.

The key rationales for a new approach stem from faults in the current system

In part, interest in a new approach has arisen from an awareness of the faults in the current system, which are documented in many submissions to this inquiry and covered in greater detail in the next chapter. Broadly, these are:

- There are insufficient resources and gaps in services in all jurisdictions and most locations, so that people with disabilities and their informal carers bear too much of the costs associated with disability.
- People with similar levels of impairment get quite different levels of support, depending on their location or the origin of the disability — what some call the 'lottery' of access to services.
- Under the current provider-centric model, the capacity for people with disabilities or their families to exercise choice about the services they use, and to have control over the financial resources allocated to them, is limited.
- Services are largely narrowly prescribed and lack participation goals, and there are insufficient opportunities for employment or participation in the community.
- People with disability and their families often do not have a reasonable level of certainty about the future (a particular concern of carers of children with a profound disability, who often worry about how their child will be supported when they get too tired, sick or die).
- There is a lack of coordination, showing up through, for example, duplicated and inconsistent assessment methods for allocating services or funding, inadequate

links between services provided by different governments, and insufficient information for planning and coordination.

- There is lack of portability of services between jurisdictions as people move.
- There are also some inappropriate models of support, such as care for young people with disabilities in aged care homes and people remaining in hospitals — and therefore blocking beds — because of insufficient funds for relatively minor home modifications.

There are strong grounds for governments to improve care and support arrangements for people with disabilities and their families. It is consistent with:

- community norms for upholding people's rights and for social justice, which are not fully recognised in current arrangements
- sharing the costs that fall on people with disability and their families among a wider group of people — through some form of social insurance — and the low likelihood that private insurance markets would function equitably or efficiently in this area
- the desirability of unlocking a poorly utilised source of productivity and social contribution (for example, through employment and community participation).

But the key test of a new scheme will be the extent to which it can address existing deficiencies in an equitable, efficient, cost-effective and accountable way.

Objectives

The shortcomings of the current system bring the objectives of a new system into sharp relief. The overarching objective should be, to the extent practicable, to enhance the quality of life and increase the economic and social participation of people with disabilities and their families. As shown throughout this report, current disability services are not meeting the needs of people with disabilities and their families. There is a widespread need for arrangements that will deliver better outcomes for clients, with services and support more readily and uniformly available and driven more by the preferences of the client. A key question is how to build a better scheme that supports and empowers people with disabilities by:

- providing long-term support for all forms of disability for those most in need, irrespective of the cause and who is at fault
- meeting the needs of people with disabilities and their families in ways that are timely and efficient
- providing national standards for assessment of need and provision of support

- providing a much greater role for decision-making by people with disabilities (and their families where appropriate and necessary)
- providing incentives for cost-effective delivery of support services
- making it sufficiently well-funded to provide timely assistance to all who need it, without unreasonably long waiting lists
- ensuring it is financially sustainable over the long term.

However, an objective is only genuinely useful if governments know whether they have succeeded in achieving it. This requires specific and assessable objectives and the means by which progress can be assessed (table 1.2).

Given the multiple objectives for a disability care and support scheme, the relative importance of these objectives will be crucial in the design of an effective scheme.

Nevertheless, it may be difficult to *fully* meet all the community's objectives of a new scheme, reflecting the need for any scheme to be financially sustainable and practical. There may also be tradeoffs between some goals. For instance:

- effective integration of support services may be costly if there is a large amount of supporting infrastructure required to do this, or significant implementation costs in changing from one type of approach to another
- giving people complete choice and power over the use of disability funding may raise accountability issues and may not always serve all people well
- more choice for individuals and families may also mean greater uncertainty for service providers and coordinators, possibly leading to less coordination and greater costs
- more broadly, governments face many other competing obligations — for example, in health care, education and infrastructure — together with the need to ensure that tax rates are set at fair and efficient levels. A new scheme which meets the above objectives is likely to entail a significant increase in funding for disability care and support. Given all the other competing claims on governments, there are likely to be some constraints in meeting *all* the preferences of people with disabilities and their families.

1.5 Some design elements for a new scheme

There are many possible models for a national disability scheme. The models could vary in scope (relevant users, types and levels of support, generosity and duration), funding sources, decision-making arrangements and governance.

Table 1.2 **Objectives and (some) indicators**

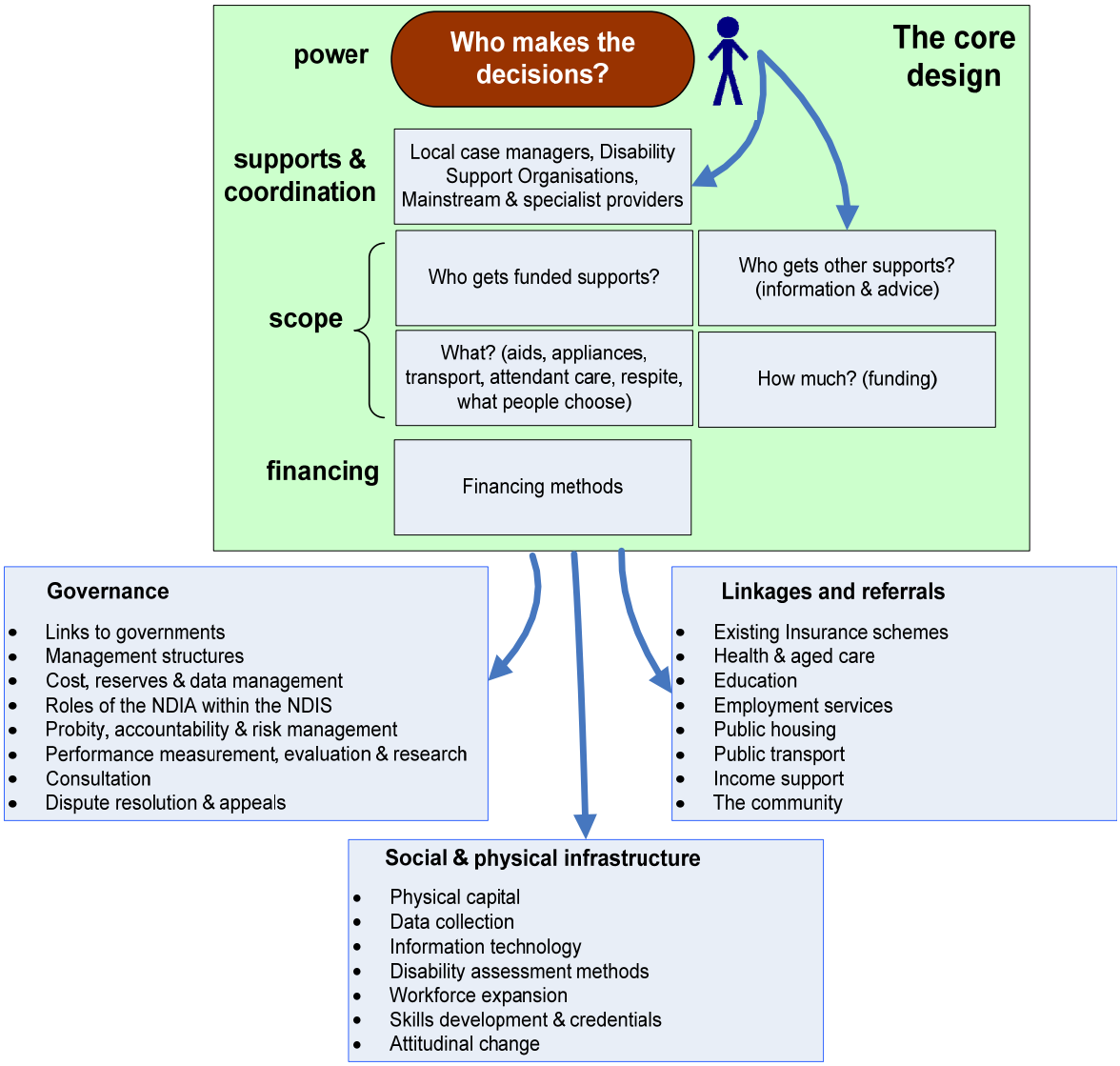
Objectives		*Some indicative measures of progress*
To improve wellbeing through funding of more integrated, higher quality support — including appropriate early intervention, and measures to lower the incidence and impact of disability	→	Improved consumer satisfaction, better continuity of support, higher social and economic participation rates, lower disability rates, reduced duration of some disabilities, lower hospitalisation rates for some disabilities
Ensure that people's assessed reasonable needs are met in a timely way as they arise, with predictability of support over their lifetime	→	Measures of support provision, unmet need, waiting lists, sustainable financing approach
Provide more comparable long-term care and support to people with similar levels of disability, regardless of the source of disability or the location of the person	→	Lower regional and state variations in support service access rates by all disability types
Provide people with disability more appropriate levels of power over their lives, and specifically over the budgets allocated to them, and with choice of providers	→	An appropriate capacity to self-direct funding (and its uptake) and to choose providers; consumer satisfaction rates with control and choice of services
Provide people with disability with better options for education, jobs, independent living and community participation	→	Participation rates in education, employment, volunteering, sports; consumer satisfaction rates with living arrangements
Shift away from an excessive and unfair reliance on the unpaid work of informal carers	→	Greater share of hours from paid support; greater independent living rates, lower depression rates and higher participation rates among carers; lower respite bed block rates
Effective management of the scheme, including cost-effectiveness and sustainability	→	Improved technical efficiency, higher support service utilisation, lower rates of multiple assessments, savings on future costs, low management costs, lower number of assessment delays, cost-effective use of new technologies, dispute and mediation efficiency, long-term scheme sustainability

One option is to substantially increase disability funding, but otherwise largely preserve the current arrangements. That would have many beneficial effects, but it would fail to overcome many of the structural deficiencies of the current arrangements. Given this and our terms of reference, the inquiry has focused on designing a coherent national system for disabilities.

As in health and aged care, there are many choices about how to design a disability care and support system. The core issues relate to who makes the decisions, who

gets supports, what supports they receive and the associated funding amounts, service delivery and financing methods (figure 1.1).

Figure 1.1 **Key design elements of a disability care and support scheme**



But realising a practically implementable and efficient scheme requires detailed attention to many other aspects of its design. Assessments of disability must be made (how?), the system must be organised and monitored (by whom?), linkages to related services and policies have to be identified and managed (which ones and how?), resources have to be built up (which ones?) and so on.

Failures in any one of these areas can undermine the capacity of a scheme to work well or meet people's reasonable expectations. For example, poor cost controls and

risk management would limit the sustainability of the scheme, while a failure to consult with, and give more decision-making powers to, people with disabilities and their families would be contrary to the goal of enhancing people's independence.

These matters are discussed in detail in the relevant chapters.

1.6 Inquiry processes

To help inform the approach taken in its issues paper, the Commission held early consultations with many people and organisations, including people with disability, carers, service providers, peak bodies, insurers and governments. These consultations provided insights into the key issues that would be involved in designing new arrangements for long-term disability care and support.

The Commission also held early discussions with the Independent Panel established by the Government to advise it and the Commission during the course of the inquiry (FaHCSIA 2010). The panel comprises people with extensive expertise and knowledge of disability issues, and the Commission has continued to meet with the panel at frequent intervals during the course of the inquiry.

These early discussions also informed the Commission about appropriate ways to engage with people with disabilities and to make it as easy as possible for them to participate in the various stages of the inquiry (including making submissions and appearing at public hearings). The Commission is particularly grateful for the assistance provided to it on this matter by the Department of Families, Housing, Community Services and Indigenous Affairs.

In May 2010, the Commission released an issues paper to inform people about the key issues being examined and to advise them how best to provide their views to the inquiry. Participants were invited to send in formal public submissions, and/or to provide the inquiry with confidential responses outlining their personal circumstances and views. At the same time, the Commission released a short paper, together with Easy English and Auslan versions, which contained questions to elicit views about the desirable features of a national disability scheme. At the time of completion of this draft report, the inquiry had received over 600 public submissions. They can be read on the inquiry website. About half of the submissions are from individuals. The inquiry also received over 100 personal responses and completed Easy English questionnaires. Further details are provided in appendix A.

We held initial public hearings in Hobart, Melbourne, Adelaide, Canberra, Brisbane, Sydney and Perth during June and July 2010. In total, people made 119

presentations over 12 hearing days (appendix A). Participants did not wish to attend hearings in Darwin in response to the issues paper, but the Commission will visit the Northern Territory following the release of the draft report to engage with a range of stakeholders. To date, consultations have been held with a wide range of interested parties, including regional services and some Indigenous services. A list of all visits and transcripts of all discussions at public hearings can be read on the inquiry website.

The Commission will hold a second round of public hearings in April 2011 to allow participants to respond to this draft report. The Commission will complete the inquiry at the end of July 2011 and hand its report to the Australian Government, which determines the public release date of the report.

The Commission thanks all those who have contributed thus far to this inquiry. In particular, it wishes to thank the following organisations, which have provided advice and data to the Commission on many occasions:

- the Accident Compensation Corporation (New Zealand)
- the Transport Accident Commission (Victoria)
- the New South Wales Lifetime Care and Support Authority
- National Disability Services
- the Australian Bureau of Statistics
- the MS Society of Australia
- Ageing, Disability and Home Care, Department of Human Services (NSW).

1.7 Structure of the report

The report begins with an introduction (chapter 1) and a discussion of why change is needed. Many participants (including providers, people with disabilities, carers and governments) think that disability services are often in crisis mode, with fragmented programs, inadequate provision of services and high levels of unmet demand. They argue that whether people get good services can be a 'lottery', based on where they live and how they acquire their disability, and that people often have little choice about what services they receive. These matters are discussed in chapter 2.

Chapter 3 looks at which groups of people would use a National Disability Insurance Scheme (NDIS) and how they would be referred to other services and supports as needed. The following three chapters look at how people with

disabilities could interact with the NDIS. This includes what support services they should be able to get access to (chapter 4), how they would be assessed for assistance (chapter 5), and the question of who should have the power to decide some of these matters (including the role of person-centred approaches) (chapter 6).

The governance of the NDIS is considered in chapter 7, while the implications for service delivery are covered in chapter 8. Chapter 9 focuses on Indigenous issues, given the higher rate of disability in the Indigenous community compared with the broader population, their low rate of claims for some forms of services and supports, and the particular difficulties of delivering these in some areas.

As many clients of the NDIS will have various care and support needs over many years, it is crucial that the long-term financial viability of the scheme be a key objective. Good quality data and evidence will be crucial in managing the scheme's costs, learning about the efficacy of alternative services and generating good outcomes for people with disabilities. This is the subject of chapter 10, while the specific question of the appropriate use of prevention and early intervention strategies is discussed in chapter 11.

The following three chapters examine how the NDIS might be financed (chapter 12), workforce issues (chapter 13) and estimates of the likely cost of the scheme under different scenarios (chapter 14).

Many participants argued that there is little justification for the striking differences in current arrangements for insuring people for injury, with coverage varying depending on the type of accident, its location and exact circumstances. Chapter 15 looks at the advantages and disadvantages of the current accident insurance arrangements, including the role of common law claims. Drawing on this analysis, chapter 16 proposes a National Injury Insurance Scheme, and discusses how it might be financed.

The measures proposed in this report are very significant and will require considerable care in their implementation. The Australian Government and all state and territory governments would need to be involved. And some changes would need to be sequenced. These matters are discussed in chapter 17.

In preparing this report, the Commission has written several appendices, but only one, that concerning consultations undertaken (appendix A), is reproduced in this report. The remainder can be read on the inquiry website at www.pc.gov.au under 'projects'. A full list of appendices is contained in the table of contents.

The structure and performance of the current system is not covered in this report in great detail because comprehensive up-to-date descriptions by the Australian

Institute for Health and Welfare (AIHW 2009b, 2010a) and the Steering Committee for the Review of Government Service Provision (SCRGSP 2011) can be readily accessed.

2 Why real change is needed

Key points

- People with disabilities and their carers are among the most disadvantaged groups in Australian society. This can be seen through measures of community access, financial status, as well as personal wellbeing. This disadvantage is linked to a lack of sufficient supports.
- There is significant unmet need for disability services in Australia, and this has been the case for decades. It affects a wide range of services at all stages of the life cycle.
- While provision of support is generally lacking, it is also inequitable. The level of support people receive is heavily influenced by where a person lives and how they acquired their disability.
- Better outcomes in the disability support sector requires both sufficient funding and efficient use of that funding. Both funding and efficiency must be improved.
- Underfunding has been a longstanding problem. It has led to rationing and the growth of waiting lists, which leads to greater unmet demand.
- The system is also inefficient in a number of ways. The fragmented structure of the disability system, and a lack of coordination between the pieces, have made it extremely difficult for service users and their families to access services.
- There are several systemic barriers that people with disability face, such as the lack of portability of disability supports between states.
- A further inefficiency is the distortion of allocation decisions due to a lack of consumer choice.
- There are various other areas of potential efficiency gains. For instance, more timely and forward looking approach to assessment and service delivery could save the disability support system money in the longer term.
- The system is lacking essential frameworks that would allow it to identify and solve its problems. These include a strong governance and coordination structure, as well as information and data systems.

2.1 Introduction

Throughout the consultation process of this inquiry, there has been no question among stakeholders (including government) as to whether support for people with disability needs to be improved. This presumption is also reflected in the terms of reference for this inquiry:

> The Government is committed to finding the best solutions to improve care and support services for people with disability.

One of the roles of this inquiry is to consider what scope of change or improvement is required. For example, changes can come from small, well targeted reforms or larger scale structural change.

This chapter considers the evidence surrounding the view, held by many, that the disability support system requires large-scale systemic changes. The analysis is based on a wide range of evidence which includes population-wide statistics, information from the disability support sector, as well as the experiences of individuals and families.

The first sections of this chapter look at the poor outcomes of the disability support sector as a whole. This involves evidence of disadvantage among people with disability and their families (section 2.2). It also involves evidence of poor outcomes of the disability support system, including the lack of service provision (unmet need), and the inequity surrounding disability supports (section 2.3).

The subsequent sections consider the potential reasons behind these poor outcomes. Section 2.4 outlines the evidence regarding the underfunding of disability supports. Section 2.5 looks beyond funding at various structural elements of the system and sources of inefficiency.

This chapter is only a brief summary of the major issues motivating reform. The chapters that follow focus more on providing solutions to the comprehensive problems facing the disability sector.

2.2 Disadvantage and disability

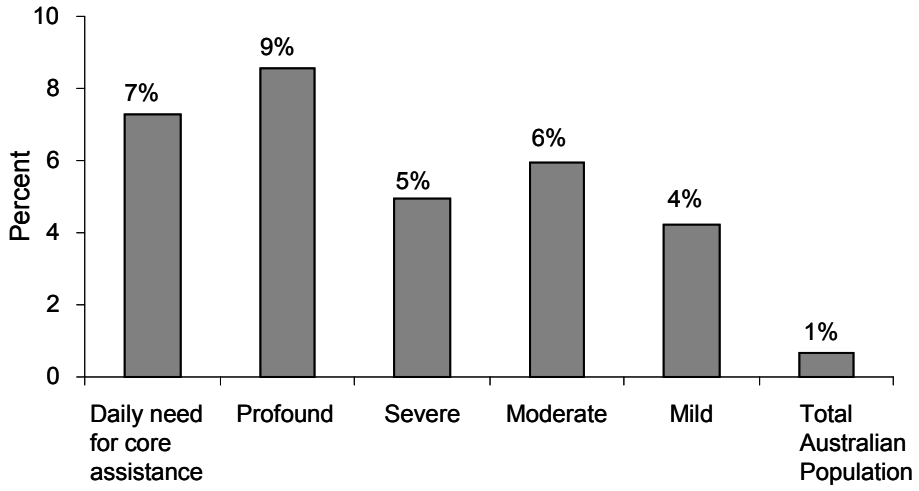
People with disability and their families face many social and financial challenges and, as a group, are among the most disadvantaged in Australia. This makes support services all the more important for the wellbeing of people with disability and their carers. While this disadvantage may not be entirely attributed to unmet need for services and supports, there appears to be a strong link between observed

disadvantage and a lack of support services. The evidence suggests that large scale support is warranted over and above what is currently provided.

Social isolation

Social isolation affects people with disability and their families at a disproportionally high rate — this was one of the major findings of the Shut Out report (Australian Government 2009a). Survey evidence shows that people with profound core activity limitation were nine times more likely than the general population not to participate in activities outside of home (figure 2.1). This appears consistent with other data showing that many carers — 18 per cent — only had face-to-face social contact either once every three months or less often (Edwards et al. 2008).[1]

Figure 2.1 **Proportion of people aged under 65 years not participating in activities outside of home, 2009**[a]



a Activities include: visiting a museum or art gallery; visiting a library; attended theatre or concert; attended cinema; visited animal or marine parks or botanic gardens; took part in sport or physical recreation; attended sporting event as a spectator; visited relatives or friends; went to restaurant or club; church activities; voluntary activities; performing arts group activity; art or craft group activity; other special interest group activities; other activity not elsewhere specified

Data source: ABS (2009a).

There are also significant differences in the levels of education and training among people with disabilities, particularly those with higher support requirements. Around 80 per cent of all Australians over the age of 25 years progress past year 10,

1 The Edwards et al. (2008) estimates were based on the Families Caring for a Person with Disability Study (FCPDS). The sample size was 1002 carers, all of whom were selected from Centrelink lists of recipients of either Carer Payment or Carer Allowance.

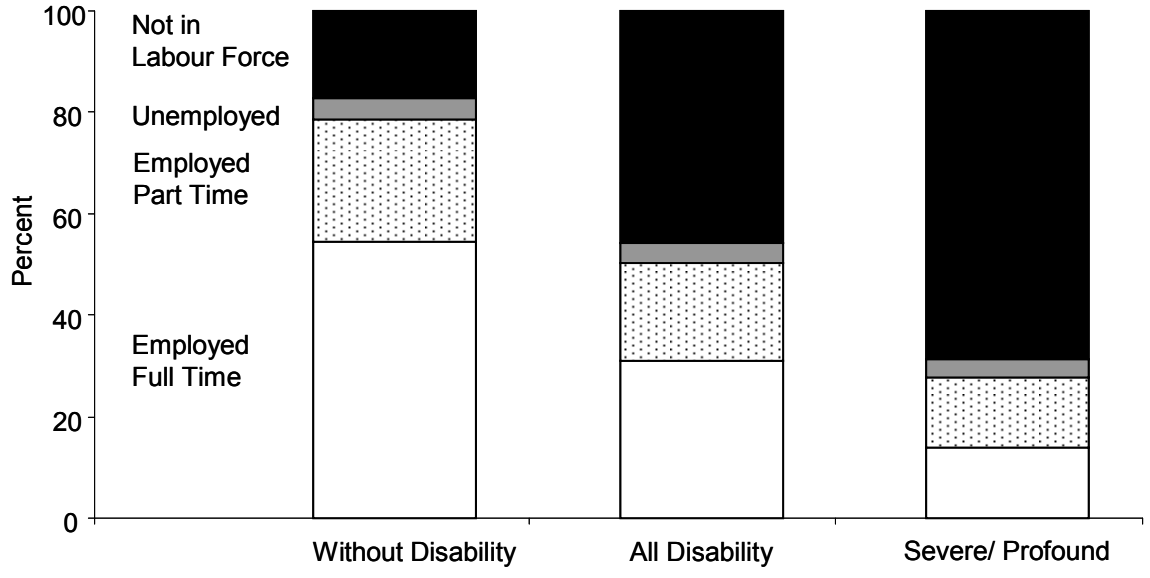
compared to two thirds of people with disability and half of people with severe or profound core activity limitations (ABS 2009a).

Families caring for people with disability are also more likely to experience relationship breakdown. Around 30 per cent of all female carers between the ages of 30 and 50 years had either separated or divorced since they had started their role as carers (Edwards et al. 2008). The probability of separating is higher in the first ten years of caring, (3 per cent on average), which is consistent with data showing the frequency of arguments and the likelihood of depression are also higher in the first years of caring.

Lower employment rates and income levels

People with disability and their carers are also less likely to participate in paid employment. Around 28 per cent of people with severe or profound core activity limitations were in the labour force, compared to 50 per cent of people with disability, and around 83 per cent of people without disability (figure 2.2). Around 38 per cent of employment for people with disability was part-time, compared to 30 per cent for those without disability.

Figure 2.2 **Disability employment for people aged 15–64 years, 2009**



Data source: ABS (2009a).

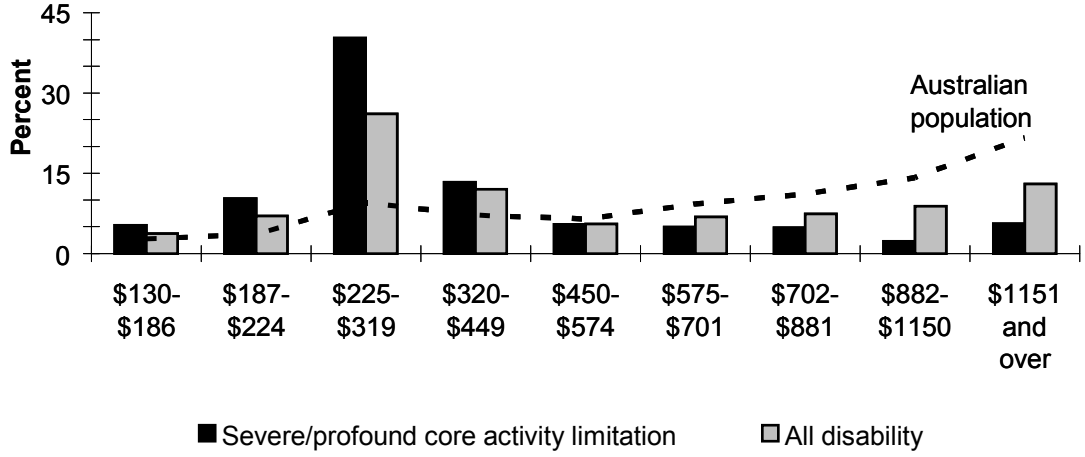
Informal carers tend to have less capacity for paid work than non-carers — around 42 per cent of primary carers spent on average 40 hours or more per week providing

care.[2] The labour force participation rate for primary carers is only 54 per cent compared to 77 per cent for non-primary carers and 80 percent for non-carers. In addition, carers were more likely to work part time. This inevitably leads to carers receiving lower incomes on average than the rest of the population — over 60 per cent of carers were in the lowest 40 per cent of income earners (ABS 2008a).

As a result of poor employment outcomes, people with disabilities are also among the most disadvantaged groups financially. The distribution of income for people with disability differs greatly from that of the wider population (figure 2.3). Still, this is likely to understate the differences, as people with disability generally have additional costs of living associated with their condition.

Employment in paid work not only has implications for income levels, skill development and participation — it also affects people's ability to save for retirement. As such, both people with disability and their carers are less likely to have superannuation or other retirement savings.

Figure 2.3 **Distribution of fortnightly income for people aged 15–64 years, 2009**



Data source: ABS (2009a).

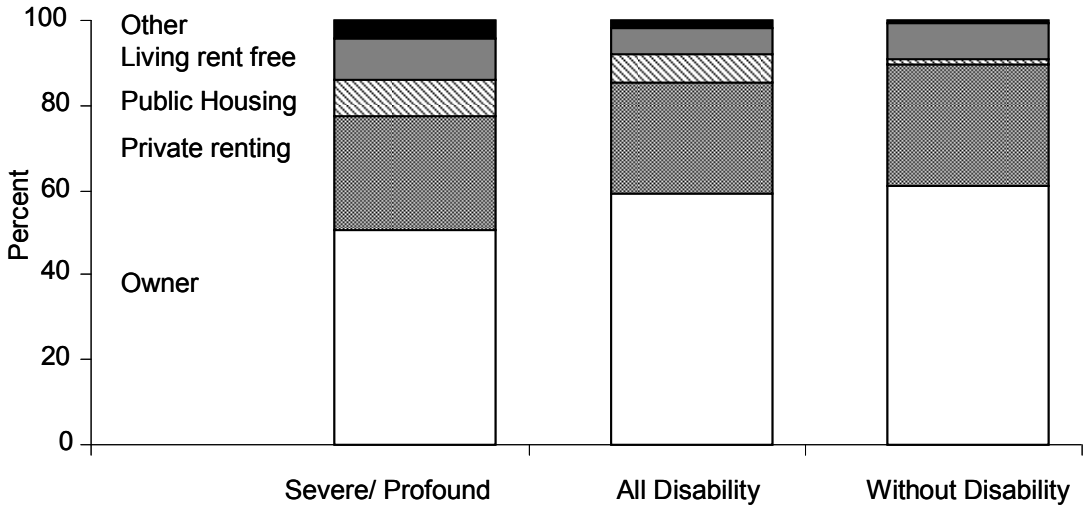
Difficulties with housing

Housing has implications for people's access to services, natural support networks and transport. People with disabilities are much more likely to live in public housing than the wider community (figure 2.4). However, many are also part of the private rental market or own homes with mortgages. In these private housing

2 Calculation includes primary carers and main recipients of care who live together.

markets, people with disability are also likely to face constrained accommodation prospects due to lower than average income levels.

Figure 2.4 **Housing situation ages 15–64 years, 2009**[a]



[a]People classified in 'other' accommodation include those not residing in private dwellings, as well as those whose answers did not fit other classifications.

Data source: ABS (2009a).

Poorer personal wellbeing of carers and families

Disadvantage is also observed in the wellbeing of carers. Both survey data and other research by the Australian Institute of Family Studies (Edwards et al. 2008) found significant differences in physical and mental health between carers and non-carers. For instance, carers were almost twice as likely to be in poor physical health than the general population. Around half of female carers and almost a third of male carers had also suffered from a depressive episode of at least six months since they had begun caring.

These results are consistent with the findings of Cummins et al. (2007), who found that carers had the lowest level of wellbeing of any group that they had studied.[3] Other groups showing low levels of wellbeing in this study included unemployed people who lived alone, and people earning very low incomes.

3 Cummins et al (2007) used a survey of subjective wellbeing. The sample of carers included those caring for people whose condition fit the following classifications: 'disability'; 'chronic condition'; 'aged and frail'; 'mental illness'. The final sample contained 3766 carers.

The experience of carers highlights an important link between a need for support and health outcomes.

> There is a clear and consistent pattern, with carers who indicated that the support they received was "about right" having significantly better mental health and vitality than carers who needed a lot or a little more support…
>
> Carers who needed a little more support had an incidence rate [of depression] 1.58 times that of carers who said the support they received was about right (54.6 per cent versus 34.5 per cent). Moreover, carers who needed a lot more support had an incidence rate 1.88 times that of carers who indicated the support they received was about right (65.0 per cent versus 34.5 per cent). (Edwards et al. 2008 pp. 79–80)

This link is not surprising, as formal supports (such as respite) directly improves the ability of informal carers to fulfil their role.

2.3 Insufficient support provision

The previous section looked at evidence of financial, social and other disadvantage among people with disability and carers. Much of this disadvantage is linked to poor provision of disability supports. Support levels are generally insufficient and the provision of support is often inequitable — this places greater costs on people with disability and their families.

Unmet need

Unmet need for disability supports has been excessively high across Australia for decades (Ohlin 1999, AIHW 2007a). Unmet need refers to situations where people are not receiving sufficient support. This may mean that:

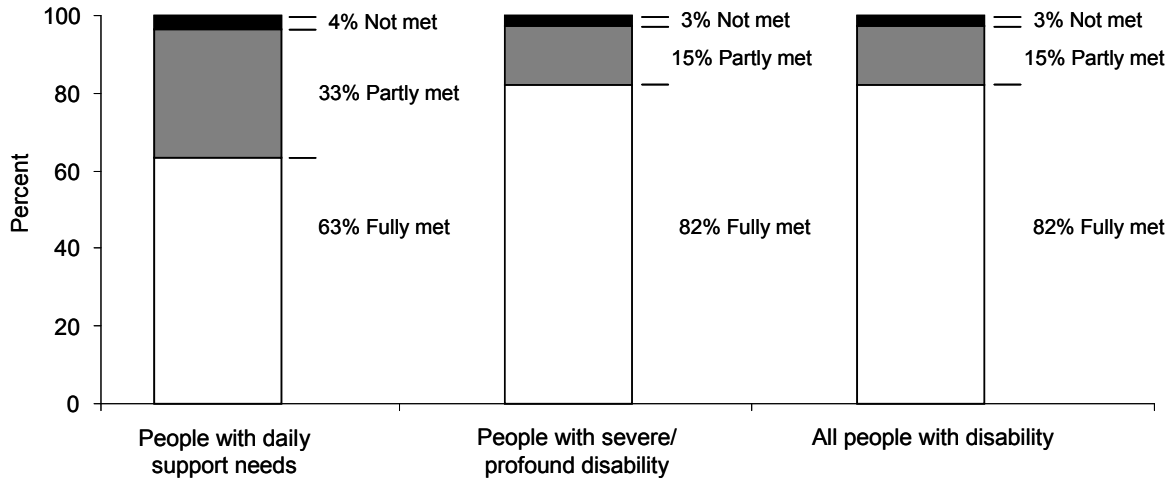
- they receive some formal support but require more than they currently receive
- they receive some types of formal support but require some other types of formal support that are not available
- they do not receive any formal support and rely solely on informal support.

The Survey of Disability, Ageing and Carers (SDAC) (ABS 2009a) shows that across different levels of disability, some people indicate not having their needs met at all by formal services (figures 2.5 and 2.6). A larger proportion of unmet need relates to 'partially met' needs, meaning that people receive some formal support but not enough. In total, around 18 per cent of people with disability indicate having an unmet need for support with self care, mobility or communication. Almost two fifths indicate unmet need for other supports.

People who require daily support with core activities are more likely to indicate an unmet need (figures 2.5 and 2.6). This is particularly the case with respect to supports for core activities. In other words, it is often the case that the under-provision of supports is greatest for those people most in need.

Figure 2.5 **Unmet need for core activities by reported level of disability, 2009**

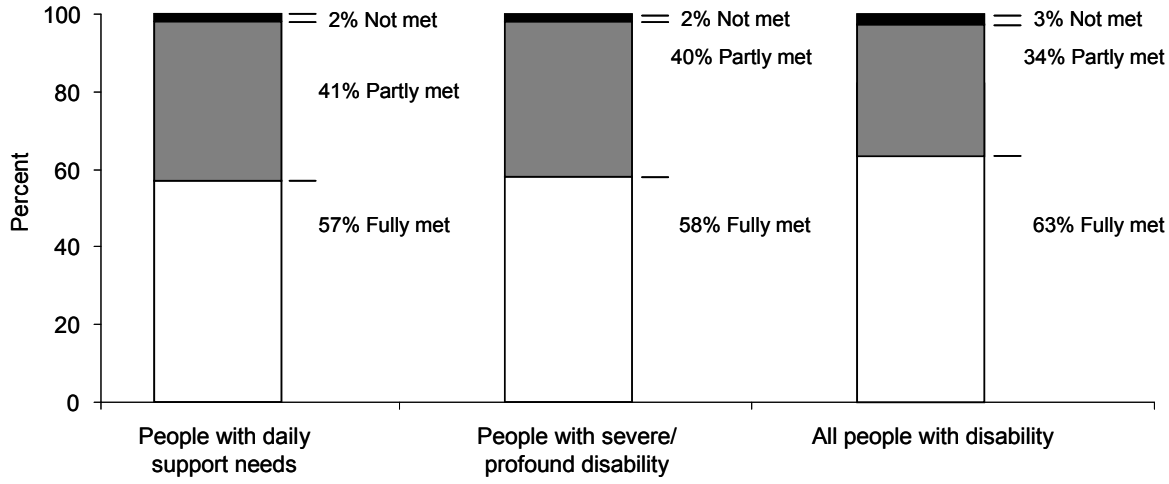
Activities include self care, mobility and communication



Data source: ABS (2009a).

Figure 2.6 **Unmet need for non-core activities by reported level of disability, 2009**

Activities include Cognition or Emotion; Health Care; Paperwork; Transport; Housework; Property Maintenance; Meal Preparation



Data source: ABS (2009a).

There is likely to be some margin of error when considering unmet need estimates based on survey data. Different people may have tendencies to either underestimate or overestimate their unmet need. Furthermore, people's responses may also differ at different points in time — particularly if the availability of support varies.

The AIHW (2007a) used both survey and waiting list data to compile estimates for unmet need for different disability supports (table 2.1). While these estimates are not based on current data, they are still useful in being somewhat indicative of the size of unmet demand. The estimates highlight accommodation and respite as a particular area where unmet need is high, where in 2005, almost 28 000 people indicate a lack of supports. Although both government spending and demand for support has risen since then, these estimates are still useful in giving some insight on the likely scale of unmet need nationally.

Table 2.1 **Waiting list data and AIHW estimates of unmet need, 2005[a]**

Number of people

	Accommodation and Respite	Community Support	Community Access	Employment	Total
Waiting List Data					
Victoria	4 254	—	507	—	4 761
Queensland	—	—	—	—	3 578
Western Australia	409	—	77	—	486
South Australia	2 147	589	533	—	2 619
Tasmania	284	122	70	—	476
AIHW Estimate					
Australia	27 800	—	5 900	2 200	—

[a]Data where available.

Source: AIHW (2007a, table 4.2).

Unmet need over the lifecycle

People with disability and their families require different supports across the lifecycle. What someone needs in early childhood is different to that of a young adult, which differs again to what is needed at an older age. This is because people tend to move through different stages of life — such as going to school, leaving school, moving out of home, finding employment, and retirement. It is important that an appropriate set of supports is available over each stage of life, as well as at the points of transition between life stages. As Anglicare Australia said:

> … Needs change over time for people with a disability as they improve or digress with their abilities, as they move through developmental milestones, as their life goals change and as they or their carers age; and it is important that those changing needs can be picked up through all intervention and prevention strategies. (sub. 594, p. 20)

It is difficult to accurately estimate unmet need for each service area of disability support. However, overwhelmingly, the anecdotal evidence indicates that support for people with disability falls short for many services and at all stages of the lifecycle. For instance, many participants note the lack of information and guidance services at the earliest stages where a disability is diagnosed or identified.

> Many families spend many distressing and difficult years trying to identify and access appropriate support and services for their child. It is frequently only through the considerable diligence and perseverance of families that relevant and appropriate information is found. Access to early information, support and advice is patchy, ad hoc and varies enormously both within States and from State to State, and is frequently dependent on both the child's diagnosis, the geographic location of the family and luck in tapping in at the right moment to appropriate information or services. (National Council on Intellectual Disability, sub. 571, p. 4)

In the area of early childhood services, many participants stressed their benefits such as in forming the 'foundation for learning, behaviour and heath outcomes' for young children (see subs. 505, 571). However, participants highlighted unmet need in this services area by such indicators as waiting times and a complete absence of services (Early Childhood Intervention Australia, sub. 450, pp. 2–3). For example, the Royal Children's Hospital Melbourne considered that:

> … there is a strong case for prompt access to community based allied health practitioners and social workers for infants and children with developmental disabilities. Current waiting lists prohibit early childhood intervention from occurring in a timely manner which can result in a child not being able to maximize their developmental potential. (sub. 405, p. 3)

Several other participants also cite the lack of early intervention services (see subs. 270, 408, 594), particularly for less common medical conditions (see subs. 296, 571, 111).

Another potentially difficult time relates to the transition out of school. This is because schooling accounts for a relatively large number of daytime care hours, and provides learning and structure for children and young adults. Once school is over, there is often a lack of services to fill this void.

> The school recently held a post school options expo at which it was explained that there is severely limited funding for disabled adults when they leave school. The information I received advised me that I could expect, in the current climate, no more than 8-10 hours per week funding for Abby to attend post school programs. (sub. 428, p. 1)

> Since she has left school after much campaigning she now attends a local day program for two afternoons a week. We as a family are paying half the current costs for this program which will be over $5000 a year … [Her day program] is another service

> created by parents for their school leavers and not provided by the local government where on the burden should rest. (sub. 189, p. 2)

Beyond school, there are a number of life stages where people with disability have cited unmet need for support. For instance, many people with disability who would like to work feel constrained by the lack of employment supports (subs. 456, 328, 366).

The lack of accommodation options (evident in the statistics) also makes it more difficult for people with disability to move out of their family home. The unmet need for accommodation and support continues well into the older ages. Carers often continue in their role well after they reach an age where they themselves need support in their daily life.

> Many have been in circumstances where they had no choice but to assume the sole responsibility of care for children with disabilities without a real prospect of those circumstances ever ending. … [The] realization that their ability to care for their children is diminishing with age and that in the not too distant future their ability to care will have disappeared… adds enormous anxiety to the already significant anxiety and stresses of their situation. (National Seniors Australia, sub. 595)

While there are varying estimates of the number of aged and ageing carers, (SCRGSP 2011) shows around 8100 primary carers over the age of 65 who are caring for a recipient of CSTDA/NDA services. Data received from Centrelink shows that among recipients of Carer Allowance, around 11 500 in 2010 were over the age of 65 years and caring for a child.[4]

Ageing carers and the availability of informal care

The lack of supports for ageing carers, in combination with demographic trends, has meant that the population of informal carers is ageing on average. Centrelink data shows that the number of people over the age of 65 caring for a child has increased over the last five years 10 per cent on average. Whilst a number of factors may have contributed to this increase, some may be attributed to an ageing parent carer population. In addition, PWC (2010) estimated that between 2006 and 2036, the proportion of carers over 65 years would rise from 16 to 24 per cent.

---

4 PC (2011) reports that there are around 8100 people over the age of 65 years acting as a primary carer for someone receiving CSTDA services, based on the National Minimum Data Set from the AIHW. Centrelink data on carer allowance recipients shows around 11 500 carers over the age of 65, with around 10 500 caring for people younger than 65 years. However, not all people with disability receive CSTDA/NDA services, and not all carers receive carer allowance. So while this estimate is internally accurate, it may be lower than the true number of aged carers. Alternatively, ABS SDAC (2003) indicated around 10 000 primary carers over the age of 65 years, however standard errors are much higher for survey data.

The ageing profile of carers is an important issue in terms of both providing appropriate care for people with disability, and achieving appropriate outcomes for the carers themselves. As people's ability to provide care reduces in older age, it becomes more likely that an informal carer receiving insufficient supports would potentially reach a crisis point and stop providing care. Unmet need would then be exacerbated by reductions in the availability of informal care.

There is expected to be a downward trend in the availability of carers in Australia. The availability of informal care is commonly estimated by the 'carer ratio', which is calculated as the number of people providing care divided by the number of people with severe/profound core activity limitations. Several studies have estimated that carer ratios will continue to fall (see PWC 2010a, Access Economics 2009, NATSEM 2004, and Jenkins et al 2003 for example). Unless addressed effectively, this will put an already overstretched system under greater strain.

Recognition of unmet need

The significance of unmet need is raised in the National Disability Agreement, where a high priority is given to the improving how need is measured (Australian Government 2009b). These improvements are expected to be incorporated in the forthcoming installments of the ABS SDAC, and the National Minimum Data Set. However, the issue of unmet need has been longstanding — it has been identified in previous surveys and recognised by previous governments:

> It was a matter of concern for Commonwealth, State and Territory governments for some time, but was probably crystallised into public consciousness following the 1993 National Survey of Disability and a subsequent Australian Institute of Health and Welfare study. (Ohlin 1999, p. 1)

The pervasiveness of unmet need suggests that several areas of policy need to be addressed in order to resolve the issue.

Inequity in disability supports

Not only is there significant unmet need across the disability support system, there is also a large degree of inequity faced by people within the system. In this respect, the current system of disability support has been widely described as a lottery. The level of support received varies greatly as a result of things that are out of people's control, such as the cause of people's disability, their medical condition, their age or their place of residence.

Differences due to how the disability was acquired

One aspect of the 'lottery' around disability supports is that people are treated differently depending on how they acquired their disability. Aside from the government funded NDA and HACC services, there are a number of other systems delivering support for disabilities acquired in accidents. These include personal insurance (although this is rare), the common law system, workers' compensation and through compulsory motor insurance schemes. In most cases the level of care and support received through these avenues is significantly better than the more general 'safety net' system.

For instance, in the NSW Lifetime Care and Support Scheme (LTCS scheme), people receive supports on a needs basis not constrained arbitrarily. The NSW LTCS scheme is a road accident scheme, which only covers people who are catastrophically injured on NSW roads. By comparison, workers' compensation schemes provide supports (including some income replacement) for a wide range of injuries, although the accident must have occurred at the workplace. The support needs for many other serious injuries, such as those that occur at home, would be covered only by the general disability system.

As a result people with the same level of disability can receive varied levels of support, depending on whether they were injured in a road accident, at work, or elsewhere. The absurdity of the situation is summed up by the Hon. Bill Shorten when he said:

> It has been said to me that the best thing to do for someone who has fallen off the roof of their home and suffered a spinal injury, is to bundle them into the car and drive it into the nearest lamppost. That grim piece of gallows humour reflects the sad truth that getting adequate compensation for a person with a serious injury is still a lottery. State borders, the whim of the courts, and the cause of the injury play a far greater role than need, fairness or justice. Yet people injured in accidents at least have the chance for some kind of compensation, and treatment that is whole-of-life and centred on the individual. They are the comparatively lucky ones. (Shorten 2009)

Differences between the various accident schemes are discussed more fully in chapter 15.

More generally, it is commonplace in the current system for people to have the same level of disability support needs, but receive different levels of support due to differences in the causes of their disability. Many disabilities are linked to medical conditions which have genetic causes, or may be acquired in the pre-natal period, or may in fact have no definitive cause. In the current system, people with these conditions would fit into the NDA or HACC services system, and are therefore

likely to have very different access to supports compared to those in road accidents or workplace accidents.

Variation across Australia

The vast majority of disability supports are managed and delivered at the state and territory level. This means that disability support schemes, including accident schemes, differ across state and territory boundaries. In practice, the level of support varies significantly across states. The reasons for this include differences in funding, the structure of the system, and the regulations involved.

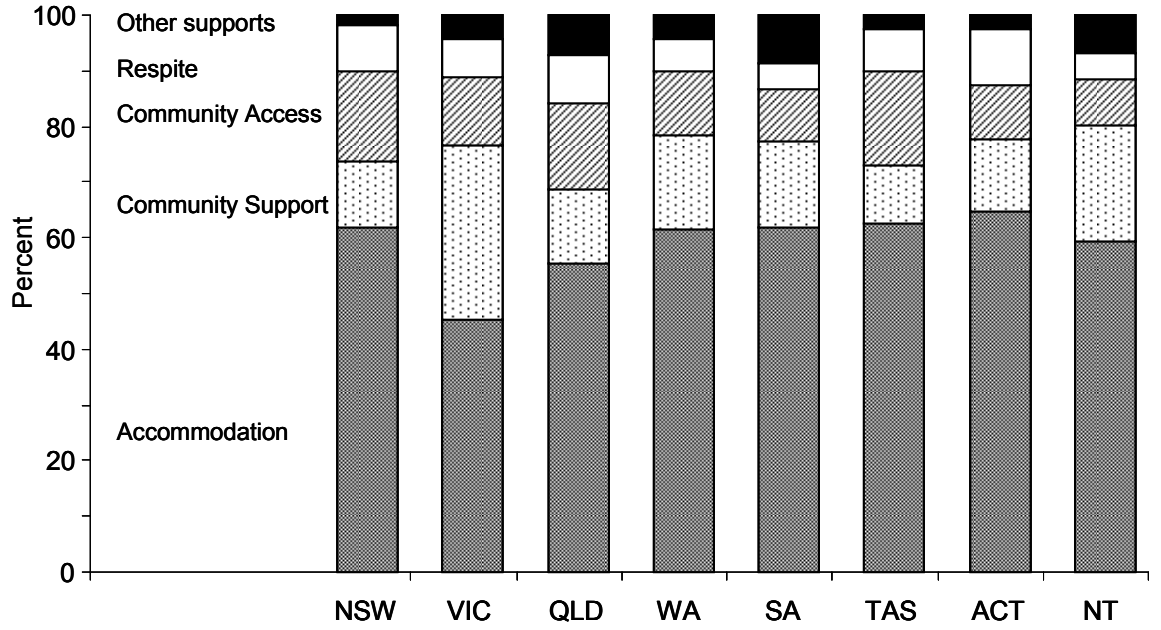
In terms of motor vehicle accident schemes, one of the main reasons for differences in service levels is that some states operate on a 'no-fault' basis, meaning that a road user would receive support in the event of an accident regardless of who was at fault in the accident. Other schemes operate such that fault must be proven before supports are granted. This one aspect can literally mean a world of difference to the person with disability. Differences between accident schemes are discussed fully in chapter 15.

Aside from accident schemes, disability supports differ on a range of aspects. One way to observe this variation is to look at how different states and territories allocate their funds. The relative emphasis on accommodation, community access, community support and respite differs (figure 2.7). The figure shows that each jurisdiction allocates the majority of their disability expenditure to accommodation, although the proportion varies. Often there is a similar proportion spent on community support and community access, although in Victoria and the Northern Territory, a much larger share is allocated to community support. Depending on which supports a person may require, they may find themselves better supported in one state rather than another.

Regional disparities within states and territories

Within each jurisdiction, there are also significant differences in the availability of supports between regions. For instance, a report into the funding of HACC in Victoria found that funding per head of the potential population varied between regions by as much as 35 per cent (Victorian Auditor General 2009). It was found that for historical reasons, one region was 15 per cent below the mean while another was 20 per cent above. People in remote areas were also less likely to use NDA funded services: in outer regional or remote areas, there were about 32 service users per thousand of the potential population, compared to 43 users per thousand in major cities and inner regional areas.

Figure 2.7 **NDA budget allocation differs between jurisdictions**



Data source: SCRGSP (2011).

In a similar audit of NSW respite, it was found that people's access to respite is not always based on need, and is influenced heavily by regional location.

> There is no consistent needs-based approach for determining who gets respite and how much they get. For historical reasons, respite centres are distributed unevenly across the state and the chances of getting centre-based respite depend, in part, on where you live. For example, only 2.3 per cent of the potential users in the southern part of the state get centre-based respite. (NSW Auditor-General 2010, p. 3)

Several participants have indicated that rural and remote areas face poorer provisions of support than would be available to cities and metropolitan areas.

> The situation regarding availability of sheltered accommodation for the disabled is bad enough in the city and regional areas but, in the rural/remote areas it is appalling. (Country Women's Association of NSW, sub. 97)

> Often barriers to services delivery are created by inflexible and "accountable" city centric models of service delivery. In an attempt to ration services or to target the most needy recipients, funding bodies risk not providing any services to people with disabilities in country areas. (Wattle Range Council, sub. 572)

The Commission also heard in public hearings and consultations that often people in non-metropolitan areas either have to go without supports, or travel long distances at considerable expense to receive supports.

Given the issues with cost efficiency and population density, it may not be feasible to have the same bricks-and-mortar infrastructure in each area. However, solutions

must be found to ensure supports are available to people in all areas. This is particularly important given that disability supports are likely to be lacking in the same areas where other human services and infrastructure also lack.

Differences as a result of being in a trial or special scheme

The disability system is divided into a multitude of programs and trials. Eligibility for programs is often highly rationed and, at times, medical conditions are used as eligibility criteria. An example would be the Better Start program:

> … eligible children diagnosed with a sight or hearing impairment, Down syndrome, cerebral palsy or Fragile X syndrome will have access to funding and Medicare rebates under the initiative. (FaHCSIA 2010)

On these grounds, people with less common conditions have noted difficulty in receiving information and support (see subs. 9, 455, 319 for example). In many cases, the level of care received will depend on whether or not a person qualifies for a particular program.

The costs associated with disability are not well spread

As in other areas of life, there is a benefit to society from pooling financial risks to reduce their impact on individuals — this is the value of insurance. Even for people who never have to make a claim, there is a benefit from knowing that there will be sufficient funds available to ensure that people receive the necessary care and support, if required.

Having a disability or becoming a carer often has serious implications for costs of living and the ability to work. The costs of disability supports over a lifetime can literally table in the millions of dollars — much more than can be afforded by the families themselves. As evidenced by the unmet demand in the current system, a disproportionate amount of this cost is absorbed by people with disability and their carers.

Spreading cost risks is usually the role of insurance companies, however for a number of reasons discussed in chapter 12, commercial insurance markets will not operate well in the area of long-term care and support for people with disabilities. Therefore, people with disabilities are left to rely on the government system to spread risk. As a result, the government must determine the ideal level of insurance, which is difficult. Among other things, it will be affected by:

- the level of risk aversion people possess

- the cost of raising funds through taxes.

While the optimal level of insurance may not be known, it is reasonable to say that the current arrangements do not provide enough support, and the support that is available varies widely. When we look at the disadvantages that people with disability face (section 2.2), it is clear that a significant portion of disability-related costs are borne by the people with disabilities and their carers. Redistributing these costs more evenly across society is not just a transfer of wealth, it is a spreading of risk that has a net positive effect on society.

2.4 Underfunding in the current system

A functional disability services system requires both adequate funding and the efficient use of that funding. While there is great potential for improvements to efficiency (see section 2.4), it is generally also agreed that much more funding would be required to meet the current demand for services. For instance, according to some State Government submissions:

> Such a scheme would have significant cost implications — given the funding required to meet unmet demand. It is only likely to be feasible with Commonwealth involvement due to the scale of the funding required, and the states' limited revenue sources. (Victorian Government, sub. 537, p.3)

> Given current funding levels fall well short of the type of care expected to be paid for by a social insurance scheme, the level of overall funding, and its growth over time, will need to be significantly greater than what is currently contributed by state and federal governments. This is especially the case if a national insurance scheme extended entitlement to the population currently not in receipt of formal disability services. (South Australian Government, sub. 496, p. 17)

> Alternative revenue sources need to be considered to address disability budget pressures and effectively meet the needs of people with a disability in NSW. (NSW Government, sub. 536, p. 39)

The extent of underfunding in the disability support system is a major argument in favour of change. However, it is not straightforward to quantify underfunding accurately, particularly given the lack of data on the current need and usage of supports. That said, all sources of data currently available reinforce the view that systemic underfunding has contributed to the shortfall in supports and continues to do so.

Underfunding has occurred for many years

The level of unmet demand is not a symptom of one government's lack of expenditure in one year. Underfunding limits the services that can be provided at any one time, but many people who miss out would still require support in the next budget period, giving rise to waiting lists. For example:

> Chronic underfunding in recurrent budgets causes a shortfall in programs which operate a subsidy, or funding to run out before the end of the financial year, for example.
>
> In the Western Sydney region of NSW, all funding for Level 2 Home Modifications for 2010 was allocated by mid 2009. Extensive waiting periods have resulted, leaving people isolated, at risk, and unable to complete daily activities or leave their house, in addition to those who have endured unnecessary periods of hospitalisation. (Occupational Therapy Australia, sub. 550, p. 7)

The rationing caused by underfunding is often best observed at the regional level. So even though the above example relates only to one particular region, it would also be relevant wherever waiting lists carry over to future budgeting periods. Without sufficient funds to meet current demand, there is less scope for forward planning or investment to meet future demand.

Over time, it can become more difficult for funding to keep up with the growth in demand for supports. Underfunding may lead to rationing, while demand continues to grow regardless. Some analysis has been made of the level of funding and the growth of unmet demand. For instance, the Disability Investment Group (DIG 2009a) noted:

> In work undertaken for the NSW Government in 2004, PricewaterhouseCoopers (PwC) analysed potential unmet need by considering the proportion of care needed over time if current service levels remain the same. PwC grouped people with severe and profound disability into relative support needs and estimated the difference between hours needed and hours provided.
>
> PwC estimated that unmet need for people requiring constant support would grow from 1 per cent of what they require in 2004 to 49 per cent by 2031. For those requiring regular support, unmet need will grow from 25 per cent in 2004 to a projected 48 per cent in 2031; and for those requiring lower support, unmet need will grow from 77 per cent in 2004 to a projected 90 per cent by 2031. (DIG 2009a, p. 18)

While these projections carry various assumptions and margins of error, it is likely that considerable increases in funding would be necessary to stave off vast increases in unmet demand over time. In this regard, the NSW Government itself has suggested that its existing funding sources will not be able to meet the growth in demand in the medium to long term (NSW Government, sub. 536, p. 5).

Consistent underfunding and the growth of unmet demand also makes reform more difficult. For instance, the Victorian experience shows that while some regions had been historically underserviced, rectifying the situation is made more difficult by a lack of jurisdiction-wide funding.

> From 2003 an additional $2.3 million above the matched funding commitments of the Commonwealth has been allocated in an attempt to remedy funding inequities. However, there has also been a commitment to maintain existing service levels to all regions, adjusted for population growth. This was because HACC demand exceeds supply in all regions within the state and the level of service to individuals is generally so low that it should not be reduced.
>
> Consequently the DHS approach to addressing funding inequity has not been to redistribute funds from relatively well resourced regions to relatively under-resourced regions.
>
> … By DHS's own reckoning it will take up to 25 years to achieve funding equity between regions using the current approach. In 2006 DHS calculated that an additional injection of $11.6 million would be needed to achieve equitable [per capita funding]. (Victorian Auditor General 2009, p. 2)

This example also shows that some outcomes (such as interregional equity) appear at first to be issues of budget management alone. In fact, the move towards greater equity is severely constrained by the overall funding level.

Underfunding in one area shifts costs to another

A lack of supports in one service area often shifts costs to other service areas. The costs are often exacerbated by the fact that the most appropriate and efficient supports are not being used. For example:

> I spent over 12 months as an inpatient in the Hampstead Rehab Centre because government funding would not help with a bathroom so I could go home to my mum. The one bathroom that we did have was probably as big as that table and it just wasn't going to be wheelchair-friendly, so we had to get one added on the back.
>
> One area of government then spent over $300 000 keeping me in the Hampstead Centre and would not give us $15 000 tops to help renovate a bathroom so I could go home. (trans., p. 318)

Several other participants have noted the greater use of hospital and health expenditure due to a lack of disability supports.

Another common example of cost shifting is in the area of accommodation and respite. Data available on the NSW respite system shows that in 2008, around 30 people with disability were using respite as longer term accommodation (in the absence of better arrangements), simply because there was no other option (NSW

Auditor General 2010). When the number of people was reduced from 30 to 12 in 2009, this allowed 130 more people to use respite services (i.e. 18 beds blocked meant 130 people missed out on respite services).

Respite itself is important in helping informal carers to fulfil their role, and for families to avoid falling into crisis. Modelling undertaken by PWC (2010a) on the NSW disability system indicates that as unmet demand for services increases, the number of crisis situations also increases. Given that crisis situations often require much greater amounts of formal support, this implies that providing such supports as respite or early intervention may help avoid greater costs in other areas.

The high costs involved with crisis situations can impede funding for other support services. This is because when faced with budget constraints, systems have little choice but to give priority to families in crisis. This means that any growth in the number of crises can cause further rationing over time (box 2.1). Moreover, when this rationing affects the availability of early intervention and respite programs, it is likely to further increase the number of families falling into crisis (hence leading to an ongoing causal relationship between respite shortages and crises).

Funding structure and stability

Funding for NDA and HACC services comprised almost $6 billion nationally in 2010. As mentioned, the states and territories provide the vast majority of funding (table 2.2). However, each jurisdiction differs in the amount invested in disability supports (as measured against federal spending or as an amount per potential participant). This diversity reflects, among other things, policy priorities.

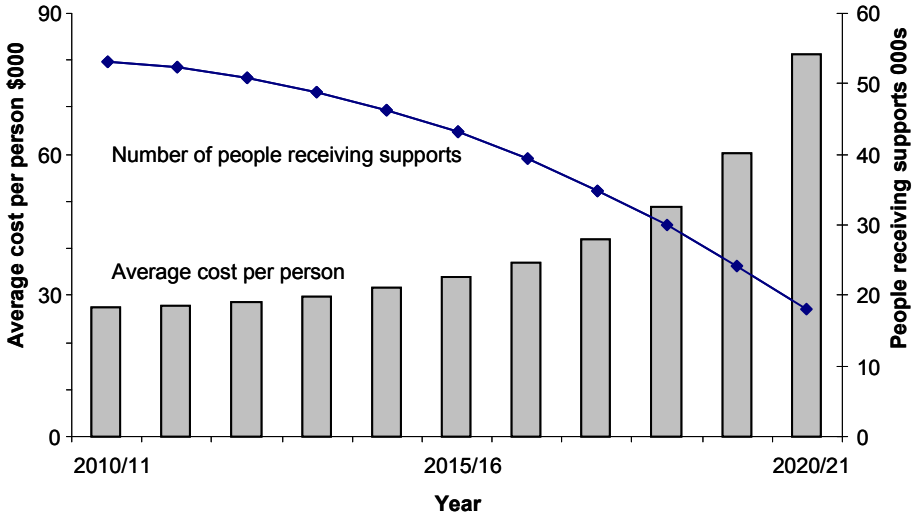
Jurisdictions are always likely to differ somewhat in their capacity to increase disability related expenditure. All jurisdictions show fluctuations in the growth of disability-related expenditure; for some jurisdictions, it is closely related to the growth of total budget expenditure.[5] In contrast, workplace compensation and motor accident schemes, which are based strictly on insurance models, are less likely to be affected by the constraints of annual budgets.

5 The Commission analysed expenditure for disability supports (SCRGSP 2011) and total budget expenditure for states and territories (ABS 2010). Spending on disability services (net of administration costs) was closely correlated with total state and territory budget spending over the years 2004-05 to 2008-09 for Queensland, Tasmania and the Northern Territory.

Box 2.1 Hypothetical projections of underfunding, rationing, and crisis based support

One of the main responses to underfunding is to prioritise between areas of support. This involves some people missing out on supports (rationing), while resources are focused on those most in need (i.e. families in crisis). This is not a sustainable approach to the provision and management of supports.

The figure below shows what could happen if real funding were kept constant (as a proportion of real GDP in that jurisdiction), and demand for supported accommodation were to increase at a rate modelled by PricewaterhouseCoopers (unpublished analysis). Due to the increasing number of families in crisis, more resources would be diverted towards more costly crisis supports and away from other less costly areas of support. As a result, fewer and fewer people would receive supports over time.



Source: Figure adapted from PWC unpublished analysis.

Insurance based schemes are also less likely to compete with other areas of state and territory policy. This is important not only in prioritising disability supports, but it may alleviate some financial strain on other service areas. As discussed, it is well documented that hospital services often have to make up for the lack of disability support funding.

All levels of government are aware of the need for better service funding. There have been a number of recent funding initiatives aimed at trying to meet the current levels of unmet need (for example, see box 2.2). Most of these initiatives, such as the Better Start early intervention program, deliver a considerable injection of funds on a focused area. While positive, they tend (by their nature and design) not to address system-wide needs. Moreover, some smaller initiatives may only have funding guaranteed for a short period.

Table 2.2 **Government spending on NDA services by jurisdiction, 2009-10**

Government/ Jurisdiction	*Total expenditure* [a]	*Share of expenditure financed by jurisdiction's own funds* [b]	*Total direct service delivery (excluding administration, payroll tax)*	*Total direct service delivery per potential recipient* [c]
	$000	%	$000	$
NSW	1 687 006	82	1 521 724	6 813
Victoria	1 374 150	85	1 247 346	7 737
Queensland	876 748	80	801 271	5 582
Western Australia	491 631	84	463 102	7 497
South Australia	373 013	74	335 780	6 737
Tasmania	131 403	79	125 225	5 666
ACT	75 040	82	66 722	7 386
Northern Territory	53 159	82	50 619	8 320
Australian Government	774 572	—	723 107	1 068
Total	5 836 721	71	5 334 896	7 881

[a] Significant amounts are spent by way of capital grants to non-government organisations. They occur irregularly and at differing levels. [b] Calculation excludes payroll tax expenditure. [c] Potential population includes people with severe or profound core activity limitations, and is adjusted for Indigenous underrepresentation.

Source: SCRGSP (2011).

An example of a broader and longer-term initiative is *Stronger Together* in NSW, which involved planning over ten years and guaranteed funding in five-year blocks. Stronger Together focuses on building capacity in disability supports in various areas such as early childhood services, respite, case management, and accommodation. It also involves some systemic changes, such as more person-centred approaches, greater transparency and efficiency. However, on the sustainability of such increased funding, the NSW Government has said:

> As the investment under Stronger Together shows, it is not sustainable for specialist disability services to continue to be funded solely from existing budgets. (NSW Government 2010a, p. 13)

The National Disability Agreement involves significant increases in general funding from the Commonwealth. However, the majority of funding will still come from state and territory budgets. As such, there remains a need to secure the majority of ongoing funding increases which would be required to cover current unmet need as well as future demand for support.

Box 2.2 **Examples of recent funding initiatives**

The new National Disability Agreement replaces the existing Commonwealth State and Territory Disability Agreement. Under the new Agreement, the Commonwealth will provide more than $5 billion in funding over five years to the States for specialist disability services. The Agreement means that in 2013 the Australian Government's contribution will exceed $1.2 billion, compared to $620 million in 2007.

Stronger Together is an initiative by the NSW Government to boost their expenditure on disability supports over ten years, from 2006 to 2016. Funding was guaranteed in five-year blocks, involving an additional $1.5 billion in the first phase, and a further increase of $2.02 billion in the second phase. Its focus is on building capacity in various areas of support, as well improving operational efficiency.

The Australian Government implemented the Better Start program (to begin in July 2011), which committed an extra $122 million funding for early intervention over four years. The program, which begins from July 2011, will involve subsidies for allied health services up to the value of $6000 per year, to a maximum of $12 000 total.

The Younger People with Disability in Residential Aged Care (YPIRAC) program is a five year agreement between the Australian Government and State and Territory governments. The Program was established by the Council of Australian Governments (COAG) in February 2006. Funding of up to $122 million from the Australian Government matched by up to $122 million from States and Territories is available. This program aims to reduce the number of younger people with disability living in residential aged care, and to provide additional support to those who remain in residential aged care.

Sources: NSW Government (2010a) and FaHCSIA website (www.fahcsia.gov.au/sa/disability/ progserv/people/Pages/early_intervenetion_better_start.aspx, www.fahcsia.gov.au/sa/disability/ progserv/ govtint/Pages/policy-disability_agreement.aspx and www.jennymacklin.fahcsia.gov.au/ mediareleases/ 2010/Pages/ypirac_ 27may10.aspx).

2.5 Inefficiencies in the current system

The disability support system does not only show signs of underfunding. There are various inefficiencies within the system that constrain the level of support provided, contributing directly or indirectly to unmet need. In many cases, the inefficiencies observed result from a combination of structural elements and underfunding. However, the inefficiencies are large enough that reform of disability services will require more than increases in funding. The evidence suggests widespread structural change would be required.

This section attempts to outline the major inefficiencies affecting the sector, which stem from *structural* elements and are not criticisms of individual agencies or governments. The term 'inefficiencies' in the context of this section refers to a wide

range of flaws in the current disability support system. These inefficiencies worsen support outcomes by constraining governance, adding complexity, and creating barriers. There are also many opportunities for efficiency gains that would significantly improve outcomes for people with disability.

While several individual cases of inefficiency have been highlighted in the Commission's consultations, the brief outline in this section attempts to fits broadly in the following groups:

- system structure and fragmentation
- consumer choice and its importance
- other opportunities for significant efficiency gains

The scale of these inefficiencies, and the extent to which they affect people's lives, present a strong justification for direct policy intervention.

System structure and fragmentation

Currently, the Australian Government and state and territory governments share funding for various disability support systems. Workplace insurance and motor accident insurance are both overseen at the state/ territory level. The delivery of supports then involves a mix of government and non-government organisations.

With the exception of employment services, the majority of disability support services are governed by states and territories. This means that regulation, budget management and delivery management occurs at the state/ territory level. This has potential advantages for governance such as:

- closer contact with families and the sector. This should facilitate coordination and feedback when making policy changes or running pilot programs.
- greater potential for coordination of policy in other areas of social services such as public transport or education.
- the ability to innovate without a one size fits all approach.

Some of the main drawbacks of the current system include that the various programs, agencies and departments that deal with disability supports are not effectively linked. As a result, navigating the system has become extremely difficult for people, raising barriers to accessing supports.

Divided and not sufficiently linked

A reality of a fragmented system is that each separate delivery system has its own jurisdiction, its own funding, and manages its operations according to those boundaries. Different states and territories provide their services according to what their funding allows, and management of this requires setting:

- eligibility criteria
- assessment tools and procedures
- conditions of service provision
- the suite of services, aids and appliances on offer

The duplication of these factors across jurisdictions means that the portability of services, funding, aids and appliances is not guaranteed. Furthermore, since case management systems do not span jurisdictional lines, there is little direct management of people moving interstate. There are currently efforts to improve the management of portability within the context of diverse systems, mainly in the form of greater information provision (box 2.3).

Box 2.3 Current initiatives on portability of aids and appliances

More consistent access to aids and equipment is one of the national reform priorities agreed to by Community and Disability Services Ministers under the National Disability Agreement. As part of this initiative, the Commonwealth is working with state and territory governments to implement an aids and equipment portability information sheet in early 2011. The information sheet will to help ensure consistent application of existing portability arrangements between states and territories and ensure individuals have continuity of access to equipment they need when moving interstate.

It is proposed that when people with disability move interstate, the guidelines of the equipment scheme of the receiving state or territory will apply, including equipment available and any co-payments, eligibility, prioritisation, environmental need and waiting list conditions. The key principle will be that people should contact their current equipment scheme prior to moving to confirm what equipment can be taken.

Source: Correspondence with FaHCSIA.

This is not to say that some instances of national coordination have not been possible within the current governance model. Some good examples include the Australian Disability Parking Scheme and the National Companion Card Scheme, which are both nationally uniform, while still being administered by state and territory transport authorities. However, these represent coordinated efforts on singular issues, which are relatively simple when compared with the more extensive

suite of services. The harmonisation of parking permits alone took several years before agreement was reached.

A similar fragmentation is evident within jurisdictions, as services are delivered by a multitude of programs, funded and managed separately. Without links between these programs, people often deal with a number of programs and agencies to receive their full suite of services. For instance, an audit of NSW respite services found:

> The absence of a coherent system across the sector and barriers to the exchange of information between and within disability providers can cause delay. It also results in carers making multiple applications with, and undergoing multiple assessments from, a range of providers. (NSW Auditor-General 2010, p. 4)

Continual establishment of new programs and pilots also adds to the complexity. The separated structure also means that there is no coordinated effort to ensure programs do not have excessive overlap, or have gaps between them.

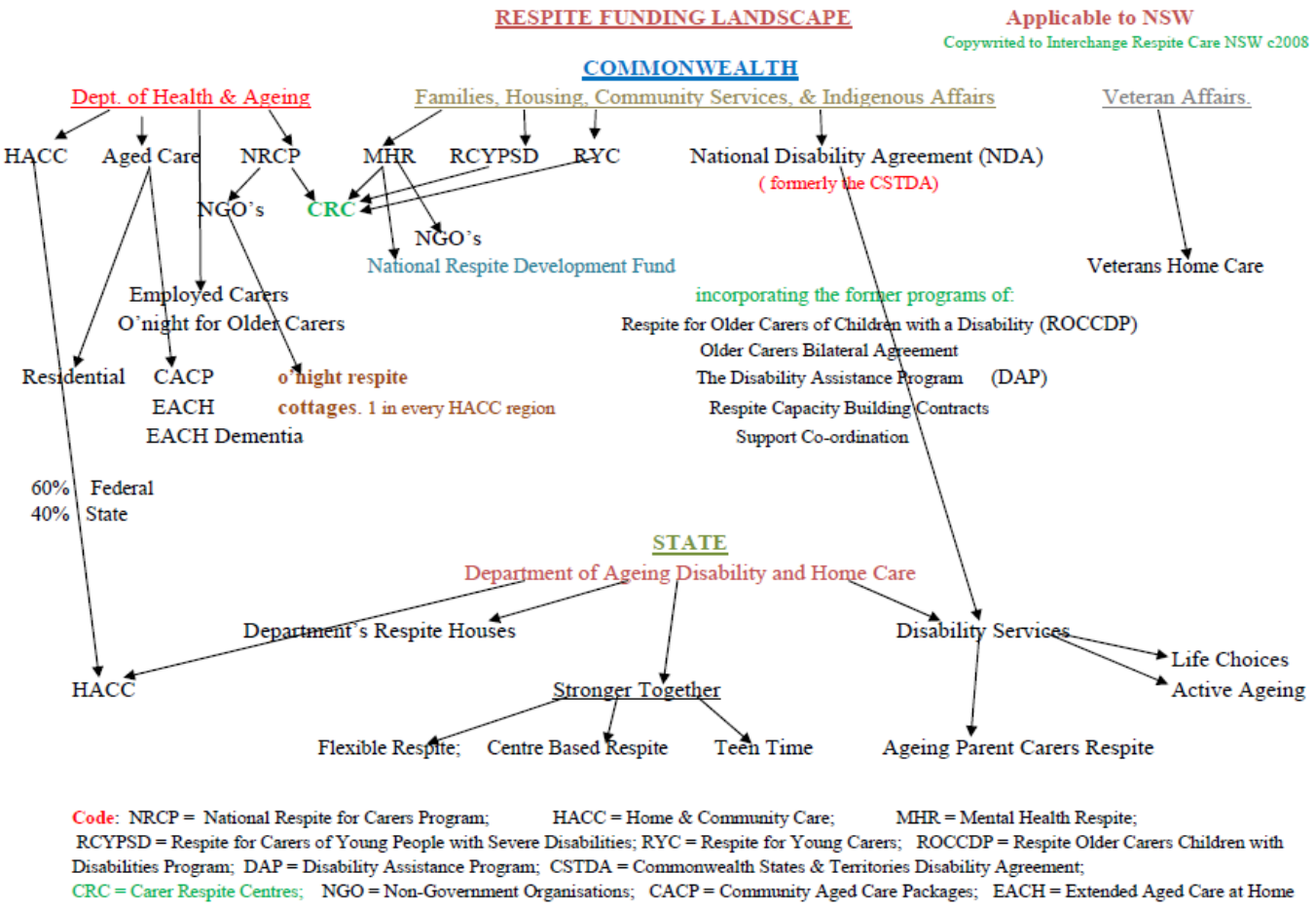
Navigating the maze

Accessing supports can be daunting for new entrants as they are confronted by services administered by local, state and federal governments and delivered by both public and private service providers. Figure 2.8 below shows how complicated the arrangements can be and this just shows respite care, one small section of disability support.

Often, there is no one to help navigate the system and as a result it is often difficult for people to determine what services exist, let alone whether they are appropriate or of high quality. Case management services can help in this navigation, however they are not always available (see chapter 8).

Gaining access to services is often a process of trial and error with large amounts of time spent researching and filling applications only to find out that a service is either not appropriate or not available due to limited funding. Not surprisingly, the system as a whole is often referred to as a maze. This creates large transaction costs, borne by the people who access the system. Worse still, they are borne not only by people receiving support, but also people still seeking support.

Figure 2.8 **Respite arrangements in NSW**



Data source: Interchange Respite Care NSW

> Whilst living in rural Victoria my daughter and younger son were assessed for services and support, by DHS, three times in six months. Each assessment consisted of twenty five pages to fill in (twice) and each time there was a change of coordinator thus requiring the next assessment, form filling in (twice) and still no services or support. We moved to Queensland six months after the last assessment (still no supports). To add insult to injury eight years later we received a letter from DHS Wangaratta informing us it was time to update support plans. A further two years later, and despite DHS having been informed that we now lived in Queensland, we received another reminder. After several years, many crises and much battling by degrees, we finally had some services and supports. (sub. 380, p. 1)

Thus, the duplication of assessment combined with general under-provision of services can mean that people receive more assessment than service. Assessment is discussed more fully in chapter 5, while transaction costs and potential solutions are discussed in chapter 8.

Effectively, transaction costs are heightened by the uncertainty at jurisdictional borders. People can spend considerable amounts of effort to secure supports, only to find that they could lose these supports by crossing state and territory borders. This leads to what are effectively barriers for people with disability, as described by several participants (box 2.4).

The importance of choice

Choice is important in many aspects of life: choice about jobs, where to live, how to spend one's time and what services to buy. In the latter area, 'consumer' choice is a way for people to signal what they value. However, choice is generally not a common aspect of the disability support system — many decisions are made by support workers, service providers and by governments. Choice in the disability system is discussed more fully in chapter 6.

Allowing people control over the decisions that affect their lives is important in its own right. Consumer choice also generally leads to more efficient outcomes, as people are usually better placed to know what would meet their needs than service providers. Consumer choice can also give service providers the incentive to innovate and provide higher quality services. In these ways, the lack of choice adds to inefficiency in the current disability support system.

Box 2.4 **The lack of portability is a real barrier in people's lives**

Several participants noted their personal experience of barriers to interstate portability of supports.

> Currently, if you are receiving services in one state and have to move interstate for any reason, you automatically go to the back of the queue. When you have waited for many years to gain access to services, you are basically trapped, especially if your son/daughter is part of a block-funded service. If, as a parent, you have the misfortune to fall ill and need to move or simply wish to retire interstate, you are in the invidious position of losing everything you have achieved over many years. The states must be able to reach some agreement over portability. We are one nation after all. (M. Dewar, sub. 317, p. 2)

> I have previously sought employment interstate to maximise my career development and opportunities. However, this was prevented by incompatible state-based disability support arrangements and an inability to transfer my current state-based disability equipment (wheelchairs, etc) and support hours to other Australian states. As a person with high support needs, I would have been unable to cover the costs of this support and equipment from my own income. This situation prevents me from moving interstate to take up career opportunities as financially I would be worse off than being on the DSP. (B. Lawson, sub. 103, pp. 2–3)

A lack of portability is not just an issue for people moving between jurisdictions. People are also concerned about losing their supports when moving between support programs.

> A significant issue facing people with blindness or vision impairment is the barrier preventing the transfer of equipment when they are undergoing periods of transition, such as primary school to high school, and school to work or post-school activities. When moving between different programs and/or funding environments, it is inefficient, unproductive and inequitable to demand that a person return customized and familiar equipment, and then go on a waiting list for new equipment (or simply have to manage without it). (sub. 438, p. 11).

The personal importance of choice

The concept of choice is central to the lives of many people with disability. It relates to the control they have over aspects of everyday life, such as when to go to bed and what to eat. The importance of these decisions are particularly apparent in the context of personal care.

> Having a disability is less about physical limitations, and more to do with a lack of choice. Everything in my life is very clinical, get up at this time, eat this time, have a shower at this time, go to bed at this time. Whilst I acknowledge this is and will always be the reality for my entire life a minimal [amount] of funding would allow me a great deal more freedom than I have access to now. The autonomy that a few more hours a week would give me should not be underestimated. (sub. 346, p. 1)

Even small degrees of decision-making power can lead to large improvements to a person's quality of life.

Block funding and consumer sovereignty

In the current system, the capacity for choice relates closely to the method of government funding of support services. Block funding is the process by which governments directly fund service providers with lump sum payments. These payments are then used by the providers to deliver support services. The alternative is 'individualised' or 'self directed' funding, where government funds can be given directly to service users to then purchase services. This would mean service providers receive funding only after being approached (i.e. chosen) by the service user. Various models are possible under these two broad descriptions, and it is possible for funding schemes to have elements of both approaches (chapter 6).

Block funding remains the dominant form of funding model, although there has been some movement towards providing the option of a more individualised approach. The potential advantages of a block funding arrangement include:

- service providers are known to government, and potentially more easily regulated
- certainty of funding for service providers, and more scope for large asset grants.

Concern has been raised regarding several aspects of block funding. It is often argued that it leads to a lack of consumer choice and to weaker market competition (see chapters 6 and 8 respectively).

By paying service providers directly, it is the government that makes the purchase. As a result, there is more of an incentive towards pleasing the government and less towards pleasing service users, since the government agency will decide whether or not to renew funding.

Block funding arrangements offer less scope for service users to take their 'portion' of funding and go to a new provider. This means that in the event of poor quality service provision, there may be no scope for service users to replace their provider.

> HACC funding is provided to the care service, out of which my funding is provided, in my case it goes to RCHCS. I have been supported by many years by such service. There have been times where I have had to suffer whatever this service provided or otherwise, quality care or otherwise, the ups and downs. There was no option, whatever this service provided, good and bad, and all in between, I had to wear it; I was in effect held hostage because I dare not depart for fear of losing funding support.

> There were times I became despondent. I do not intend to illustrate specific instances of bad care or good care. The fact is, I was held virtual hostage to one service because of HACC being the nature it is, not supporting portability. (sub. 120, p. 1)

Furthermore, an improvement in consumer choice may benefit service outcomes due to the natural asymmetry of information — service users generally know their preferences.

Opportunities for efficiency gains

Some of the most significant inefficiencies in the disability support system are clear opportunities to improve service outcomes, affordability, and the quality of life for service users. Several specific areas have been highlighted as inefficient in the course of this inquiry. While not exhaustive, the issues covered in this section are indicative of the kind of efficiency gains that could be achieved with a coordinated reform agenda.

Timely support that is forward looking

An important criticism of how disability supports are delivered is that they generally do not account for people's future needs. This is not surprising given that it is difficult for the system to provide enough support to even meet current needs. However, there are potentially large efficiency gains if assessments were forward looking (discussed in chapter 5) and the delivery of services were timely.

The timeliness of support can, for example, have a direct influence on the effectiveness of the support. In some cases, it can reduce or prevent further injury or ill health.

> Long delays in service provision often result in avoidable ill health which results in unnecessary presentations with trauma and other illness to tertiary hospital emergency departments (with or without an associated admission). Furthermore, long delays result in reduced independence and participation in the community and associated feelings of depression and helplessness. (Friedreich Ataxia Clinic, sub. 423, pp. 2–3)

People with disability and their families are sometimes able to contribute to the costs of supports, either in part or in full, in order to reduce waiting times. However this is often discouraged by poor incentives or uncertainty regarding their eligibility for subsequent reimbursements.

> In some cases public patients travel interstate and or visit a private provider and pay for the cost of the [prosthetic] limb up to $20 000 out of their own funds to avoid waiting times even though they are eligible for government funded prosthetics. In cases such as this individuals forego any opportunity for funding support. (sub. 301, p. 11)

In cases such as this, greater flexibility around copayments could lead to shorter waiting times.

In some instances, timely supports may potentially save money from the disability services budget over the longer term. A good example of this relates to pressure ulcers:

> While not all pressure ulcers can be prevented, many are caused by inadequate equipment, notably seating and mattresses. Providing the correct pressure relieving equipment is not optional for the individual, however the waiting times and limits on types of products make it so.
>
> It is common for people with MS with pressure ulcers unable to get the right equipment to spend up to 6 months in hospital recovering. Such a stay costs in the vicinity of $80-100 000, and can result in increased community care costs and carer burden upon discharge. The purchase of an $8000 mattress and good seating in addition to self management support can prevent such episodes. Saving just one hospital admission per lifetime for a person at risk of pressure ulcers justifies the investment. (National Aids and Equipment Reform Alliance, sub. 530, pp. 6–7)

Often these kinds of potential savings are not realised due to the separation between the service area that bears the cost and the service area that would benefit from the saving. At other times, aids and appliances are not available to take advantage of these benefits.

Supporting carers' employment

There is considerable potential to encourage carers' employment. Any improvements in care and respite support would clearly improve the ability of carers to participate in the workforce. However, a more direct approach may also help to ensure that incentives are not misaligned. For instance, high effective marginal tax rates, as well as inflexibilities regarding current transfer payments, may reduce the incentive to participate in paid work:

> There is no capacity for dividing Carer Payment as an incentive to sharing the care between more than one person; income and assets tests are based on couple rather than individual income.
>
> For Carer Payment recipients, the 25 hour maximum work, care or study and travel rule may result in a reluctance to loose income security and health card benefits. (Carers Victoria, sub. 475, p. 23)

Similar issues regarding other transfer payments, such as the Disability Support Pension (which supports around 793 000 people), may deliver large and widespread efficiency gains. That is not to say that either people with disability or their carers

should be forced into the labour force. Rather, those who would like to work should not be discouraged by these policies.

Improving data systems

Several areas of governance, regulation and research could benefit from greater collection and availability of data. Currently, the availability of data in the disability sector is not sufficient, especially given its importance to efficient management and policy development. As characterised by the Insurance Council of Australia:

> … there is a lack of robust actuarial data in regards to the cost of care. There is also a lack of data concerning the prevalence of the various disabilities potentially covered by the scheme. (sub. 553, p. 15)

Data in all areas of disability could be improved, particularly data on the experiences and outcomes of service users, on unmet need, and on the costs and efficiency of providers (see subs. 270, 237, 371, 571 for example). The current deficiencies in data collection are discussed fully in chapter 10.

The scope for data collection has sometimes been reduced by concerns about people's privacy. Under the Home and Community Care (HACC) scheme, the emphasis on *needs based* supports involves a decision not to collect information regarding the cause of disability. This protects from the potential for support allocation to become *condition based*, but at the same time limits the potential for management, research and policy development.

Often, the absence of data collection is not a deliberate decision, rather it is a continuation of historical practice. For instance, with regard to NSW respite:

> AHDC does not maintain information on how NGOs prioritise clients and allocate respite. Under the funding agreements established before 2006, NGO's determined who they give respite to and how much they give. (NSW Auditor-General 2010, p. 13)

Clearly, the lack of data systems has important implications for transparency and efficient management. As a result, NSW ADHC is to implement an online booking system for respite in 2011, which will 'consider client mix and staffing requirements to maximise occupancy and ensure quality of care' (NSW Auditor-General 2010, p. 13).

Moreover, the current system structure does not lend itself to the collection of data across different support programs, different regions or different jurisdictions. A more coordinated delivery system, or perhaps better coordination between current administrative systems, could lead to more comparable and valuable data. The possible role of the NDIS in data collection is also discussed in chapter 10.

2.6 Conclusions

People with disability and their families often experience severe social, financial and personal disadvantage over their whole lives. While some of this is due to disability in the first place, much is also due to the dysfunctional nature of the 'system' providing them with support. The problems in the system appear to be so widespread and severe, that effective large scale reform is justified.

One solution would be additional funding to address the high level of unmet need, but it is clear that underfunding is not the only contributor to the poor outcomes of the system. Several systemic inefficiencies are also responsible for the lack of support, as well as constraining people's decisions on where (and how) to live. The inefficiencies often stem from structural elements of the system. Broad structural change is as important as adequate funding in improving outcomes for people with a disability and their families.

3 Who is the NDIS for?

Key points

- The Commission proposes that the NDIS have three main functions and associated with them, three different populations of 'customers':
  - minimising the impact of disability by promoting opportunities for people with disability and creating awareness of the issues that affect people with disability
  - information and referral services
  - provision of funded individualised supports.
- All Australians would be potential beneficiaries of the first tier of services, while the second tier is targeted at all people with, or affected by disability. The third tier is targeted at people with support needs that would otherwise not be reasonably met without taxpayer funding, and that are not more appropriately met by other systems, like the National Injury Insurance Scheme and the healthcare system.
- A person getting individualised support would have a permanent disability, (or if not permanent, expected to require very costly disability supports) and would meet *at least one* of the following conditions:
  - have significant limitations with communication, mobility or self-care (3a in figure 1) and accounting for about 225 000 people
  - have an intellectual disability (3b) (about 50 000 people not included in 3a)
  - be in one of two early intervention groups (3c) (about 80 000 people). One group would be those for whom there was a reasonable potential for cost-effective early interventions that would improve their level of functioning (as in autism, acquired brain injury, cerebral palsy and sensory impairments). The other would be those with newly diagnosed degenerative diseases, such as Multiple Sclerosis and Parkinson's disease, for whom early preparation would enhance their lives.
  - have large identifiable benefits from support that would otherwise not be realised. This takes account of the difficulties in slotting everyone into the specific groups above. Guidelines would inform the use of this last criteria.
- There would be significant overlap between the categories. A substantial number of people with intellectual disability would for example, also have significant limitations with communication, mobility or self-care.
- While those accessing funded supports (around 360 000) would be a fraction of those people who access (or are the targets of) tiers 1 and 2, the overwhelming costs of the NDIS will relate to tier 3, and it is here where good governance will be critical to ensure high quality supports and scheme sustainability.

3.1 Introduction

The Australian Government is committed to enhancing the quality of life and increasing economic and social participation of people with disability. It is against this backdrop that the Commission has considered the functions and potential users of a National Disability Insurance Scheme (NDIS).

People with disability have different needs and aspirations and encounter different barriers. So different approaches for realising participation and quality of life goals are appropriate for different people. More inclusive social attitudes, having more accessible buildings, more disability inclusive education and employment policies, and addressing deficiencies in the health care system, will assist many people with disabilities. They may be all that is needed by many people with less restrictive disabilities.

For others, information and referral services may substantially increase their wellbeing. For a smaller subset of people, often those with more severe disabilities, individually tailored, funded supports may be the key to increased social participation and an improved quality of life.

Given this diversity, the Commission proposes that the NDIS have a number of functions, each aimed at achieving better outcomes for different groups of people.

3.2 A tiered approach to providing supports

The Commission considers that the NDIS should have three main functions, and associated with them, three different populations of 'customers' and costs (with the costs inversely related to the size of the populations concerned) (figure 3.1).

Tier 1: Absolutely everyone

In one sense, the NDIS is for every Australian, since it provides insurance against the costs of support in the event that they acquire a disability. Insurance is valuable, even if someone does not make a claim. (Many people for example, insure their house against loss. Most never make a claim, nor do they expect to, but they willingly pay premiums each year to cover the risk). People in the community could take comfort in knowing that a strong support system exists for their loved ones if they were ever to need it.

An important role of the NDIS would also be to minimise the impacts of disability. This includes:

- promoting opportunities for people with disability
- creating awareness within the general community of the issues that affect people with disability and
- drawing on its data and research capabilities to engage with other agencies to improve public health and safety.

In the awareness area for example, the NDIS could recognise and encourage employment of people with disability and try more generally to combat stereotypes that reduce opportunity. The potential benefits of a more inclusive society also extend to the wider community, including to employers. While the 'tier 1' function would involve the whole community, the costs associated with this function would be very small and in some cases would come from existing resources.

Tier 2: People with, or affected by, disability

Anyone with, or affected by, disability could approach the scheme for information and referral services (as distinct from individually-tailored funding). This would include providing linkages with relevant services for which the NDIS was not directly responsible, such as mainstream services and community support groups. The scheme would also provide general information about the most effective care and support options. However, it will be critical to provide any referral and information services cost-effectively, with strict cost limits. As in tier 1, the population of potential 'customers' would be very high, but the overall costs would be small.

Tier 3: People with disability for whom NDIS-funded, individualised supports would be appropriate

Individualised supports, provided under tier 3, would be targeted at people with support needs that would otherwise not be reasonably met without taxpayer funded services. The extent of the funded support would depend on:

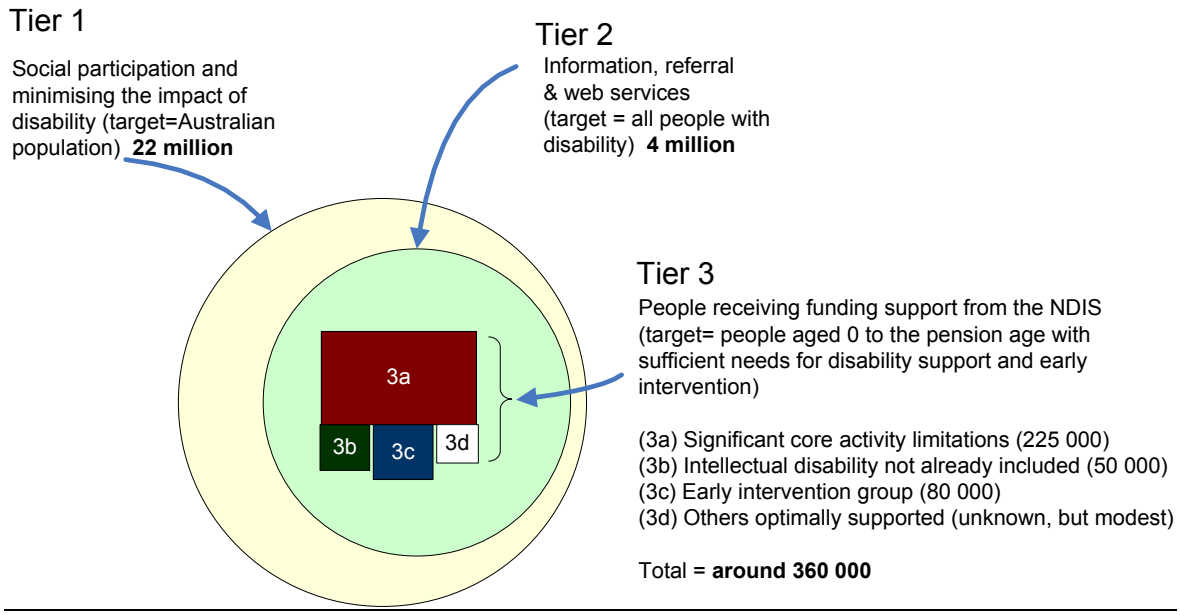
- assessment criteria that would identify whether there was a need for NDIS-funded support
- given the existence of sufficient needs, a careful assessment process that would determine the nature and levels of supports, and the individual budget required to fund those supports.

These assessment processes would not be ad hoc, but would reflect the framework for categorising disability (the International Classification of Functioning, Disability and Health) and would provide objective assessment of the types of needs that

require funded support. (The exact assessment arrangements and their underlying framework are addressed in chapter 5.)

The number of people accessing funded supports would be a small fraction of those people who access (or are the targets of) tiers 1 and 2. Even so, this tier will account for the majority of scheme costs.

Figure 3.1 **The three tiers of the National Disability Insurance Scheme**



This chapter considers a range of practical issues that affect how the three tiers of the NDIS would operate. Section 3.3 considers the role of the scheme in respect of minimising the impacts of disability. Section 3.4 outlines the scheme's role in assisting individuals to navigate the spectrum of mainstream and specialist services both public and private.

The remainder of the chapter is dedicated to the design of tier 3 — the provision of NDIS-funded, individualised supports. Accounting for a significant majority of the scheme's budget, the design of tier 3 will be particularly important and will need to canvass:

- assessment criteria for funded support, including how to ensure that the scheme takes full advantage of opportunities for cost-effective early interventions (section 3.5)
- the role of the NDIS compared with other government services used by people with disability, such as those for aged, health, mental health and palliative care and the proposed National Injury Insurance Scheme (section 3.6)
- how many people might access individualised supports (section 3.7)

- practical issues that affect the transition to a new scheme (section 3.8).

The more elaborate assessment process that would determine the nature and levels of supports, and the individual budget required to fund those supports is covered in chapter 5.

3.3 Tier 1 — minimising the impacts of disability

Public campaigns that promote opportunities for people with disability have the potential to benefit the entire Australian population. Currently, broad disability awareness campaigns are carried out by several bodies including government departments and agencies, and non-profit organisations. The NDIS would not duplicate the campaigns provided elsewhere (box 3.1). Rather, where appropriate and where it saw an advantage in doing so, it would provide information to the government and non-profit organisations running public campaigns.

In some instances, the NDIS would be best placed to fund and carry out such programs directly. This would constitute a very small proportion of the scheme's budget.

Societal attitudes, awareness and inclusion

It has often been stressed that aside from direct support, what people with disability require is greater acceptance in society on a day-to-day basis. This was a major theme of the Shut Out report (Australian Government 2009) which contributed to the National Disability Strategy.

> Lack of social inclusion and the multiple barriers to meaningful participation in the community faced by people with disabilities were the most frequently raised issues in the submissions and consultations. More than half the submissions received (56 per cent) discussed the experience of exclusion and the impact of negative social attitudes on the lives of people with disabilities and their families, friends and carers. (p. 12)

Several participants in this inquiry noted that societal attitudes are a major influence on a person's ability to participate in daily life (box 3.2). The Commission recognises that societal attitudes and practices are potentially just as disabling as the conditions themselves. In this sense, influencing attitudes and practices in society may be one of the most significant roles of the NDIS, outside of its role of directly providing much needed supports.

Box 3.1 **Disability campaigns for awareness and inclusion**

Public initiatives

- The Don't Dis My Ability campaign promoted awareness and appreciation of people's *abilities* rather than their disabilities. Both confronting and inclusive, it used real people to challenge misconceptions of helplessness. The campaign used print and television commercials and arts events, as well as various ambassadors both with and without disability. The face of the campaign — *First Flight Crew* — was a breakdance troupe made up of people with various disabilities.
- The Prime Minister's Employer of the Year Awards recognise employers who excel in employing and retaining people with disability. The awards also promote the efforts of employment service providers which are organisations that help people with disability gain and keep a job.

Private initiatives

- The Australian Network on Disability (AND) is a non-profit organisation comprised of employers who are committed to greater awareness and inclusion of people with disability. AND is resourced by its diverse membership of over 100 organisations, such as Westpac Group, IBM Australia, Compass Group, the Children's Hospital at Westmead, and the Australian National University.
  - An example of the initiatives by AND members are awareness strategies by McDonald's, where disability awareness training is integrated into corporate policy and all levels of employee education. The awareness covers both the needs of employees and those of customers.

International examples

- The New Zealand Government announced in 2010 that it would invest NZ$3 million over three years into a campaign to improve the lives of people with disability by 'changing the attitudes and behaviours that limit their opportunities'. The program will involve partnerships with employers, human services, community organisations and the media. Consultation undertaken for the development of the New Zealand Disability Strategy identified negative attitudes, at all levels of daily life, as the major barrier to inclusion and participation in society.

The NDIS is likely to be a valuable vantage point for both widespread general campaigns and more targeted messages on awareness and inclusion. Given its connection with a wide range of people with disability, it would be well placed to seek information and feedback on people's experiences of social inclusion. It may then be possible for the NDIS to direct such campaigns to areas where problems of discrimination are common or to find and promote examples where inclusion has clear beneficial outcomes for both parties. In practice, this may involve working with other agencies such as the Australian Human Rights Commission.

Box 3.2 The personal importance of societal awareness and inclusion

A number of participants in this inquiry remarked that societal attitudes are a major influence on a person's ability to participate in daily life.

> There would clearly be roles for institutions administering a NDIS in relation to awareness raising and attitude change pursuant to article 8 comparable to roles of other social insurance agencies such as OHS and motor accident authorities … For example, organisations in the mental health area have described a large scale awareness program comparable with road safety campaigns as a necessary equivalent in providing community inclusion for people affected by mental illness to processes of installing level or ramp access in providing for participation by people with physical disability. (Australian Human Rights Commission, sub. 72, p. 19)

> … any new scheme must recognise that the person with disability is not the problem nor "burdensome" but rather that it is the social impacts of living with disability – societal barriers, prejudices and attitudes, as well as lack of supports – which cause burden. (Queensland Parents for People with a Disability, sub. 262, p. 3)

> Indeed, perhaps educating the public through such avenues as disability advocates raising disability awareness in local communities could be important in reducing stigma, and may help to reduce barriers to participation for people living with disabilities. (Korey Gunnis and Laurie Strathdee, sub. 132, p. 4)

> The social model of disability proposes that barriers, prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who is disabled and who is not in a particular society. It recognizes that while some people have physical, intellectual, or psychological differences from a statistical mean, which may sometimes be impairments, these do not have to lead to disability unless society fails to accommodate and include them in the way it would those who are 'normal'. (Mental Health Coordinating Council, sub. 263, p. 2)

The NDIS would also be well placed to recognise and encourage the inclusive practices and initiatives of private enterprise. The NDIS could for example, publicise examples of inclusive, non-discriminatory environments and their outcomes. This work may involve coordination with the Department of Education, Employment and Workplace Relations, as they will continue to deliver most disability employment supports.

Awareness of the scheme and its staged roll out

The general community, people with disabilities and their carers, and service providers will need to be informed about the new scheme. A public information campaign will need to occur before the commencement of the scheme. Given that the NDIS will effectively provide insurance cover to everyone, it would be important for people to understand their own coverage. For people seeking information, referrals or funded assistance, they will need to know what services are

available from the NDIS. The NDIS should work with disability organisations to promulgate messages about the scheme through their own networks. Information sessions held for stakeholder groups would inform them of the new scheme and the staged rollout. Information would be made available to support groups and through a range of publications, free media and contact points such as Post Offices, Centrelink offices, Medicare offices, medical practices and health centres.

3.4 Tier 2 — ensuring appropriate support from any system

The current system of disability services has often been described as a maze (notably, the Association for Children with Disability's guide to services and support is entitled 'Through the Maze'). Even within a jurisdiction, people deal with a multiple of programs and agencies, few of which coordinate or share information (chapter 2).

Bringing specialist disability services under a single umbrella — the NDIS — will go a long way to streamlining the system. But regardless of the size and scope of the NDIS, it will always be just one part of a broader suite of services that are potentially relevant to people with disability. There will for example, continue to be a need for mainstream services such as in the areas of health, housing, education, transport and employment. Community support groups will also continue to play a valuable role. As such, information and referral services are likely to be of great value to people with disabilities, their families and carers.

For all the services that the NDIS is not directly responsible, the Commission proposes that the scheme would provide information on available services to allow people to more easily connect with appropriate services. The information provided should match people's needs and locality to providers and organisations, though would not be qualified the same way that a GP's referral would. One aspect of this — discussed in chapters 8 and 10 — is a centralised electronic database of service providers that would indicate the ranges of products and services, availability and links to measures of performance and quality (draft recommendation 8.1).

The scheme should also provide more general information about specific disabilities including their expected impacts and the most effective care and support options. Some participants in this inquiry commented that they did not have adequate information on which to base decisions. Others reported spending considerable time and effort undertaking their own research. As one participant in the Canberra hearings observed:

> In the weeks after diagnosis, families are asked to make these massive clinical decisions … families have to come to grips with all of this material and try and make these decisions for themselves without being given — you know, they don't have the skills to read the research and understand what it's about and yet that's the only way that they have any chance of actually dealing with this. So what we need to do is actually have centres that actually offer all of the reasonable options and give parents the real information in an unbiased way. People who are not involved in particular ideologies about how to deal with disability need to be actually giving the information to families and then the families can make the choices. (Bob Buckley, trans., p. 377)

A maze with extra barriers

Finding the most appropriate services, support groups or organisations is often made more complicated by cultural barriers. This was noted in both the Shut Out report (Australian Government 2009) and in submissions to this inquiry:

> For families from different ethnic backgrounds, the issues are compounded. Many people from different ethnic backgrounds are not aware of their rights — to benefits, services, supports or respite. Due to the isolation felt by many carers and people with a disability from different ethnic backgrounds, language barriers or low levels of English proficiency still mean that these families do not access information and are unaware of what is available. (Australian Government 2009 p. 57)

> [A] targeted promotion strategy aimed at people from NESB [Non-English Speaking Backgrounds] with disability is needed to ensure that awareness of available support and programs is increased. This is particularly necessary when the new scheme is introduced. (Multicultural Disability Advocacy Association of NSW, sub. 604, p. 18)

The provision of information and referral services should take account of cultural and lingual diversity, for example by working with existing community liaisons, particularly in non-English speaking and Indigenous communities. The importance of these contacts would be paramount during the implementation of the NDIS, as well as any other time of service and scheme reform.

Information and referral processes should be available to anyone with, or affected by, disability.

3.5 Tier 3 — individually tailored funded supports

The terms of reference for the inquiry indicate that the scheme is not intended to address the *care and support* needs of all individuals, but rather should focus on those where such needs are greatest.

Such a focus is consistent with the fact that risk-pooling through insurance tends to focus on higher-cost, less frequent events, like early death, serious injury and property loss. Many families and individuals have an ability to bear and finance some risks themselves, and this is often a more efficient and flexible way of addressing smaller and more common risks than formal risk pooling through insurance.

Of the 3.8 million people with a disability living in households, some 39 per cent reported that they do not require assistance (ABS SDAC 2003).[1] For others, the supports provided under tiers 1 and 2 of the NDIS will be all that is needed. To that extent, it is not credible that the true potential population for individually tailored, NDIS-funded supports amounts to 4 million — though as we discuss later, it could well exceed the existing population of people receiving publicly-funded services.

Hence, in contrast to the other tiers of the NDIS, the delivery of individualised, funded support under tier 3 of the scheme would be targeted at a subset of individuals. They are people whose support needs:

- would otherwise not be reasonably met without NDIS-funded services and
- are not more appropriately met by other systems, like the National Injury Insurance Scheme or health care.

The question of whether the support needs of some individuals are best addressed by other systems is examined in the following section. The remainder of this section grapples with how to translate the first notion into workable and 'balanced' assessment criteria.

On the one hand, the assessment criteria will need to be clear and precise. If the NDIS used wide or vague criteria for individualised, funded support it would create inconsistencies, divert resources away from greatest need, undermine community acceptance of adequate public funding and threaten scheme sustainability. But on the other hand, the criteria should not be unduly prescriptive, such that individuals who did not neatly 'slot' into categories missed out on much needed supports.

Using severe and profound as a basis

The terms of reference for the inquiry indicates that the scheme is broadly intended to address the long-term care and support needs of individuals with a 'severe and profound' disability. However, it does not indicate what criteria would need to be met in order for someone to be regarded as having such a disability. That said, the

1 The equivalent data are not yet available in the most recent SDAC.

ABS employs these terms in its Survey of Ageing, Disability and Carers (SDAC), as follows:

Profound core activity limitation: where a person is unable to do, or always needs help with, a core-activity task (communication, mobility or self-care).

Severe core activity limitation: where a person sometimes needs help with a core-activity task; has difficulty understanding or being understood by family or friends; or can communicate more easily using sign language or other non-spoken forms of communication.

While the terms severe and profound, as used by the ABS, are suggestive of high-level disabilities, this is not necessarily the case. For example, the ABS definition of *severe* would capture the following individuals:

- person 'A' who has a bad back that flares up once every six months and so needs occasional help getting up out of a chair
- person 'B' who has asthma and while having an attack is unable to communicate
- person 'C' who suffers from migraines two to three times a year, and when they occur, can do little else but retire to bed, until the migraine passes.

These are all rated as 'severe' since they 'sometimes' need help with 'core' mobility, communication or self-care activities. But these individuals would not be considered likely candidates for individualised supports. While the limitations they experience relate to 'core activities', given their frequency and intensity, they could nonetheless be self-managed (perhaps assisted by family or friends), or addressed by other publicly funded services such as those provided by the health sector.

In contrast, the ABS would not categorise around 40 per cent of individuals with intellectual disability with life-long care and support needs as having a severe or profound disability (AIHW 2008). While they do not face a specified core activity limitation, their actual capacity to participate in society may be lower than those identified as having one.

As noted by the AIHW:

> People with intellectual disability encounter special challenges that are different from people with other types of disabilities in a number of important aspects. For example, they have difficulty learning and applying knowledge and in decision making. They may have difficulty identifying and choosing options at key life transition points. They often have difficulty adjusting to changed circumstances and unfamiliar environments and therefore need high support during times of change.
>
> Need for help with core activities may not fully reflect the level of support that an individual with intellectual disability requires to participate in society. Even though

> they may function relatively well in the familiar routines of self-care and domestic life, and be independently mobile … It is therefore important to also consider the level of support that is needed in non-core activity areas, especially making friendships, maintaining relationships and interacting with others (pp. 1–2).

These views were echoed by the NSW Council for Intellectual Disability:

> We think that support is really important for transitions and life changes. This is when big changes in your life happen. It might be moving from one stage of life to another. Or it might be moving from one type of support to another. Some examples of life changes are: Moving from school to work; Moving out of home; Learning how to deal with loss. (sub. 546, p. 11)

This does not mean that assessment criteria for the provision of individualised supports should disregard the notion of core activity limitations. But rather, that existing ABS definitions are intended for classification purposes and are unlikely to equate with people's usual understanding of severe and profound or be an appropriate definition for access to such services.

A further limitation of adopting an ABS-based definition of severe and profound relates to the expected duration of the disability. The current definition of disability covers people whose limitations are expected to last more than six months, and so would include people with disabling conditions that last for relatively short periods. For example, the ABS classifies around 2000 women with a menopausal disorder as having a disability (ABS 2003). However, this condition tends to be relatively short-lived, with symptoms lasting from several years to a month.

Further, there may be risks that characterising people with shorter-term core limitations as 'disabled'. Labelling a condition a disability and treating it as such might prolong recovery. A number of studies have found that positive expectations about recovery are associated with better health outcomes for a number of conditions, even after controlling for symptom severity (see for example, Gross and Battié 2005 and Turner et al. 2006).

Using existing state and territory definitions of disability

State and territory definitions of disability (for the purposes of identifying potential service users) are slightly more nuanced, as is the definition employed in the (now superseded) CSTDA. (The current inter-governmental agreement covering disability services, the National Disability Agreement, contains no such definitions.)

In addition to requiring that individuals have a *significantly* or *substantially* reduced capacity in a number of areas, typically communication, self-care, learning and mobility, the reduction in capacity must also give rise to a 'need for support'. Most

jurisdictions go further and specify that the need for support must be 'continuing', 'ongoing' or 'long-term'.

While Tasmania, the Northern Territory and the ACT only make reference to communication, learning and mobility limitations, the remaining jurisdictions take a broader perspective, adding variously, self-care, self-management, decision-making and social-interaction. South Australia takes a slightly different approach, covering those individuals who experience: *'significantly reduced functioning in most of the following areas: communication; self care; mobility; community access; health and safety; domestic activities; social; self direction; work and leisure'* (Disability SA 2008). Such definitions might better capture individuals with intellectual disability whose support needs may relate to non-core activities. In contrast, Victoria makes separate, distinct provision for those with intellectual disability (Disability Services Division (Victoria) 2009).

All States and Territories include some reference to permanence in defining disability for the purposes of their respective Acts, typically represented as 'permanent or likely to be permanent' that 'may or may not be of a chronic episodic nature'. South Australia goes on to say 'and is not likely to resolve with medical treatment', while Queensland provides the following guidance:

> … permanent or likely to be permanent refers to the irreversible nature of the disability, even though it may fluctuate in severity over time — that is, it may be of a chronic episodic nature (Disability Services Queensland, Eligibility Policy, p. 2).

State and territory definitions are a useful starting point — they take broad account of the nature, frequency, intensity and duration of care and support needs. However one major limitation is that they place undue emphasis on an individual's present state of functioning. The remainder of this section discusses the benefits of a more forward looking approach.

Capturing the gains from early intervention

The Australian Government regards a focus on early intervention as an important contribution to the National Disability Strategy. The Commission, as part of this inquiry, has been asked to examine options that provide incentives to focus investment on early intervention. Such an approach is consistent with the 'Wellness approach', which focuses on optimising an individual's functional and psychosocial independence with a view to achieving positive and long reaching benefits.[2]

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2 An overview of the wellness approach is included in the report 'The Active Service Model: A conceptual and empirical review of recent Australian and International literature (1996-2007)' authored by the Australian Institute for Primary Care.

By focusing on an individual's present state of functioning and/or the current resources of government, opportunities to help avoid rising levels of need and costs at a later stage are often ignored. As the Victorian Government observed:

> Incorporating a strong commitment to early intervention will need to address a number of challenges, particularly in relation to eligibility boundaries and cut-offs. Individuals with degenerative conditions, for example, may not qualify for support initially if the scheme is limited to people who have catastrophic, severe or profound disability. Early intervention, however, could assist in delaying deterioration of their condition and therefore reduce the downstream support needs. Similarly early intervention for those children and young people with congenital disabilities supports improved outcomes and supports families. (sub. 537, p. 18)

This view is consistent with experiences in the United Kingdom, where there is some evidence to suggest that when access to individually funded social care services is restricted to only those with the very highest needs, it leads to a short-term dip in the number of people eligible for social care, followed soon after by a long-term rise (Commission for Social Care Inspection 2008, p. 41).

Few states and territories include specific early intervention criterion, though in practice they are pursuing this as a policy direction (chapter 11). The South Australia Government reports that it extends access to disability services to children under five years with a significant global developmental delay (Disability SA 2008). The Victorian Government advises that it also makes provision for children with a developmental delay (Disability Services Division (Victoria) 2009). (Services for this group are also the responsibility of the Victorian Department of Education and Early Childhood Development and form part of a comprehensive program of early childhood services.)

People often equate early interventions with interventions that occur in the first few years of life or when a disability first arises. However, early intervention can also involve making investments around specific transition points, such as leaving school or home, or entering the workforce.

Bringing it all together

Assessment criteria should use the mixture of indicators that best measure support needs. Sometimes these will be functional measures, sometimes condition-based measures, and sometimes hybrid approaches. Functional definitions of 'mild' disability encompass a very broad group, many of whom would not require NDIS-funded supports. However, as noted earlier, some people categorised as having a 'mild' intellectual disability would benefit from some ongoing support in areas such as interpersonal relations, learning, work, accommodation and community life.

Combining functional and condition-based criteria can sometimes identify the group needing help better than using functional tests alone, despite the latter's apparent theoretical elegance. Having regard to this, and the need to provide for cost-effective early interventions, the Commission has developed the following assessment criteria:

A person getting funded support would have a permanent disability (or if not permanent, expected to require very costly disability supports) and would meet one of the following conditions:

- have significant limitations in communication, mobility or self-care (3a in figure 3.1)
- have an intellectual disability (3b)
- be in an early intervention group (3c). This would include two groups of people. One group would be those for whom there was a reasonable potential for cost-effective early therapeutic interventions that would improve their level of functioning (as in autism, acquired brain injury, cerebral palsy and sensory impairments). The other would be those with newly diagnosed degenerative diseases, such as Multiple Sclerosis (MS) and Parkinson's disease, for whom early preparation would enhance their lives. For instance, assisting in retaining bladder control can benefit people with worsening MS.

A research arm of the agency overseeing the NDIS — the National Disability Insurance Agency (NDIA) — would build an early intervention evidence base to guide the development of protocols governing the optimal intensity, timing and duration of interventions. In many cases, this would involve other key stakeholders such as health departments and research institutions.

As is usual for most taxpayer-funded services in Australia, the NDIS would not provide individualised funding for people who are not permanent Australian residents.

Safety nets

As noted earlier in this chapter, the assessment criteria should be clear and precise without being unduly prescriptive such that individuals who did not neatly slot into categories missed out on much needed supports and services. The Commission has tried to cast assessment criteria (3a through 3c) as clearly as possible, so that potential users know if they are likely to receive funded supports. But it is hard to anticipate all of the circumstances under which it would be appropriate for the

NDIS to provide individually-tailored, funded supports let alone capture them in three relatively simple criteria.

The Commission considers that there needs to be sufficient flexibility, albeit with concomitant checks and balances to ensure sustainability, so that the scheme has the scope to provide people with individualised supports where it makes sense to do so. That is, when:

There are large identifiable benefits from support that would otherwise not be realised.

This fourth criterion is intended to be used in a discretionary, rather than routine manner. Indeed, such a broadly cast assessment criterion could undermine the sustainability of the scheme if not administered well. Hence, the Commission also recommends the development of some clear guidelines around its use.

Among other things, the guidelines should directly address how to ensure that the criterion's use would not compromise scheme sustainability. At its simplest, the guidelines might call for annual reporting on the criterion's use and the associated costs. More comprehensive approaches might require that the NDIA weigh up the costs and benefits of using the criterion on a case by case basis.

Initial assessment could often be simple

Assessment should be multi-tiered, with the ultimate goal of directing people to the right supports, inside or outside the NDIS, and where inside, the quantum of support. A short upfront assessment module would establish whether an individual would benefit from funded support. In many cases, this stage would be waived for:

- individuals who unambiguously experience significant limitations in mobility, self care and or communication, such as those with quadriplegia, or
- where the scheme had already identified opportunities for cost-effective early interventions across a group of individuals.

Having an initial assessment would reduce the overall costs of detailed follow-up assessment, as the NDIS would not be the appropriate source of support for some people.

3.6 Taking account of the broader context of service delivery

Not all individuals who meet the criteria will receive individualised support from the scheme. For example, some will be supported by palliative or aged care, others will be captured by the 'sister scheme' of the NDIS, the National Injury Insurance Scheme (NIIS). It will be important to make clear where these boundaries lie. The Commission proposes that the NDIS proactively seek memoranda of understanding with the health, mental health, palliative and aged care sectors, so that individuals do not 'fall between the cracks' of the respective schemes.

Intersection with accident-based schemes

As noted in chapter 16, the Commission recommends the creation of a National Injury Insurance Scheme (NIIS). Given the timeframe for transition to any coherent injury scheme and other practical reasons the Commission considers that the NIIS should be (initially) run parallel to, rather than incorporated into the NDIS. The NIIS would cover catastrophic injuries, including those related to motor vehicle accidents, medical treatment, criminal injury and general accidents within the community or at home. (The Commission has also flagged arrangements for state and territory governments to transfer the care and support of catastrophic workplace claims to the NIIS through a contractual arrangement with their respective workers' compensation schemes. This reflects the fact that the incidence of catastrophic injuries under Workcover schemes is low and that their systems are not well geared to provide coordinated lifetime care for such cases.) These individuals would not therefore receive individually tailored supports from the NDIS. Those individuals covered by no-fault, non-catastrophic Workcover arrangements would also be excluded, as these appear to operate reasonably well in each jurisdiction and reforms are already underway in the areas where changes are needed.

Aged care is a particularly important parallel support system

A large group of people with a disability will get their support through the aged care system rather than the NDIS or NIIS. While in the main, the clients of the aged care system are people who acquire a disability because of natural ageing, the system also currently funds and supports many older people who acquired a disability prior to the pension age.

Drawing the exact boundaries between the responsibilities of the two systems is not straightforward. Medical conditions are not a robust basis for differentiation, as

some ageing-related conditions can also be important sources of disability among people aged less than 65 years. For instance, of the people with a severe/profound core activity limitation, around 31 000 people aged between 0 and 64 years report stroke as a health condition compared with 126 000 people aged 65 years and over.[3]

Moreover, while there are many similarities between the conventional disability system and the aged care system, there are also many differences, such as in philosophy, employment and participation goals, the duration of care and support, and the areas of greatest competence (such as management of dementia). As an illustration, many people in the disability system aspire to employment, which is not a priority for most people experiencing ageing-related disability. These differences suggest there are grounds for two distinct, but linked systems.

There are also differences in fair and efficient financing sources, which would be confused were the systems to be fully integrated. There are strong grounds for people who have accumulated significant lifetime assets prior to the pension age to contribute financially to their own *aged care* — the likelihood of disability in old age is high, can be anticipated, and people can save to meet those costs. Making people who acquired their disability when young pay for their care and support needs *before* the pension age would fail to meet the equity and insurance rationales for the NDIS and NIIS. Any such expectation would discourage employment and saving by young people with a disability.

While the two systems should not be integrated, they nevertheless have to interact efficiently and meet people's reasonable preferences. The critical issue is to ensure that people would be able to use the support system that best met their needs, regardless of the funding source.

The Commission is proposing that upon reaching the pension age (and at any time thereafter), a person with disability could elect to stay with the NDIS or move to the aged care system. A younger age threshold would apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

- If a person elected to move to the aged care system, then they would be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches).
- If a person elected to stay with the NDIS, their support arrangements would continue as before, including any arrangements with Disability Support Organisations, their accommodation, their case manager or their use of self-directed funding. For example, someone who managed their budget using the

[3] These data are drawn from the 2003 SDAC, comparable data are not yet available from the most recent SDAC.

NDIS framework for self-directed funding would be able to continue doing so after reaching the pension age, rather than trying to use the aged care system, which might have different rules and kinds of support. Similarly, someone who had developed a rapport and trust with a local case manager in the NDIS would not have to change to new managers in the aged care system.

- *Either way*, after the pension age, the person with a disability would be subject to the co-contribution arrangements set out by the Commission in its parallel inquiry into aged care. In most instances, the caps and means tests applying to those co-contributions would mean people who acquired a disability early in their life would not have to pay anything (PC 2011, chapter 6 and appendix D). However, some people who acquired a disability say just prior to the pension age may have built up sizeable assets and pension income and, like any other aged person, would be expected to contribute to their aged care (whichever system provided that care). It would be inequitable if there were no such co-contribution requirement. Moreover, it would prevent people with assets from attempting to enter the NDIS prior to the pension age to escape the co-contribution arrangements in the aged care system.
- If a person over the pension age required long-term aged residential care then they would move into the aged care system to receive that support.

There would also be scope for people with a disability who are aged *less* than the pension age to use the services and features of the aged care system, with the costs being met by the NDIS until the person reached the pension age. For instance, people acquiring dementia when aged 63 years would be able to use service providers linked into the aged care system. As Alzheimer's Australia noted:

> Regardless of the age at which a diagnosis of dementia is made, those affected should be able to benefit from quality care delivered by well trained service providers who can meet their needs. This should be independent of the potential source of the funding, whether disability, aged care or otherwise … Transitions between care types regardless of the Government funding sources should depend on change in need, not be based … on age alone. (sub. 478, p. 2)

The advantage of these flexible arrangements is that the NDIS would — from the perspective of any client — become a lifetime scheme if they wanted that. This would resolve the present problem that some people with lifelong disabilities (such as intellectual disability) have difficulty accessing appropriate types of support and care as they age:

> People with a lifelong disability who are older are not simply older people; their lifelong disability has a significant impact on the processes of aging and the types of needs they have when they are older. They require ongoing access to disability specific supports as well as access to expertise from the aged care system. (Professor Christine Bigby, sub. 384, p. 2)

While removing barriers to accessing the features and services of the two systems would overcome any major problems associated with a non-integrated system, it still leaves open the question of *public* funding arrangements. Overly elaborate arrangements for dividing the funding responsibilities are not justified since the Australian Government would be the sole source of new *public* funding for both the disability and aged care systems. To be workable, any division of *public* funding responsibilities should be simple, easy to understand, and not represent a marked divergence from past responsibilities unless change was clearly warranted. There are several available options.

The first option is that regardless of when or how people acquired their disability, and irrespective of which system they elected to be in:

- the NDIS would fund the care and support needs of people aged up to the pension age, including for disability arising from age-related conditions like strokes and early onset dementia. (A younger age limit would apply to Indigenous people.)
- the aged care system would fund the care and support needs of all people over the pension age. If a person elected to stay in the NDIS, the assessment tools from that system would be used to determine their funding. This would ensure that people who acquired a disability before the pension age would have the assurance that they would not get a different level of care and support.

The only exception to these arrangements would be people over the pension age who have catastrophic injuries, such as from a motor vehicle crash. The NIIS would fully fund people's support needs associated with such accidents. The aged care system would still meet any ageing-related costs as they grew older — as in the arrangements under the Victorian Transport Accident Commission and in the New Zealand Accident Compensation Corporation.

A second option would be for the NDIS to continue to fund people with an earlier acquired disability *after* the pension age, but with the aged care system funding the *incremental* support costs associated with natural ageing (appendix C). This involves several complexities and some methodologies for allocating responsibilities carry with them the risks of unintended outcomes.

Under either option, the source of the *public* funding component would remain invisible to the user. They would simply choose their preferred system.

The first funding arrangement is the simplest and is closest to the status quo of current responsibilities — and for that reason it is currently the Commission's preferred option. This issue will be examined more closely after the draft report.

While the Commission has proposed a simple approach for the separate funding responsibilities of the aged care and disability sectors (draft recommendation 3.5), the Commission seeks feedback on other possible funding approaches.

Intersection with the health system

The Commission recommends that primary care and hospital (in-patient and outpatient) based services and medical and pharmaceutical products remain outside the scope of the scheme (chapter 4). Even so, it is likely that some ambiguity will remain around the respective responsibilities of the health and disability systems. Many health conditions, such as cancer, heart disease and diabetes, result in functional limitations. Some participants have argued that NDIS supports be extended to individuals with these, and other chronic conditions:

> These distinctions between disability and chronic illnesses are largely historical and over time some chronic illnesses have been recognised in terms of their impairments while others have not. There is little appreciation by the public and in policy for instance of the debilitating effects of arthritis, Meniere's disease, Crohn's disease and epilepsy. We would urge any review of disability services to ensure that these attitudes towards chronic illnesses and the impairments related to them be included in that review with a view of doing away with such false distinctions. (Chronic Illness Alliance, sub. 215, p. 3)

Most jurisdictions rely on the concept of permanence to distinguish between the respective roles of the health and disability systems. Queensland, for example, offers the following guidance:

> … the disability will not be considered permanent where there is a need for specific health services for a defined period following physical trauma or the onset of an acute episode of illness. A person in this situation may only become eligible for disability support services once their medical needs have stabilised and the long-term nature of their disability becomes apparent (Disability Services Queensland, Eligibility Policy, p. 2).

In other jurisdictions, such as South Australia, a diagnostic approach helps differentiate the responsibilities of the two systems. For example, individuals with cancer and heart disease are covered by the health system (sub. 496).

But gaps between disability and health services persist. Individuals with chronic health conditions note that in some cases, they simply cannot access the services they need:

> There is an assumption that the costs of such care for people with chronic illnesses are met through the health and medical system. But this is not entirely the case. Often people with chronic illnesses find they cannot access the services they need which are

> related to living in the community rather than to their health needs. They are not eligible for some disability services and the services they need are not available from medical services. An example of this is that some people with chronic illnesses do not fit the criteria of eligibility for aids and equipment from state-based services, which are poorly funded and inadequate to meet the needs of those who require them. (Chronic Illness Alliance, sub. 215, pp. 2–3)

Both the South Australian and New South Wales Governments made recommendations about the division of responsibilities between the NDIS and the health system. The South Australian Government proposed, at least initially, that coverage under the Scheme extend only to those disabilities that are not the result of chronic disease processes and that a diagnostic, as well as functional definition, be applied to exclude people with chronic health conditions. They went on to note that:

> Any extension of the eligibility criteria to other groups (aged or chronic health) will make the scheme too complex and will increase the risk of the scheme failing to meet the needs of people with disabilities. (sub. 496, p. 4)

In contrast, the NSW Government advocated a broader approach. They proposed including people with chronic illness, where their condition requires long-term support and care with activities of daily living. (sub. 536, p. 62)

Boundary issues between the health sector and the NDIS are not limited to coverage of individuals with chronic health conditions. Other issues include which sector should be responsible for research and early intervention.

The Commission proposes that the NDIS agree to a common memorandum of understanding (MOU) with the health sectors in each state. The aim of the MOU would be to ensure:

- the health, care and support needs of individuals with chronic and progressive health conditions were met in an integrated fashion
- adequate incentives existed for investments in research, prevention, early intervention and timely service delivery in cases where:
  - both health and the NDIS would be joint beneficiaries
  - where responsibility for the intervention or service would lie with health but the NDIS would be the main beneficiary
  - where responsibility for the intervention or support would lie with the NDIS but the main beneficiary would be health (such as in the provision of suitable accommodation to facilitate timely hospital discharge).

Given historical arrangements, it is likely that parties to the MOU would employ a diagnostic lens. If this is the case, emphasis should first be given to high cost and/or prevalent conditions.

Estimates of the number of NDIS participants and scheme costs do not encompass all individuals with chronic conditions that meet the assessment criteria. That is not to say that they would not access NDIS services, but rather that some of the costs would be met by health departments. The conditions that underpin the Commission's cost estimates are outlined in chapter 14. That chapter also includes a range of sensitivity analyses, one of which explores the possible cost implications of including a more comprehensive range of conditions.

Mental health

As in other Western countries, mental illness is common in the Australian population. Mental illness encompasses a diverse range of behavioural and psychological conditions of varying expected durations. The most common include anxiety disorders (such as agoraphobia), affective or mood disorders (for example, depression) and substance use disorders (such as alcohol dependence). The National Survey of Mental Health and Wellbeing (NSMHW) 2007 is the most recent comprehensive measure of Australia's mental health. According to that survey, one in five Australians aged 16-85 years experienced one of these more common mental illnesses in the preceding 12 months. This is equivalent to around 3.2 million people (ABS 2008b).

Mental illness also includes 'low prevalence' conditions, such as schizophrenia, bipolar disorder and other psychoses, though these were not specifically counted in the NSMHW. Some estimates suggest that these conditions affect another 2 to 3 per cent of the adult population. Psychotic illnesses are frequently very disabling and extend over long periods of the person's life. These illnesses are the traditional focus of state and territory mental health services. According to the Department of Health and Ageing (2010), they account for most of the costs of specialised mental health care in Australia.

The suite of services provided by the mental health sector includes those delivered in community and inpatient settings (box 3.3).

Box 3.3 An overview of mental health services

Acute services: those which primarily provide specialised psychiatric care for people with acute episodes of mental illness. Acute episodes are characterised by the recent onset of severe clinical symptoms of mental illness that have potential for prolonged dysfunction or risk to self and/or others. The key characteristic of acute services is that treatment effort is focused on the short term. Acute services can focus on assisting people with no previous psychiatric history, or individuals with a continuing mental illness for whom there has been an acute exacerbation of symptoms.

Ambulatory care services: those dedicated to the assessment, treatment, rehabilitation and/or care of non-admitted patients, including, but not confined to, crisis assessment and treatment services, mobile assessment and treatment services, outpatient clinic services (whether provided from a hospital or community mental health centre), child and adolescent outpatient treatment teams, social and living skills programs (day programs, day hospitals and living skills centres), and psychogeriatric assessment teams and day programs.

Community residential services: which employ mental health-trained staff on-site; provide rehabilitation, treatment or extended care to residents in a domestic-like environment and that is intended to be on an overnight basis; and encourage the resident to take responsibility for their daily living activities. All these services employ on-site mental health trained staff for some part of each day. Some services employ mental health trained staff on-site for 24 hours per day. Services that are not staffed for 24 hours per day must provide mental health trained staff on-site for a minimum of 6 hours per day and at least 50 hours per week.

Inpatient services: mental health services that provide admitted patient care. These are stand-alone psychiatric hospitals or specialised psychiatric units located within general (non-psychiatric) hospitals.

Non-acute services: provide rehabilitation and extended care services to patients who usually show a relatively stable pattern of clinical symptoms. Rehabilitation focuses on intervention to reduce functional impairments that limit the independence of patients and seek to promote personal recovery. They are also characterised by an expectation of substantial improvement over the short to medium term. Extended care services provide care over an indefinite period for patients who have a stable but severe level of functional impairment and an inability to function independently without extensive care and support (including those with high levels of severe unremitting symptoms of mental illness). Treatment effort focuses on preventing deterioration and reducing impairment. Improvement is expected only over a long period.

Source: SCRGSP (2011) based on AIHW (2006); DoHA (2005).

The cost of delivering these services was around $5.6 billion in 2008-09. State and territory governments made the largest contribution ($3.5 billion) although this included some Australian Government base grant funds. The Australian

Government spent around $2.1 billion (SCRGSP, 2011). To put this in context, the budget for the National Disability Agreement was $5.3 billion in 2008-09.

Mental health conditions do not necessarily result in disability. Around 917 000 people reported having a mental health condition in the 2003 SDAC. Of those individuals who reported mental health as their primary condition (some 446 000 people), only 214 000 had a disability (around 70 per cent had core activity limitations, while the remaining 30 per cent were restricted in non-core areas, such as schooling and employment).

At present, the disability and mental health sectors are largely separate. (While in some jurisdictions, they are funded by the same departments, operationally, they are distinct service areas). Services appear to be poorly coordinated between the two:

> The official rhetoric that mental illnesses and disorders are just another category of disability is simply not matched by the practices of funding agencies and (almost all) service providing organisations. (Advocacy Tasmania, sub. 483, p. 6)

> Mental illness can be a major disabling condition for many people. Governments often seem to reduce costs by simply moving people between health and disability services. The person then 'falls through the cracks' and receives little or no real support for their problems. (Disability Professionals Association - SA Chapter, sub. 316, p. 2)

The current lack of cohesion between the two sectors disadvantages people with dual disabilities in particular:

> Studies have shown that up to two out of every three people who have experienced an ABI may develop a major mental illness over the course of their lifetime. Depression, anxiety disorders, mood and personality disorders, schizophrenia and panic disorders may all be present after an ABI. In addition, they are at a higher than usual risk of suicide than the rest of the population … It is Brain Injury Australia's experience that people with a dual diagnosis of ABI and mental illness are regularly either refused assistance by mental health services or, where they are accepted by a mental health service, they may receive treatment for their mental illness, but have their ABI ignored. Receiving the wrong intervention can exacerbate mental illness, jeopardise recovery from ABI and result in the person with an ABI being 'bounced' between services. (Brain Injury Australia, sub no. 371, p. 6, p. 11)

> Mental health issues are a common experience for many people with disabilities. Young people spoke about a double-bind that saw them rejected from mental health services, which were ill-equipped to support their needs in relation to their disability and then turned away from disability services because they were 'too unwell' to be taking part in various programs or crucial support planning.
>
> "I am having some mental health issues and really need some supports. But my plan was put on hold because of mental health issues. The disability agency said I was too unwell to be supported by them – Psych services said that they did not have expertise in disability". (Youth Disability Advocacy Service, sub. 487, p. 12)

> Poor services and outcomes are experienced by individuals with complex problems crossing more than one service agency/portfolio, for example individuals with intellectual disabilities and mental health issues, and/or substance abuse, and/or involvement in the justice system, and/or with a disability as a result of a traumatic injury e.g. an acquired brain injury. (UnitingCare Australia, sub. 291, p. 17)

A number of participants have suggested that NDIS coverage should extend to individuals whose disability arises purely from a mental health condition:

> The MHCA and the NMHCCF support eligibility for access to this scheme for disability acquired through a 'health condition' (not just through accident or misadventure), however want to be clear that this also refers to a mental health condition, as physical disability is often what people think of as a 'disability' (Mental Health Council of Australia (MHCA) and National Mental Health Consumer & Carer Forum. (NMHCCF sub. 357, p. 5)

> The inclusion within the proposed NDIS of people experiencing disability related to mental illness is strongly endorsed. That the scheme be proactive in contacting people with mental illness who may be eligible for supports. (Catholic Social Services Victoria, sub. 453, p. 4)

But resolving how the NDIS might best work with the mental health sector to support these individuals is complex. Only a few participants made suggestions about how this might best occur:

> Whilst their mental health needs should remain treated within the mental health sector, their support needs in relation to participation in activities for a reasonable quality of life should be met within the disability system. We also note that many people with long-term disability (including physical, intellectual and neuro-degenerative) experience periods of poor mental health, which are often associated with dips in functioning and consequent increases in need for support. In both cases, an individual may require intervention from more than one sector. (Wesley Mission Victoria, sub. 541, p. 8)

> … eligibility for people with a mental illness should only be considered when a person needed ongoing support to live within their community or to obtain and maintain employment. The treatment provided for the mental health condition, however, should remain the responsibility of the health sector. This scheme should not cover health expenses or those associated with treatment in acute hospitals. (National Disability Services, sub. 454, p. 7)

> That the scheme [NDIS] develop and implement agreements with relevant agencies, departments and schemes to ensure that scheme participants continue to access non-scheme funded services and supports to which they are entitled, particularly health and mental health services. (Yooralla, sub. 433, p. 20)

> It is urged that the NDIS acknowledge the border between mental health and disability, so that both are funded, developed, improved and sustained separately. In individual instances, there will be crossovers to which both systems should respond collaboratively. (Novita Children's Services, sub. 560, p. 26)

Some divisions of responsibilities are reasonably clear

One simple principle could be that each sector should focus on their area of comparative expertise. So for example, the mental health sector would be responsible for:

- specialised services such as psychology, psychiatry (which would include early intervention), acute and inpatient services and pharmaceuticals for all types of mental illness
- provision of all services to people with non-permanent mental illnesses (such as many affective disorders).

The NDIS would have a significant role in meeting the support needs of individuals with a dual diagnosis, such as those with an intellectual disability and a mental illness.

Responsibilities in other areas are less clear

The question of which system is best suited to meet the *support* needs of those individuals with long lasting mental health conditions (such as schizophrenia) that result in disability is more complicated.

There are good reasons why it would be appropriate for the mental health sector to play a role. The expertise already exists within the mental health sector — the sector already provides a range of services targeted at meeting ongoing support needs. These services are delivered through community mental health initiatives as non-acute services (box 3.4).

> In the mental health sector, the term 'community mental health services' covers much more than primary health care as it also encompasses a range of secondary and tertiary mental health care delivered by services based in community settings outside hospital campuses. This includes both clinical treatment, and support and recovery care (Mental Health Council of Australia 2010, p. 2).

Moreover, some individuals with significant and ongoing functional limitations resulting from a mental health condition, do not see themselves as having a 'disability', and so would approach the mental health sector, rather than the NDIS for supports. As the Mental Health Council of Australia and National Mental Health Consumer & Carer Forum note:

> The disabling impact of mental illness … is frequently lacking recognition in disability discourse … physical disability is often what people think of as a 'disability'. (sub. 357, pp. 2, 5)

People who cross the divide between medical conditions and disability, such as those with psychosocial disability … which, under the UN CRPD and the DDA are defined as disabilities but ... may not be treated as such by individuals or society at large. (Australian Federation of Disability Organisations, sub. 495, p. 6)

Box 3.4 Specialist supports in the mental health sector

A number of state and territory governments offer a range of non-clinical specialist mental health services. These include:

- **Planned respite** — these services provide a short-term change in environment for people with a mental illness and a break for carers, and include both formal and informal psychosocial rehabilitation components. Planned respite services may involve social and recreational day activities, including in-home support, holiday activities and residential components.
- **Mutual support and self help** — these services provide information and peer support to people with a mental illness and/or their carers. This can involve the sharing of experiences and coping strategies, the provision of information and referral services, and the promotion of community awareness.
- **Residential disability support services** — residential rehabilitation services provide intensive psychosocial rehabilitation and support in group accommodation to prepare residents for independent living. Emphasis is on developing or regaining skills to enable each resident to deal with daily living activities, developing confidence to commence or continue schooling, training or employment, as well as supporting positive contact with their family and friends.
- **Disability support services encompassing outreach, day programs and social support** — rehabilitation day programs assist people with severe psychiatric disabilities to improve their quality of life, participate in everyday living activities, and function as independently as possible in the community. This may involve the development of social and living skills in a group context, through centre-based and community access programs. Home based outreach services provide support to consumers living in their own homes, or other community residential settings.

On the other hand, it could be argued that the NDIS should meet the support needs of these individuals, as it will be meeting the needs of other individuals who have similar functional limitations (albeit the result of another condition).

Moreover, services in the mental health sector (including community mental health services) are not adequately resourced. As in the disability sector, many individuals go without much needed supports:

Secondary and tertiary mental health care is more complex. What is provided, how, and by whom, currently varies across states and territories, and urban, rural and remote areas. What services are available will often depend on where you live, and to some extent on your level of disposable income, rather than your treatment and care needs.

> Services also differ in terms of management, governance arrangements and sources of funding, and the titles of comparable service types (Mental Health Council of Australia 2010, p. 6).
>
> So many parents left to care for adult children with serious mental illnesses get minimal support and face mounting anxiety about the future of their "children" (Patrick McGorry, The Age, 30 January 2011).
>
> Mental health services are either in crisis or under sustained duress across this nation. Every aspect of the service system is desperate for some additional funding (ConNetica Insight, John Mendoza, 2010).

The dilemma here is the extent to which the NDIS should address the poor performance of the mental health system in providing support to people with a mental illness. The first best policy response is an adequately funded and properly governed mental health system of the kind advocated by many in that sector. Absent that initiative, the NDIS could, in theory, take over responsibility for those non-acute services directed at ongoing support of people with a mental illness. That would help people with mental illness in at least one important area of their support needs. On the other hand, it might risk losing some of the benefits of the integration of such non-acute services into the wider mental health system and might encourage cost shifting by those funding the mental health system.

Clearly, the boundaries between the roles of the disability and mental health sectors are blurred for the most severe and enduring mental illnesses. People with these illnesses will sometimes need daily supports that are akin to those of people with a disability generally. The Commission has included some provision for the daily support costs (not clinical services) of people with severe mental illness in its preliminary cost estimates. However, the Commission is aware that the mental health system is under review and that this may affect the appropriate system for providing supports. The Commission is seeking feedback on where the boundaries should be drawn.

The Commission seeks feedback on where the boundaries between the mental health sector and the NDIS might lie. In particular, the Commission would appreciate feedback on which system would be best placed to meet the daily support needs (not clinical needs) of individuals with a disability arising from long lasting mental health conditions (such as schizophrenia), including:

- *which services would be provided by the NDIS and not the mental health sector and how these could be clearly identified*
- *the magnitude of the budget that would be required*
- *how to guard against cost shifting*

- *how the NDIS would practically integrate any role in ongoing non-acute services with the wider mental health sector, including any shared responsibilities of case managers in the two systems.*

Intersection with palliative care

Individuals in the final stages of their life traditionally receive palliative, or end of life care. These individuals share some common care needs with those with a disability and both should have their needs met in a sensitive manner. However those with terminal illness might also require

- care focused on making the individual comfortable, including medications and treatments to control pain and other symptoms
- services for themselves or their families to help deal with the medical, psychological and spiritual issues surrounding dying.

The Commission recommends the following arrangements for individuals with terminal conditions. Where an individual:

- first approached the scheme for individually funded support *after* their terminal condition had become sufficiently advanced, such that they were in the very final stages of their life, they would be referred to the palliative care sector. (The NDIS would have a role in connecting such people to palliative care services. For example, that might involve helping identify the relevant provider in their area.)
- was in receipt of individually funded support and their condition subsequently deteriorated such that they were in the final stages of their life, they would continue to have their care and support needs met by the scheme. The NDIS would source, and the palliative care sector would fund, any specialist services to address their palliative aspect of their care needs. Such an approach would ensure continuity of care in the individual's final stages of life.

3.7 How many people are likely to receive individualised supports

Estimates of the number of individuals likely to access individualised supports are *indicative only* as the proposed assessment criteria do not map directly to existing data and not all individuals who meet the assessment criteria will elect to take up services. That said, the Commission estimates that the potential population of

NDIS-funded, individually tailored service users (based on 2009 population and prevalence data) would be around 360 000.

As a comparator, about 172 000 people used specialist disability services under the National Disability Agreement (NDA) in 2008-09 (SCRGSP 2011) (excluding Australian Government employment services).[4] Around 200 000 people aged under 65 years used Home and Community Care (HACC) in 2008-09 for services such as nursing care, allied health, and the provision of aids and equipment that were not available under the NDA. (Though several used very little HACC services — approximately one hour of care a fortnight.) Current total service users are less than the sum of both NDA and HACC users, since people often use both services (around 20 per cent of people using NDA specialist services — excluding employment services — also access HACC services).

The assessment criteria lead to coverage that is broader than those associated with criteria employed in other countries. For example, applying the criteria for entry into long term care and support schemes in Sweden and Singapore to the Australian population yields potential populations of *about* 220 000 and 290 000 respectively.

It is important to emphasise that not all individuals who meet the assessment criteria will elect to take up individually funded services. This is currently the case with state and territory disability and accident-based schemes. As the NSW Government observed:

> … a person may be eligible for the system but, due to their capacity to self care or due to strong family support, may not access any services in the immediate future. (sub. 536. p. 63)

The above criteria identify those who would benefit from support, but it would not indicate the form or value of supports. More detailed objective assessments would identify people's support needs and the appropriate level of supports, after taking account of the roles performed by other publicly-funded services and the reasonable contributions of volunteers, family, friends, employers and the community (these issues are canvassed in chapter 5).

It should also be emphasised that the population of people using individualised supports is not a reliable guide to scheme costs. Many people will use services irregularly (for example, periodically getting a new wheelchair or an hour of counselling every so often to maintain a high level of functioning). The largest costs and the challenge for scheme management will be for the relatively small population of people with very high support needs, particularly those with high attendant care costs (chapter 14).

4 As noted in the following chapter, in the main, the NDIS will not provide employment services.

3.8 Implementation issues

Access to funded services would apply to the entire stock of relevant people with disability, and not just to the flow ('incidence'), as was the case with the NSW Lifetime Care and Support Scheme. Any restriction along these lines would mean the persistence for decades of sub-standard support for hundreds of thousands of people.

While such restrictions will apply to the NIIS (chapter 16), the Commission recommends that individuals with disabilities that are the result of a catastrophic accident prior to the onset of the NIIS (or comparable state-based schemes such as those operating in NSW, Victoria and Tasmania) be covered by the NDIS, subject to meeting the broader assessment criteria. (In some cases, exclusion periods might apply, while in others, people may have lump sums to help finance their use of NDIS services.)

Given that the potential population of the scheme significantly exceeds the number of current NDA service users and that traditional service users are captured by the proposed assessment criteria, the overwhelming majority of current users would be likely to access their supports from the NDIS after its implementation. Indeed, most would get more supports given the expanded funding of the NDIS and an obligation for the system to deliver the supports determined by the independent assessment process. This feature is an essential element of avoiding the chronic underfunding that has beset past allocation systems. To a large degree, this should allay the concerns of people that they might receive no or fewer supports under the NDIS after years of fighting or waiting for adequate services.

While current users of NDA services will overwhelmingly receive funded supports under the NDIS, the same may not be true of all HACC users. HACC services currently cover a wider range of individuals than are the target of funded supports under the NDIS. While 'high-level' HACC users (those who receive more than one hour of support per day) would be covered by the scheme, there will be some instances where some 'low-level' HACC users would not get the same level of services using the NDIS assessment criteria. It is impossible to determine the numbers involved since so little is known about the characteristics of current HACC users, including the nature and severity of their disabilities. Consideration will need to be given, at the time, to what arrangements would be appropriate in these instances. Agreed arrangements should be reflected in the MOU with the health sector.

This raises the question of whether a so-called 'no-disadvantage' test should apply. The Commission understands the intrinsic appeal to current service users in no-

disadvantage tests and that people would seek some undertaking that they be no worse off under new arrangements. However, beyond the much greater funding of the NDIS, a further protection against the risk of losing supports is that the nature, frequency and intensity of a person's support needs would comprehensively and objectively assessed. The assessment process would be person-centred and forward looking. It would consider the supports that would allow a person to fulfil a range of functions, rather than only respond to what an individual cannot do.

In that context, the Commission does not consider that 'no disadvantage' tests would be appropriate. This reflects the practical complexity of such arrangements, the fact that needs change from year to year anyway and their unfairness — given assessment of needs under the NDIS will be objectively based rather than inferred from past service use.

DRAFT RECOMMENDATION 3.1

The National Disability Insurance Scheme (NDIS) should have three main functions:

- ***to cost-effectively minimise the impacts of disability, maximise the social and economic participation of people with a disability, and create community awareness of the issues that affect people with disabilities. These measures should be targeted at all Australians***
- ***to provide information and referral services, which should be targeted at people with, or affected by, a disability***
- ***to provide individually tailored, taxpayer-funded support, which should be targeted at the subset of people with disabilities who are assessed as needing such support.***

DRAFT RECOMMENDATION 3.2

Individuals receiving individually tailored, funded supports should be Australian residents, have a permanent disability, (or if not a permanent disability, be expected to require very costly disability supports) and would meet one of the following conditions:

- ***have significant difficulties with mobility, self-care and/or communication***
- ***have an intellectual disability***
- ***be in an early intervention group, comprising:***
  - ***those for whom there was a reasonable potential for cost-effective early therapeutic interventions (as in autism and acquired brain injury)***
  - ***those with newly diagnosed degenerative diseases for whom early preparation would enhance their lives (as in multiple sclerosis)***

- ***have large identifiable benefits from support that would otherwise not be realised, and that are not covered by the groups above. Guidelines should be developed to inform the scope of this criterion.***

DRAFT RECOMMENDATION 3.3

The NDIS should provide advice to people about those instances where support would be more appropriately provided through non-NDIS services. Support should be provided outside the NDIS for people whose:

- ***disability arose from a workplace accident or catastrophic injury covered by insurance premiums***
- ***support needs would be more appropriately met by the health and/or palliative care systems, comprising:***
  - ***those who would benefit from largely medically oriented interventions (including less restrictive musculoskeletal and affective disorders, and many chronic conditions)***
  - ***many people with terminal illnesses***
- ***support needs would be more appropriately met by the aged care system***
- ***needs were only in relation to mainstream employment, public housing or educational assistance.***

DRAFT RECOMMENDATION 3.4

The NDIS should put in place memoranda of understanding with the health, mental health, aged and palliative care sectors to ensure that individuals do not fall between the cracks of the respective schemes and have effective protocols for timely and smooth referrals.

DRAFT RECOMMENDATION 3.5

Whatever the actual funding divisions between the NDIS and aged care that are put in place, people should have the option of migrating to the support system that best meets their needs, carrying with them their funding entitlement.

Upon reaching the pension age (and at any time thereafter), the person with the disability should be given the option of continuing to use NDIS-provided and managed supports or moving to the aged care system. If a person chose to:

- ***move to the aged care system, then they should be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches)***

- ***stay with NDIS care arrangements, their support arrangements should continue as before, including any arrangements with disability support organisations, their group accommodation, their case manager or their use of self-directed funding.***

Either way, after the pension age, the person with a disability should be subject to the co-contribution arrangements set out by the Commission in its parallel inquiry into aged care.

If a person over the pension age required long-term aged residential care then they should move into the aged care system to receive that support.

In implementing this recommendation, a younger age threshold than the pension age should apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements.

DRAFT RECOMMENDATION 3.6

Following the transition spelt out in draft recommendation 17.1, the NDIS should fund all people who meet the criteria for individually tailored supports, and not just people who acquire a disability after the introduction of the scheme.

DRAFT RECOMMENDATION 3.7

The supports to which an individual would be entitled should be determined by an independent, forward-looking assessment process, rather than people's current service use.

4 What individualised supports will the NDIS fund?

Key points

- The NDIS will fund a broad range of individually tailored supports. Key supports will include aids and appliances, personal care, domestic assistance, respite, home and vehicle modifications and community access.
- More flexible funding arrangements, including the option for self-directed funding, will allow NDIS provided supports to be better tailored to individuals' needs.
- The NDIS will provide and fund specialist disability supports on a 'reasonable and necessary' basis.
- Access to individually tailored supports will not be subject to means testing. However, there will be some cases where people would pay an upfront contribution (a so-called 'front-end deductible') of, say, $500 per annum.
- Front-end deductibles will be waived where people (and families) already make a significant contribution towards the costs of their support through unpaid care.
- The scheme would fully fund the number of episodes of therapy supported by clinical evidence, with people choosing further episodes meeting their full costs.
- The provision of health, education, employment, housing, transport and income support will generally remain a mainstream concern. The NDIS would however, have a role in connecting people to, and where needed, supporting the activity of people in mainstream services.
- The NDIS should not respond to problems or shortfalls in mainstream services by providing its own substitute services. To do so would undermine the sustainability of the scheme and the capacity of people with disability to access mainstream services.

4.1 Introduction

Supports and assistance aim to increase opportunities for people with disability by tackling such things as inadequate housing and the need for personal care and assistance in getting about and participating in the community. Sometimes, just

simple things — a wheelchair, an hour or two of planning help every so often, or a Braille machine — can allow a person to live a full life in the community. In other cases, more intensive supports are required. The first part of this chapter considers the supports and assistance of relevance to people with disability, these include:

- specialist disability supports, such as attendant care, community access and home and vehicle modifications (section 4.2)
- generic or 'mainstream' services and assistance available to the whole population, including health, housing, transport, education and employment services (section 4.3)
- income support, including the Disability Support Pension and Carer Payment (section 4.4)

The second part of this chapter looks at how the NDIS would provide specialist supports tailored to a person's individual needs, including:

- what constitutes 'reasonable and necessary' (section 4.5)
- what role, if any, means testing, front-end deductibles or co-contributions should play (section 4.6).

Information and referral services target a much broader group of individuals. The role of the scheme in providing these services is outlined in the previous chapter.

4.2 Specialist disability supports

This section deals with the proposed *scope* of specialist disability supports to be funded by the NDIS. As noted by the AIHW, these are supports that 'enable people with disabilities to participate in society by meeting their disability-related needs' (2007, p. 95). Specialist disability supports will be oriented to people with support needs that would otherwise not be reasonably met without NDIS funding, or that are not more appropriately met by other systems (chapter 3).

The broader issue of self-directed funding and which supports would form part of an individual budget is explored in greater detail in chapter 6. But anticipating that chapter, the Commission considers that there is a strong rationale for people with disability to have more power over the way support services are delivered to them and their type. Self-directed funding — the capacity (but not the obligation) for people to make choices about how to spend their individualised budget — will be key in giving people with disability greater autonomy.

The NDIS would provide the full range of specialist disability supports currently provided under the National Disability Agreement (NDA) (box 4.1).

Box 4.1 Specialist disability supports provided by the NDIS

Aids and appliances — a range of products to improve functioning, enable a person to live at home and in the community, and enhance independence. These would range from low to high-tech aids and encompass toilet supports or hand-held showers, continence aids, wheelchairs, hearing aids, mechanical lifters, electronic communication devices and artificial limbs.

Home modifications — modifications to the structure, layout or fittings of a home to enable an individual to utilise the home's standard fittings or facilities.

Vehicle modifications — modifications which allow individuals to access, travel as a passenger or drive a motor vehicle.

Personal care — supports that enable an individual to take care of themselves in their home and community. These include help with showering, bathing, dressing, grooming, personal hygiene including bowel and bladder care/toileting, assistance with eating and/or drinking, mobility and transfers; health maintenance, such as oral hygiene, medication use or regular and routine exercises and stretches. This would also include nursing care when this was an inextricable element of the care of the individual (for example when meeting the care and support needs of a ventilated quadriplegic).

Community access — to provide opportunities for people with a disability to enjoy their full potential for social independence. The intention is to allow people a lot of choice in spending in this area. Supports would focus on developing skills and independence in a variety of life areas (for example, self-help, social skills and literacy and numeracy) and enjoyment, leisure and social interaction. The supports would:

- include facility and home-based activities as well as those offered to the whole community
- include supervision and physical care
- range from long-term day support to time-limited supports.

Respite — to provide a short-term and time-limited break for people with disabilities, families and other voluntary carers of people with a disability. These services are designed to assist in supporting and maintaining the primary care giving relationship, while providing a positive experience for the person with a disability and include:

- respite care provided in the individual's own home
- respite care provided in a community setting similar to a small 'group home' structure
- host family respite that provides a network of 'host families' matched to the age, interests and background of the individual and their carer
- 'recreation/holiday programs' where the primary purpose is respite.

(Continued next page)

Box 4.1 **(continued)**

Specialist accommodation support — such as group homes and alternative family placement encompassing support for clients to carry out essential activities of daily living (net of the standard contribution from a person's income for rent). The NDIS would not necessarily *own* the 'bricks and mortar' but the funding it provided would cover the cost of capital.

Domestic assistance — to enable individuals to live in the community and live on their own, such as meal preparation and other domestic tasks; banking and shopping; assistance with selecting and planning activities and attending appointments.

Transport assistance — provision or coordination of individual or group transport services, including taxi subsidies.

Specialist employment services — that provide or prepare people for jobs (including transition to work programs).

Therapies — such as occupational, speech and physiotherapy, counselling, and specialist behavioural interventions.

Case management, local coordination and development — which are broad supports, including individual or family-focused case management and brokerage, as well as coordination and development activity within a specified geographical area. They aim to maximise people's independence and participation in the community. An individual could also elect to have a disability support organisation assist with case management and advocacy.

Crisis/emergency support — following, say, the death of a family member or carer, including emergency accommodation and respite services.

Guide dogs and assistance dogs — including the reasonable costs of being assessed for the dog, the dog, user training and veterinary costs.

Since the Commission favours a significant capacity for someone to tailor their supports, box 4.1 focuses on the *intent* of the proposed supports, rather than their precise form. Self-directed funding would open up opportunities for more innovative and imaginative approaches to service delivery. For example, community access for individuals with an intellectual disability may take the form of going to the movies rather than more traditional, costly and often less effective day programs.

Given the capital-intensive nature of specialised accommodation services and the current deficit of places, this particular issue warrants further discussion. The provision of prostheses and the incremental costs of running specialist disability equipment are also discussed in more detail — both were raised as issues by participants.

Specialised accommodation

Individuals with disability have diverse housing needs, so it makes sense for the NDIS to employ a range of options to address those needs (table 4.1). In some cases, mainstream housing services will be the most appropriate solution, and where people need assistance, the role of the scheme would be to refer people to public housing or to act as their advocate in dealings with public housing authorities. (Mainstream housing is discussed further in section 4.3.) Some people (irrespective of whether they live in public housing or in their own homes), may require modifications to make their homes more accessible. The need for housing modifications would form part of a broader assessment of need for people receiving individually tailored supports.

Table 4.1 **Responding to diverse housing needs**

Affected individuals	*Range of possible NDIS supports*
People seeking independent living arrangements	• Referral to public housing
Public housing tenants	• Advocacy services • Home modifications (subject to a person occupying the house for a reasonable period of time)
People residing in their own home	• Home modifications (subject to a person occupying the house for a reasonable period of time)
People residing in private rentals	• Home modifications (subject to a person occupying the house for a reasonable period of time and this being reflected in a tenancy agreement)
People who require specialist disability accommodation	• NDIS-funded specialist housing which would enable people to move out of home in line with community norms
Homeless people	• Outreach services

For another, smaller group of people, specialist accommodation, which encompasses support for activities of daily living, will be the most appropriate response — so called 'group homes'. Currently, specialist accommodation is in short supply. This gives rise to a number of serious problems. It is common for people to remain in their parents' homes for longer than is appropriate. Some people (typically those with a newly acquired disability) remain in hospital due to a lack suitable alternatives. In other cases, people are placed in respite on an ongoing basis. Not only is this an inappropriate outcome from the individual's perspective, it effectively 'blocks beds', such that many other families can no longer use respite services. In more critical cases, parents who can no longer cope, relinquish care of their children. A number of participants highlighted the significant problems arising from shortages in this area:

> Clinicians in Queensland have identified that the lack of ABI [Acquired Brain Injury] beds and slow stream brain injury rehabilitation beds is causing significant "bed block" in the acute sector. (Brain Injury Australia, sub. 371, p. 22)
>
> I spent over 12 months as an inpatient in the Hampstead Rehab Centre because government funding would not help with a bathroom so I could go home to my mum. The one bathroom that we did have was probably as big as that table and it just wasn't going to be wheelchair-friendly, so we had to get one added on the back. One area of government then spent over $300,000 keeping me in the Hampstead Centre and would not give us 15,000 tops to help renovate a bathroom so I could go home. (Melissa Leckie, trans., p. 318)
>
> Confused and heartbroken here I sit. Two weeks ago I made a decision that for the sake of my personal health and my family's wellbeing I could no longer care for my almost 11 (big boy) year old son due to his ongoing unpredictable aggression, epilepsy and autism due to Tuberous Sclerosis Complex. Naively I thought there would be a group home somewhere for him to have a controlled and structured environment with all of the emotional attachment. Now he is in a respite centre blocking a bed. (Gippsland Carers Association Inc, sub. 133, p. 12)

The NDIS would provide specialist accommodation services, subject to an assessment of need. The scheme would not necessarily own the 'bricks and mortar', but the funding it provided would cover the cost of capital. Given the shortfall in specialist housing, and the consequent impact on families, the Commission has explored some more inventive housing options.

An innovative approach to specialist disability housing

The choice of housing for any individual involves a series of tradeoffs — people make choices, constrained by their budgets, about location, amenity and whether they live alone or with others. For example, a person might choose to live closer to town but be prepared to share the expense of doing so by living with others. Alternatively, one might value living alone and so elect to live further out. For others, being close to family or friends or proximity to public transport might be paramount. However, for many people with disability — particularly those that require *specialist disability housing* — their choices are constrained. This is partly due to scarcity, but also reflects the inability of the current systems to take account of individuals' preferences.

The Commission considers that there are strong grounds for individuals to have the capacity to cash out *specialist disability* housing (where the NDIS has assessed individuals as needing this form of accommodation). This would involve estimating the value of rent (priced at the market rate, not the subsidised rate) for a given person using specialist disability housing services, which then could be cashed out

for accommodation services. This process would allow the person to make more flexible decisions about accommodation.

For example, people could make choices about who they lived with. Alternatively, they (or their family) might add some funding to pay a higher rent for a private dwelling in a more convenient location or with features better suited to the person. Similar arrangements apply in other countries such as the United States, though they do not specifically target people with disability (US Department of Housing and Urban Development (2011).

This approach could also extend to the purchase of housing. This would involve estimating the present value of the expected stream of rents over a much longer period of time, say for example 40 years. Individuals would have access to an amount of that value, to use to purchase a dwelling (though they would be expected to pay an amount in interest equivalent to the cost of capital to the NDIS, based on the long-term bond rate). The scheme would have an equity stake in the dwelling, which would decline over time and be extinguished after a given number of years had elapsed (40 years in this example).

While theoretically elegant, extending the 'cashing out' model to the purchase of housing is far more complicated. To be workable, there would need to be clear guidance on matters such as who would be responsible for undertaking repairs and whether a party's equity stake would change if they undertook capital improvements.

Inevitably, the NDIS will not be able to meet *all* of an individual's housing preferences. But the provisions outlined above would allow individuals to decide which preferences they valued most highly and which preferences they were prepared to trade off.

The issue of age-appropriate transitions to independent living affects a broad group of people with disability (not just those requiring specialist accommodation) and is discussed further in section 4.5. But anticipating that section, the Commission considers that the NDIS should facilitate the transition of young adults, into public or private housing or supported accommodation, if they wished to do so, in line with community norms.

Homeless outreach

At present, people with disability are over-represented among the homeless. As UnitingCare Australia observed:

> We now know that people with a mild intellectual disability and or mental illness are over represented in the criminal justice system, in licensed boarding houses and among the homeless. (sub. 291, p. 17)

Similarly, Brain Injury Australia noted:

> A number of local surveys have attempted to estimate the number of people with an ABI who are homeless. A 1998 "Down and Out in Sydney" project found that 10% of people using inner city Sydney hostels and refuges had cognitive impairment as a result of alcohol-related brain injury or TBI [Traumatic Brain Injury].[1] (sub. 371, p. 6)

Traditionally, these individuals do not access disability services. Some jurisdictions currently provide outreach services, in an effort to improve the access of homeless people to mainstream and disability supports. The primary purpose of outreach services is to connect people to support, and educate people about the services available within their community, so that they are better equipped to independently access supports in the future.

While an important goal of the NDIS will be to assist people with disability to access suitable and secure housing, outreach services will still be required. The Commission considers that the NDIS should provide homeless outreach services.

Prostheses

The use of prostheses is relevant not only to disability supports but to aged care and health more generally. According to the Australian Orthotic Prosthetic Association (2010), there are more than 20 000 amputees in Australia, three quarters of whom are over 60 years of age. Of the 2500 new amputees each year, 75 per cent occur as a result of vascular disease. The remaining 25 per cent of amputations result from injuries, tumours or congenital conditions.

Prostheses in Australia are currently subject to many of the same problems facing the disability system generally. Namely, that the provision of prosthetics is reported to be insufficient, and subject to delays and rationing (sub. no. 301). For instance, waiting times in the public health system are reported to be a *minimum* of three months (sub. no. 241 and 301). As one participant observed:

> Amputees also indicate that current waiting times are between three and 12 months within the public system, causing lengthy periods without mobility or independence. (Ms Noonan, Limbs for Life, trans., p. 862)

Participants also noted the inequity of support across jurisdictional boundaries, or between people who had acquired their amputation from different causes, as well as

[1] TBI refers to an injury which is the result of force applied to the head from a motor vehicle accident, a fall or an assault.

those who were eligible for compensation or private insurance and those relying on the public system. (for example, subs. 237; 241 and 301)

How prostheses should be managed in future

There are valid arguments why the NDIS might cover certain prostheses:

- Prosthetics, particularly for limbs, have the same functional purpose as wheelchairs and other mobility aids that would be covered by the NDIS. In some cases, they may be substitutable — a person who does not have access to a prosthetic may require a wheelchair.
- Like many other aids and appliances, prosthetics used for mobility would generally be on a long-term basis, and require maintenance and replacement. In this way, the ongoing costs would be similar to those for aids and equipment.
- There may also be scope for consolidation of current delivery methods. Limbs 4 Life note that there are over ten different funding programs for prosthetics (sub. 301). In the interests of equity, administrative simplicity, as well as economies of scale, there could arguably be some form of consolidation of these programs.

That said, it would not be appropriate for the NDIS to fund all prostheses. Some would be more suitably funded and provided by the health system:

- Health currently provides and funds hip replacements and artificial internal implants, sometimes described as 'internal prosthetics'.
- There is a wide range of prostheses, some of which would not be directly related to disability as such, but to medical conditions (for instance, pacemakers or cardiac stents).

The Commission considers that the NDIS should fund artificial limbs and seeks feedback on the desirability and practicality of this option. What items should be included if in the NDIS?

Additional costs of everyday living

In addition to the costs of supports and aids and appliances, several participants pointed to the additional costs of everyday living they face. Examples include higher electricity costs due to the use of medical equipment or to provide temperature control, and higher water costs for washing clothes:

> Many disabilities have difficulty stabilising body temperature and require air-conditioning to assist sleeping, comfort and prevent seizures. Incontinence results in washing machines going regularly. (Alison Bennett-Roberts, sub. 319, p. 3)

Similarly, Stewart MacLennan, citing MS Australia, said that 'heat intolerance is a major issue for people with MS'. Reflecting this, a number of state governments have implemented electricity rebate schemes to help people with multiple sclerosis and certain other conditions (sub. 184, p. 4).

In the case of electricity, some state governments already provide concessions under certain circumstances for people with disabilities. For example, in Victoria:

> The medical cooling concession … provides a 17.5% discount off electricity costs over a six month period from 1 November to 30 April for concession cardholders with multiple sclerosis and other qualifying medical conditions such as Parkinson's, motor neurone disease, scleroderma and lupus. (DHS Victoria 2011)

The Queensland Government provides financial assistance to low-income Queenslanders with a medical condition which requires the use of electricity for cooling or heating. Assistance of $216 per year is provided for two years, at which time eligibility is reviewed. The concession is provided to assist individuals with increased electricity costs incurred by frequent operation of an air-conditioning unit in order to regulate body temperature.

Similarly, in New South Wales, the Medical Energy Rebate is for eligible customers who have a medically diagnosed inability to self-regulate body temperature when exposed to extremes (hot or cold) of environmental temperatures. Generally associated with certain medical conditions such as Parkinson's disease and multiple sclerosis, the rebate provides $145 a year for eligible customers, rising to $161 a year from 1 July 2011.

The Western Australian Government provides a subsidy of $502 per annum to help offset energy costs for financially disadvantaged persons or their dependents with thermoregulatory dysfunction. The subsidy is aimed at persons who hold means-tested concession cards (or the dependants of such people), who require heating and/or cooling to control the temperature in their homes under specialist medical advice.

It is not clear the extent to which these schemes sufficiently cover the additional costs of electricity arising from the disabilities concerned, nor whether the eligibility criteria are sufficiently broad for people with disabilities to benefit from these concessions. The Commission considers that the cost of the various rebates should be transferred to the NDIS and seeks feedback on arrangements for unavoidable electricity costs.

The Commission seeks feedback on the arrangements that should apply in relation to higher electricity costs that are unavoidable and arise for some people with disabilities.

In addition, medically necessary diets can increase food bills (Eleanor Lord, sub. 569, p. 1). Northcott Disability Services argued that:

> … the scheme should not fund general lifestyle needs (eg food) but should fund these needs if they would not have existed in the absence of a disability (eg. specialised food /formula required for a person who is PEG fed). (sub. 376, p. 17)

The Commission considers that the NDIS should cover the costs associated with PEG feeding.

4.3 The role of 'mainstream' services

Mainstream services are those that people generally use. They may include government-funded services (education, health care, public housing and transport, and employment services) and services provided by the private sector (a swimming pool, gym, the theatre, holidays). People with disabilities use these services like anyone else. It is generally accepted that disability services should not replace mainstream or other specialist services available to the broader population, or be expected to meet all the needs of people with disability. Indeed, a key policy goal is to move away from primary reliance on specialist disability services to the use of mainstream services or at least to a mix of the two (KPMG 2009). The former often isolates people with disability and reduces their power and choice. Strengthening access to mainstream services for people with disability is one focus of the current intergovernmental agreement on disability services.

But, as KPMG has observed, achieving change requires a new way of thinking:

> These reform directions require a shift from seeing the disability service system as the source of all support for a person with a disability, to seeing the disability service system as one part of a broader service response that complements other informal and formal supports (including health, education, housing, employment and income support). This shift towards more inclusive mainstream services and a greater emphasis on informal supports is in line with progressive thinking that is at an early stage internationally (2009, p. 2).

Access to generic services, such as health and housing, can affect demand for NDIS-funded services, and vice versa. It will be important for the scheme not to respond to problems or shortfalls in mainstream services by providing its own substitute services. To do so would weaken the incentives by governments to

properly fund mainstream services for people with disability, shifting the cost to another part of government (such as from a state government to the NDIS, or from one budget 'silo' to another). This 'pass the parcel' approach would undermine the sustainability of the scheme and the capacity of people with disability to access mainstream services. If governments and departments thought that the NDIS would address both specialist and mainstream service needs, people with disability may well be seen as a lesser priority for the generic services provided by government.

However, while most agree that people with disability should have access to the general services provided by government as well as specialist services, the exact boundaries of the roles of these two tiers of services is often fuzzy. In many cases, cooperation and collaboration between the NDIS and other service programs may offer the best way to meet the needs of people with disability, both in terms of efficiency and quality of outcomes for the person.

The remainder of this section considers each of the key mainstream services. The Commission considers that such services should mainly remain outside the scope of the NDIS. That said, the NDIS should have a role in connecting people to them and, where needed, supporting the activity of people in mainstream services. Several participants recommended this approach, including the South Australian Government:

> People with disabilities need a multitude of services, some of which would be the responsibility of other areas of government (housing, health and aged care, also public transport, education etc.). While a new disability care and support system is unlikely to be able to provide and finance all of these services, the system should link with other service providers to ensure that people with disability have equal access to the community. Existing disability services have tended to assume a 'whole of life' responsibility, including care and support as well as education, accommodation and employment. This has limited the capacity of the disability system to adequately meet demand. It also denies people with disabilities the same access to mainstream services as all other members of the community. There is significant room for increased mainstreaming of services. (sub. 496, p. 11)

Employment

Any disability policy should strongly encourage employment, since it is a major route to financial and social independence, as well as a general contributor to the community as a whole. Given that, access to employment services should be freely available to all people with disability, not just those in the scheme.

A variety of disability employment services are already provided by the Australian Government, primarily through Disability Employment Services and Assistance, the

Employment Assistance Fund and JobAccess and Job Network services. These services focus on both the person with disabilities and prospective employers, with many tailored to specific groups, including young people with a disability, Aboriginal and Torres Strait Islander Australians.

A recent OECD report (based on 2003 data) indicated that, Australia has the seventh lowest employment rate in the OECD for people with disability and mental illness. It is not quite clear why this is the case. One explanation could be the damaging effects of the Disability Support Pension (DSP) on people's incentives to work, rather than the disability employment services themselves. The Australian Government has taken some steps to address these disincentives by making it easier for people on DSP to get help to find work (box 4.2). But more reform is warranted (section 4.4).

Box 4.2 Removing the disincentives for people on DSP to seek work

The Government has made it easier for people on Disability Support Pension (DSP) to access help to find work.

Access to employment services for people on DSP has in the past been hampered by the requirement that people undergo a full eligibility review to access support, raising the fear that eligibility for the DSP may be withdrawn. This requirement for a full eligibility review became a disincentive for people on DSP to enter the workforce.

The requirement was withdrawn in September 2008. Since then, more than 30 000 DSP recipients have sought employment assistance. Of these, 29 000 were referred to Disability Employment Services, and of these over 3000 have been already been placed in employment.

Source: DEEWR.

The Commission considers that employment services should remain a mainstream concern. However, a clear exception would be 'job readiness' programs (targeted support) currently provided by the disability services sector. These intensive post-school programs last around two years, and help people in the transition to the workforce. The 'Transition to Work' program in NSW is a good example.

Housing

People with disability are key users of mainstream housing assistance provided by the Australian and state and territory governments. Assistance takes a variety of forms, including public and community housing, home purchase and home

ownership assistance, Indigenous housing, state and territory private rental assistance and Australian Government rent assistance. Of these, two are of particular relevance — Commonwealth Rent Assistance and public housing.

While the exact number of people with disability receiving Commonwealth Rent Assistance (CRA) is unknown, around one in five (220 000) recipients also receive the disability support pension. The Australian Government provided $2.9 billion for CRA in 2009-10, and the average payment across Australia was around $2500 per year.

Public housing

Public housing is an important source of affordable, stable accommodation for people with disability. At 30 June 2008, 31 per cent of public housing households contained a household member with disability (SCRGSP 2010). Across Australia, the average annual cost (including of capital) per public housing dwelling was $27 345 (SCRGSP 2011)[2].

Three aspects of public housing are particularly relevant to people with disability — the general availability of dwellings, the appropriate location of the dwellings and the suitability of the dwelling for the person. Some have expressed concerns about the adequacies of all three aspects:

> … the stock of public housing in Australia has fallen … much of this stock is seen to be physically inappropriate for persons with a disability because of the design of the dwelling, distance from public transport, poor quality maintenance etc. (Beer and Faulkner, p. 49-50).

The availability of public housing has decreased over recent years, with the number of dwellings falling from 343 000 in 2005 to 333 000 in 2010 (SCRGSP 2011). By comparison, there are around 200 000 applicants on the waiting list for public housing (table 4.2).

However, the share of special needs households[3] — including those with a household member with disability — is increasing as a proportion of all new households allocated public rental housing. Nationally, new public housing tenancies allocated to households with special needs was 65 per cent in 2009-10

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2 This figure is the cost of providing assistance (including the cost of capital) per dwelling (excluding payroll tax) expressed in 2009-10 dollars. For more detail refer to table 16A.4 in SCRGSP 2011.

3 Other households defined as having special needs are those with a principal tenant aged 24 years or under, or 75 years and over, or has one or more Indigenous members.

(table 4.2). Moreover, surveys suggest that the vast majority of public housing tenants for whom location was important, reported that their needs were met.[4]

Table 4.2 **Public housing shortages by jurisdiction**

	Total number of public rental dwellings at June 30, 2010	*Applicants on waiting list at June 30, 2010*	*New allocated households 2009-10*	*New allocated households for people with special needs[a] 2009-10*
	no.	no.	no.	no.
NSW	115 686	60 444	5 861	3 766
Victoria	65 064	50 716	3 799	2 298
Queensland	51 705	30 593	3 886	2 813
South Australia	42 010	25 302	2 249	1 575
Western Australia	31 501	23 723	2 400	1 490
Tasmania	11 460	3 675	921	605
Northern Territory	5 099	3 163	455	304
ACT	10 858	2 479	557	287
Australia	333 383	200 095	20 128	13 138

a Special needs includes any household meeting one of the following criteria: is an Indigenous household; has a household member with disability; the principal tenant is aged 24 years or under; the principal tenant is aged 75 years or over.

Source: AIHW (2011).

Problems regarding the availability and location of dwellings are common to all prospective clients of public housing. For that reason, decisions about where to locate public housing and how much to invest, should remain a mainstream policy concern. Nevertheless, there is scope to trial innovative models of service delivery that are more consistent with self-determination for people with disability. These include 'cashing out' (for accommodation purposes only) the value of public housing and allowing people more flexible accommodation choices.

The exact mechanism for doing this in relation to specialist disability accommodation, which was examined earlier, could also apply to public housing generally. And there are strong grounds for doing so. The availability of public housing is often a precondition for independent living. This model would require co-operation with state and territory governments.

4 As part of a national survey, tenants were asked whether particular aspects of the amenity and location of their dwellings were important to them and, if so, whether they felt their needs were being met. 86 per cent of survey participants, who identified location as being important, reported that their needs were met.

Even if access to public housing were improved, there is still the issue of dwelling suitability. All new public housing dwellings should meet any minimum standards for disability access and suitability. Nevertheless, that would still leave a legacy stock that may not meet even those standards, and even new dwellings may not meet the needs of a particular person. Nationally, around three quarters of public housing tenants for whom 'modifications for special needs' were important, reported their needs were met (AIHW 2011). As noted earlier, the NDIS would fund home modifications on a reasonable and necessary basis for people in both public and private housing.

Education

People with disability are more likely to experience poorer socio-economic outcomes. As the NSW Government observed, 'education has an important role to play in addressing this issue and preparing young people to participate in a rapidly changing and increasingly complex world' (2010b, p. 5).

Over the last two decades, there have been significant changes in the approach to educating students with disability. A driving force has been the assertion of the rights of students with a disability to be educated on the same footing within regular or 'mainstream' classrooms rather than in segregated settings. These changes have also been motivated by greater recognition that:

- children and young people with a disability need opportunities to learn and socialise with a broad range of other students if they are to maximise opportunities to participate in the workforce and community life
- mainstream participation of students with disabilities can reinforce positive attitudes to diversity, leading to social inclusion in the community. When children with and without disability interact together on a daily basis, there is potential for long-term acceptance and mutual support
- disability labels can be stigmatising and can lead to lower educational expectations. (NSW Government 2010b)

A significant and growing number of students with disability have enrolled in mainstream education over recent years. For example, in NSW, just under half of students with disability attend mainstream classes in mainstream schools. A further 40 per cent of students attend support classes in mainstream schools (NSW Government 2010b, p. 14).

This transition has been facilitated by several measures, including the Commonwealth Disability Discrimination Act and the Disability Standards for Education. These seek to overcome discrimination based on stereotyped beliefs

about the abilities and choices of students with disability. The standards cover enrolment, participation, curriculum development, accreditation and service delivery and student support services (box 4.3). The standards apply to government and non-government education providers. Under section 32 of the Act, it is unlawful for a person to contravene a disability standard and a complaint can be made to the Human Rights Commission.

The Disability Standards for Education require providers to make 'reasonable adjustments' to accommodate a student with disability. That might involve structural modifications for buildings to ensure better accessibility, aids and appliances to increase educational opportunity, teacher aides, development of new curriculum materials, and teacher training. Many of these expenditures are hard to attribute to a specific individual, since they often meet the needs of many students with disability.

Despite these measures, there remains considerable scope to improve education services and outcomes for people with disability. For example, a NSW Legislative Council Inquiry into the provision of education for students with a disability or special needs found that:

> The overwhelming view among inquiry participants is that there are significant inadequacies in the NSW education system for students with disabilities and special needs. The Committee believes that the NSW Government needs to take immediate action to address these inadequacies if it is to meet its legal obligations to ensure equal access to the education system for all children.
>
> Inquiry participants argued that one of the major barriers to the effective inclusion of students with disabilities and special needs in the education system is the lack of appropriate funding in both the government and non-government sectors (NSW Government 2010b, p xii).

The education sector should not have to meet all of the needs of students with a disability. At the same time, shared responsibilities needs to work effectively and not result in unreasonable loads on the individual or their carers. For example, Queensland Parents for People with a Disability highlighted the example of a child with disability attending a mainstream school where the parent was required to attend the school up to three times per day to toilet their child (trans., p. 598).

Rather, partnerships are essential for achieving positive outcomes for students with a disability. These include partnerships between families, communities and schools that are effective in identifying and responding to the needs of individual students as well as inter-agency approaches through collaborative planning and delivery of services.

Box 4.3 **Disability standards for education**

The *Disability Standards for Education 2005* aim to clarify the obligations of education and training service providers, and the rights of people with disability, under the *Disability Discrimination Act 1992* (DDA).

The Standards give students and prospective students with disability the right to education and training opportunities on the same basis as students without disability. This includes the right to comparable access, services and facilities, and the right to participate in education and training without discrimination. Education providers have a positive obligation to make changes to reasonably accommodate the needs of a student with a disability. The Standards apply to the provision of education and training to persons with disability by 'education providers', including the Commonwealth, states and territories and their public authorities, as well as private sector organisations.

An education provider must make 'reasonable adjustments' to accommodate a student with disability. An adjustment is a measure or action taken to assist a student with disability to participate in education and training on the same basis as other students. An adjustment is reasonable if it does this while taking into account the student's learning needs and balancing the interests of all parties affected, including those of the student with the disability, the education provider, staff and other students.

In determining whether an adjustment is reasonable, an education provider should take into account information about:

- the nature of the student's disability
- his or her preferred adjustment
- any adjustments that have been provided previously
- any recommended or alternative adjustments.

The provider may consider all likely costs and benefits, both direct and indirect, for the provider, the student and any associates of the student, and any other persons in the learning or wider community, including:

- costs associated with additional staffing, providing special resources or modifying the curriculum
- costs resulting from the student's participation in the learning environment, including any adverse impact on learning and social outcomes for the student, other students and teachers
- benefits of the student's participation in the learning environment, including positive learning and social outcomes for the student, other students and teachers, and
- any financial incentives, such as subsidies or grants, available to the provider if the student participates.

The DDA and the Education Standards do not require changes to be made if this would impose unjustifiable hardship to a person or organisation.

Source: Attorney Generals Department.

In this context, the NDIS would have a role in meeting some of the needs of students. This would be centred on the provision of goods and services that would be needed regardless of whether a person was attending school or not (personal attendant care, a hearing aid, or a wheelchair).

Health

Primary care and hospital (in-patient and outpatient) based services and medical and pharmaceutical products should remain a mainstream concern. As is the case with the community more generally, people with disability will continue to access the existing health care system as the need arises. Exceptions to this would be when an individual needs care that a familiar personal support worker is best placed to provide or where nursing care is an integral part of the care of the individual (for example, when meeting the care and support needs of a ventilated quadriplegic).

However, people with disability, and in particular intellectual disability, encounter a number of barriers to good health care. As Lennox et al. (1997) and the Centre for Developmental Disability Health Victoria observed:

- communication difficulties between patient and doctor may lead to difficulty in the reporting of symptoms and past history
- carers may not know, or be able to provide, an accurate and reliable history of the person's symptoms or previous medical care
- difficulties using transport can make it hard to independently access medical services and/or independently follow recommendations
- they may experience difficulties understanding the importance and long-term implications of healthy diet, lifestyle choices, and disease screening
- limited literacy may mean they miss out on health information in magazines, books and public health campaigns.

In these instances, the NDIS would have a role in reducing disability-specific barriers.

Transport

Access to transport is often a necessity for employment, social participation and access to other services such as health and education. As noted in the National Disability Strategy Consultation Report *Shut Out* (2009):

> Few things are more fundamental than the ability to get where one needs to go. Without access to transport, participation in such critical activities as education, employment

and health care is difficult, if not impossible. Yet this is the situation many people with disabilities find themselves in. (pp. 44-5)

However, access to transport is often poor for people with disability (box 4.4).

The goal of policy is to improve all aspects of transport for people with disability — through better access to mainstream public transport (for example, wheelchair accessibility) and private transport (such as by modifying vehicles), and through specific subsidies or provision of taxis and community buses. In some cases, this can be targeted directly by the NDIS. However, in many other cases, these goals will have to be pursued in the course of wider transport policy by state and territory governments.

Public transport

Many people with disability are physically able to use public transport, either with or without assistance. In 2003, around 87 per cent of people with a core activity limitation indicated that they could use all forms of public transport. A further 9 per cent indicated that they could use some forms of public transport, while 4 per cent said they could not use any (ABS 2003). Barriers to the use of public transport take several forms.

A significant proportion of the public transport network is not accessible to some people with disability. A five year review by Allen Consulting Group (2007) noted that the introduction of the Disability Standards for Accessible Public Transport in 2002 had led to a focused and systematic approach to improving accessibility. That said, the review also highlighted the lack of comparable data to properly gauge the impact of the Standards.

Improvements in accessibility generally relate to the replacement of legacy vehicles. As such, the improvement of accessibility to public transport mainly depends on state and territory governments' ongoing upgrades of public transport.

Barriers do not solely relate to the physical accessibility of public transport and associated buildings and infrastructure. The affordability of public transport can be a major issue for people with disability as well as the wider community. Some initiatives have been able to reduce the additional costs faced by people with disability. For instance, the Companion Card allows free public transport travel for carers and attendants of people with disability.

Box 4.4 The importance of public transport

Several parties raised concerns about the availability of accessible and affordable transport:

> A priority is the need to ensure people have access to affordable transport. The public transport system is generally hard to navigate in the Perth metropolitan area, and taxis are expensive — even when subsidised with a taxi voucher. (Headwest Brain Injury Association of WA, sub. 448, p. 12)
>
> The lack of cheap and accessible transport continues to be a barrier for community access, employment, social and recreation options even attending health & medical appointments. Transport options for people with disabilities needs to be a major consideration, if community inclusion and participation are to be achieved. (City of Port Adelaide, sub. 64, p. 2)
>
> Restricted access for people with disabilities to mainstream public transport, and transport funded under other programs such as HACC, places pressure on the CSTDA and/or on people with disabilities themselves to locate and pay for appropriate transport services. There have been anecdotal reports of CSTDA flexible respite funding being used to pay for transport assistance (AIHW 2007).

Lack of accessible public transport was also raised as an issue during consultations for the 'Shut Out' report:

> Submissions consistently reported that lack of access to transport significantly curtails the ability of people with disabilities to participate fully in community life — more than 29 per cent of submissions argued that difficulties with transport act as a barrier in their day-to-day lives. And while most agreed some progress has been made, all said that the timetable for change is far too long. As many noted, the Disability Standards for Accessible Public Transport (2002) has a 30-year timetable. These same standards stipulate that only 50 per cent of buses have to be accessible by 2012.
>
> For most, the inaccessibility of public transport leaves them reliant on family or friends or on the taxi system. Both compromise their ability to live independently. And while most states operate a taxi voucher scheme, few provide enough assistance to meet day-to-day needs. This leaves people with disabilities and their families with no other option but to meet all additional costs (p. 45).

The availability of public transport is also an issue for people with disability. But a lack of services, particularly in regional areas, is an issue for the wider community. The Commission considers that the provision of public transport, including the planning of public transport routes, is and should remain a mainstream concern. However, an NDIS may be well placed to contribute to future discussions of national accessibility standards, provide useful data, as well as help identify barriers and failures in public transport.

Australian disability parking scheme

State and territory disability parking schemes were made nationally consistent from September 2010. Under the Australian Disability Parking Scheme, a single permit

allows the same parking rights within and across states. The distribution of disability parking permits continues to be a function of state and territory road authorities.

The NDIS would not be well placed to take over the assessment for *all* parking permits, simply because the population accessing permits is likely to be broader than those receiving NDIS assessments (including those with temporary injuries). As such, state and territory road authorities should continue to oversee access to such permits. However, the scheme could act as an assessment agent (on behalf of state and territory road authorities) for NDIS clients who require disability parking permits and, with the agreement of states, issue these permits. The Commission has explored a number of options to help minimise multiple, often duplicative, assessments (chapter 5).

Accessible taxis

Taxis provide one of the main modes of transport currently available to people with disability, particularly for those for whom public transport is not accessible. Each jurisdiction has a subsidy scheme for taxis. However, many people continue to experience great personal expense when reliant on this form of transport:

> By far my most significant on-going expense is the cost of transport to and from work. I am totally reliant on using taxis as I cannot access other forms of public transport. This costs me an average of $120 each week in taxi fares. This figure is after the 50% discount I receive on the metered fare from the NSW Taxi Transport Subsidy Scheme and $40 a week I receive from the Commonwealth Mobility allowance … The high cost of transport is an active disincentive in obtaining and maintaining employment, especially at the lower end of the wage scale … I travel a distance of 11.2 km each work each way. Many people with disabilities would need to travel much further to access suitable employment.
>
> … since 1990 when I began work, taxi fares have increased by an average of 2.5% per year. In 1990 the trip cost $12 each way, which is $6 after the subsidy. Now the same metered fare is $30 to $32 each way or $15 to $16 after the subsidy is considered … In the same time, the phone booking fee has increased from $0.50 to $2.20. The hiring fees has gone up from $1.00 to $3.30 When these fare increases are combined with the many tolls that apply in the Sydney metropolitan area the distance that can be travelled with a $30 fare subsidy is continually shrinking. (Margaret Ann Burke, sub. 197, pp. 2-3)

This not only highlights the real reduction in many taxi subsidies over time, but also the potential expense in the subsidies themselves. Overall, taxis will continue to be of great importance, particularly given public transport networks are not fully accessible. The need for these services (and the associated budget) would be considered as part of people's individual NDIS assessments.

The Commission seeks feedback on how to ensure that funding support given for taxis under the NDIS is kept within reasonable bounds.

Encouraging savings

Private funds have been seen as a partial remedy to the chronic rationing of disability services. The Australian Government introduced Special Disability Trusts in Australia in 2006 to help people privately finance essential supports for people with disability. Disability trusts have some advantages over other trusts.[5] To address possible risks of being misused, disability trusts are subject to strict criteria covering the trust's purpose, beneficiary, and size.

Disability trusts have historically had low take-up rates. In 2008, there were 33 active disability trusts, although another 262 applicants had been granted eligibility (Senate 2008). Indeed, several commentators have questioned whether disability trusts are practical for the majority of people with disability, noting the large costs involved, and hence the emphasis on larger, rather than smaller asset pools. Moreover, Disability Trusts have been characterised as a way of transferring assets rather than a way of promoting savings:

> … because SDTs are individual trusts they are expensive to establish and maintain as they need auditing, and they are likely to pay retail rather than low-cost wholesale fund management fees (DIG 2009, p. 34).
>
> … Nor is the Special Disability Trust viable for small amounts of capital that are still of a size to affect the pension entitlements. The message for parents is make no provision for your family member unless you have the capacity to provide considerably. (sub. 43, p. 2)

Special Disability Trusts appear to be of limited use for most people with disability, bearing in mind that many families experiencing disability have lower assets and income. Further, with a fully functional NDIS, there would be much less need for such measures. The Commission considers that the role of Special Disability Trusts should be reviewed once the NDIS is up and running.

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5 For example, Special Disability Trusts offer concessions on means and assets tests for social security payments. These concessions apply to payments for both the beneficiary and the contributors of the trust. By forming a disability trust, a parent caring for a child with disability may transfer assets to the trust, and thereby not have these assets counted towards the means test of a social security payment.

Improving access to mainstream services

As noted earlier in this chapter (and in chapter 3), the Commission considers that the NDIS should have a role in connecting people to mainstream services. Where people approach the scheme for supports that would be more appropriately addressed by a mainstream provider (public or private), the scheme should endeavour to 'connect' people to the relevant provider. That might be as simple as giving them a contact name or number. In other cases, that might involve making an introductory call on their behalf. These 'warm referral' services might be important for particular groups, for example, those with intellectual disability, or in particular circumstances, such as in more urgent or serious matters. In other cases, it might be appropriate for the NDIS to act as an advocate for individuals when dealings with mainstream providers.

The Commission considers that the NDIS should also have a public reporting role. This would involve reporting annually on the progress made by governments, in the areas of education, housing and transport, to improve services to people with disability. In doing so, the scheme could draw attention to both good and bad examples.

4.4 Income support

The Australian Government is responsible for the provision of income support targeted to the needs of people with disability, their families and carers (box 4.5). As well as the DSP (described earlier), income support payments and allowances include Carer Payment, Carer Allowance, Sickness Allowance, Mobility Allowance and Child Disability Assistance Payment.

The Commission considers that the DSP should be outside the NDIS. It is an income support payment, like an unemployment benefit. It covered 793 000 people in June 2010, well beyond the numbers eligible for funded support under the NDIS (around 359 000). It includes people whose incapacity for work is due to illness or injury and people without a lifelong disability, who do not need the individualised supports that the NDIS would provide.

However, there are grounds for (further) reform of the DSP, given that its design can significantly undermine the NDIS's goals of better economic, employment and independence outcomes for people with a disability. Successful reduction in DSP numbers would also provide a financial offset for the NDIS, noting that the present value of 30 years of one person's entitlement to the DSP is around $500 000 and that the budgetary cost of the DSP was around $12 billion in 2009-10.

Box 4.5 Australian Government income support payments and allowances

Under the National Disability Agreement, provision of income support for people with disability, their families and carers is a key responsibility of the Australian Government. Outlays on income support payments and allowances to people with disability and their carers in 2009-10 (on an accrual basis) amounted to $11.6 billion for the Disability Support Pension, $2.3 billion for the Carer Payment, $1.5 billion for the Carer Allowance, $83.7 million for the Sickness Allowance, $124.0 million for the Mobility Allowance and $152.3 million for the Child Disability Assistance Payment. The Carer Supplement was not paid in 2009-10.[6]

At 30 June 2010, there were around 792 600 recipients of the Disability Support Pension, 168 900 recipients of the Carer Payment, 508 600 recipients of the Carer Allowance, 57 300 recipients of the Mobility Allowance, 6700 recipients of the Sickness Allowance and 152 400 recipients of the Child Disability Assistance Payment.

Source: SCRGSP (2011, box 14.3, p. 14.8).

Reforms would aim to encourage the view that the norm for many people should not be the long-term use of the Disability Support Pension (unlike the current 'until death or aged pension us do part'). Those changes would be mainly orientated to people with typically non-permanent conditions, like anxiety and depression, and at people who could have much higher hopes for employment participation (for example, those with sensory impairments or mild intellectual disabilities). Some policy measures could include additional payments for people to work, targeted rehabilitation, employer support, measures to encourage people to get a small foothold into work (even if just a few hours a week), and temporary rather than effectively permanent entry to the Disability Support Pension for those with reasonable prospects of employment (with periodic re-assessments). There may be other ways of providing people with disability better opportunities for employment.

New measures would save taxpayers' money, but the prime motivation would be to improve people's genuine participation in society and to raise their lifetime income — consistent with the goals of the NDIS. This issue will be examined more closely after the draft report.

Other payments sometimes classified as income support — Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance, and the Child Disability Assistance Payment — are really payments for support of people with a disability,

6 The first payments of Carer Supplement were made in June 2009. Future payments of Carer Supplement will be paid to those who are receiving Carer Payment and/or Carer Allowance on 1 July each year, starting from 1 July 2010.

since they encourage the provision of informal care or address people's mobility needs. These payments apply to a broader population than that covered by the NDIS (particularly care for the aged).

One option would be to add the value of any relevant payments to the individualised packages of people with a disability who qualify for funded supports under the NDIS. (People outside the NDIS would continue with the current arrangements.) Where individuals opted for full self-directed funding, the person with a disability or their guardian would manage the funds. That way, people with a disability would have maximum flexibility and might decide to choose alternative carer options. The inclusion of payments, which aim to encourage informal care (such as Carer Payment), would be particularly relevant if the NDIS ultimately permits payment of family members. It would be incongruous not to combine the pools of money and allow people to determine how much they want to pay family carers or others to provide support.

However, this is a complex area, and the Commission seeks feedback about this option. Either way, NDIS assessments should take account of any of these payments — with information sharing with Centrelink.

The Commission seeks feedback about whether Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance, and the Child Disability Assistance Payment should fall within the scope of the NDIS.

4.5 The basis for providing specialist disability supports

A key point of distinction between existing arrangements and those proposed under an NDIS would be the obligation for the scheme to deliver the package determined by the independent assessment of need, rather than the present arbitrarily rationed amount. This feature is an essential element of avoiding the chronic underfunding that has beset the current disability system. However, that does not mean that the provision of supports will be unconstrained. Indeed, in other, better resourced schemes — such as no-fault accident insurance schemes that provide lifetime care and support for catastrophic injuries — service provision is 'bounded' by the concept of reasonable and necessary.

For example, in NSW, the Lifetime Care and Support Authority stated:

> we will pay your reasonable and necessary treatment, rehabilitation and care services … This is decided on a case by case basis, and means you will get what you need — not things that are simply nice to have … (LTCSA 2011).

Both the NSW LTCSA and the Transport Accident Commission (TAC) in Victoria have refined the concept of 'reasonable and necessary' in general terms, as well as for the provision of specific services, such as home modifications (box 4.6). The guidelines provide a useful template that could be adapted by the NDIS. As is the case with LTCSA and TAC, 'reasonable and necessary' guidelines will need to change over time, to take account, among other things, of changes in technology and community norms.

'Reasonable and necessary' criteria

The NSW Lifetime Care and Support scheme has particularly well developed general guidelines for determining whether a support or service is reasonable and necessary. Guidelines are based on a number of considerations, many of which would be equally relevant for a NDIS. Guidelines would inform resource allocation decisions. (Where an individual elects to have self-directed funding, they would have greater flexibility to decide how best to use that budget to meet their needs.) The Commission recommends the following guidelines, adapted from the NSW Lifetime Care and Support scheme:

- the benefit to the participant
  - there are goals, expected outcomes and an expected duration for the requested support or service
  - there is evidence to show the requested support or service will benefit the participant. For example, the outcome will progress or maintain the participant's functionality
- appropriateness of the support or service request
  - the service is in keeping with current clinical practice, evidence-based practice and/or clinical guidelines
  - other services or supports will not provide an improved or equal outcome
  - the requested service or support is consistent with the participant's other supports and relates to their goals as outlined in their individual support plan
  - the support request would meet the community's perception of what is appropriate, given that the NDIS reflects the pooled contributions from all Australians.

- appropriateness of the provider
  - the provider is appropriately experienced to provide the support service (and *where appropriate* qualified and/or registered)
  - the provider does not have conflicts of interest that may result in over-servicing or direction of people to less effective supports or services
  - the provider is appropriate considering the participant's age, ethnicity and any cultural and linguistic factors
- cost effectiveness considerations
  - consideration has been given to the long-term compared to the short-term benefits of the service, based on evidence-based practice, clinical experience or consensus
  - the long-term and short-term benefits, including social benefits, and expected outcomes of the proposed support or service have been considered and are likely to outweigh the costs
  - the cost of the proposed support or service is comparable to those charged by providers in the same geographical or clinical area
  - the support or service represents the most cost-effective option of those available. For example, where equipment or modifications are required, factors relating to lease or rental have been carefully considered and compared to the cost of purchase.

The Commission proposes a further criterion, that being:

- the support or service would be most appropriately provided through the NDIS
  - the support or service would not be more appropriately delivered by a mainstream government service (like the health system)
  - taking account of community norms, the support or service would not be addressed better at an individual, familial or informal support network level. For example, community norms suggest that parents would provide sleepover care for a young child who was a passive sleeper.

Box 4.6 Applying the concept of 'reasonable and necessary' to the provision of home modifications — an example

The NSW Lifetime Care and Support Authority takes account of a range of factors when deciding if a home modification is 'reasonable and necessary'. These include:

- the anticipated length of time that the participant will need home modifications and whether this need is likely to change
- structural constraints, for example, size, surrounding terrain and the condition of the home
- ownership of the property
- permission of the owner or body corporate to temporarily or permanently undertake modification to the home
- local planning regulations and building permits
- length of lease of a rental property
- anticipated period of occupancy of the home to be modified
- the scale and cost of the proposed modifications relative to other residential options.

Source: LTCSA 2010 — Lifetime Care and Support guidelines, part 14.

An important implication of this last criterion relates to the transition to independent living. Under current arrangements individuals with disability, particularly intellectual disability, remain in the family home for considerably longer than is the community norm (figure 4.1).

The scheme would facilitate the transition of young adults into independent living or supported accommodation, if they wished to do so, in line with community norms.

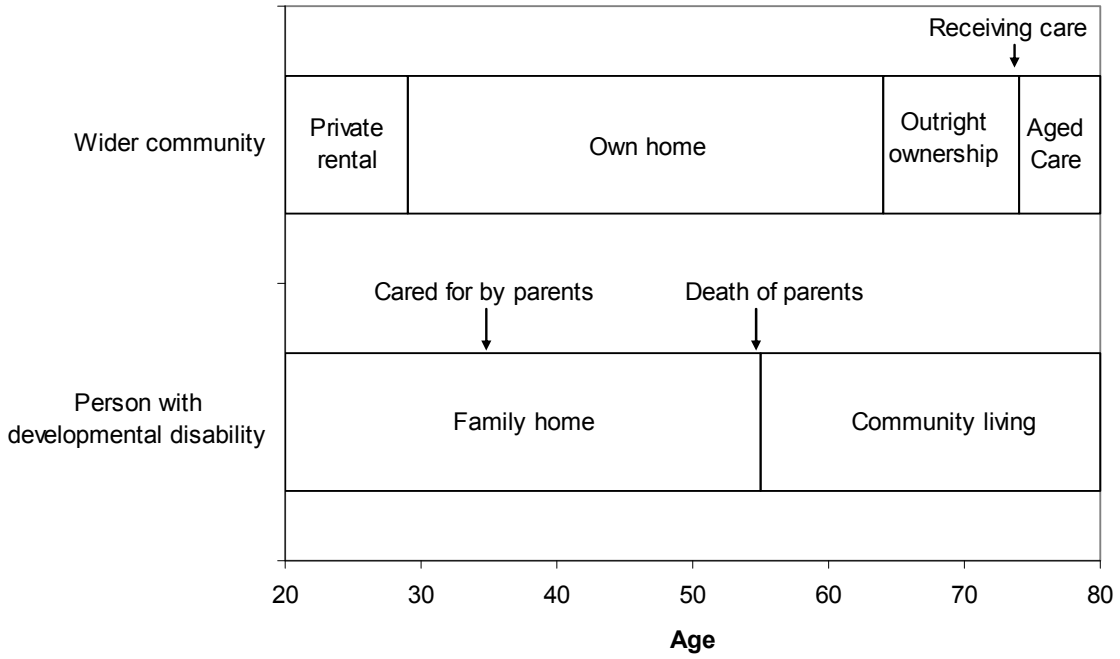
A number of participants supported this objective:

> All young adults with a physical and/or intellectual disability have the right to move out of home, be settled and live their own lives and, in a compassionate society, parents should be able to see their child successfully settled in their own home, with a working and appropriate support system in place, long before death! I want to see my daughter in her 'own' home long, long before I am no longer able to look after her myself. I don't want to be carted off to the Nursing Home or Crematorium, while my daughter stands bewildered at the front door of the only home she has ever known, while a stranger packs her suitcase (personal response).
>
> I am the mother of a 13 year old with Rett Syndrome. My daughter does not speak or walk, is incontinent and has uncontrolled epilepsy. She needs me or another carer to look after her every need.

I love having her at home while she is school age but I do not want to be taking care of her in our home for the rest of my life. I would like to have my daughter set up in a home with one or a few other children like her by the time she is 21. (Katrina Clark, sub. 391, p. 1)

I am the same as any parent. I love both my sons, I want them to live with me for about 20 years and I want them to be happy and safe for their whole lives. (name withheld, sub. 74, p. 17)

Figure 4.1 **Indicative housing careers**[a]



[a] Housing careers are indicative of trends in large groups, and will not apply in many individual situations.

Data source: Adapted from Beer and Faulkner (2008, figures 2.2 and 2.5).

4.6 Means testing, front-end deductibles and co-payments

Means testing is a common feature of long-term care and support schemes internationally, particularly in those schemes that target the aged.

Income and assets are relevant to a NDIS in two ways.

- In theory, some people could be unable to access individually-tailored, NDIS-funded services *altogether* because their income or assets exceeded a threshold level. (This is a common feature of income support payments from the Australian Government). However, it does not apply to Medicare, with people eligible for subsidised services regardless of income.
- People could pay a greater co-contribution if they had sufficient means (as in the Pharmaceutical Benefits Scheme (PBS)).

So long as the disability is sufficiently severe, there are weak grounds for removing access to services based on a person's income and assets. In effect, a tax-funded NDIS amounts to the compulsion for people to insure themselves for the costs of support associated with a disability.

Under the Commission's proposed funding arrangements, the well-off would pay a much larger contribution towards the NDIS than medium and low income earners.[7] It would be both inequitable and inefficient to exclude people from NDIS supports solely on the basis of income. It would be inefficient because high-income people still value insurance for catastrophic events, and would not be able to participate in the most efficient way of providing that insurance (or in some instances to access any insurance at all, such as when there might be a family history of certain conditions). It would be inequitable in that high-income people would have to contribute to the costs of a scheme that they could not actually draw on, even when facing a catastrophic disability.

Moreover, such arrangements are likely to dampen incentives to work and/or save, by acting as a high effective marginal tax rate. A number of participants commented on the adverse incentives embodied in such arrangements:

> The scheme must not be means-tested. The disincentives to workforce participation inherent in a means-tested scheme would far outweigh any savings to be made. (Maree Ireland, sub. 233, p. 2)
>
> I strongly believe that a long-term disability support system must be needs based and not income based … To do otherwise provides a huge disincentive to people with disabilities seeking employment, and the improvements in socio-economic circumstances that brings (name withheld).

[7] The Commission's preferred funding option is for the Australian Government to direct payments from consolidated revenue into a National Disability Insurance Premium Fund. Since Australia's tax system is progressive, the well-off would make a higher contribution.

Hence, the Commission proposes that the NDIS would not include any income or assets test.

A second, related question is whether individuals should face:

- a requirement to pay a fixed upfront contribution to the NDIS, with free access to services after that point (so-called 'front-end deductibles'). In effect, a front-end deductible is a dollar amount below which an insurer, in this case the NDIS, would not share in the costs of care
- a contribution to the costs of services as they are used (such as in PBS prescriptions)

Front end deductibles

Front-end deductibles routinely feature in insurance products, including motor vehicle and health insurance. They are seen as desirable by insurance providers since:

- the administrative costs of dealing with small claims offset some of the benefits of insurance and so make full coverage undesirable
- when insurance covers the costs of a service, people will request more services than they would without insurance, and these incremental services will be valued by the individual less than they cost the insurance pool (often referred to as 'moral hazard')
- deductibles enable governments to charge lower premiums for a given budget
- they are an upfront fixed cost and so beyond the initial threshold, do not affect individuals' decisions around whether to engage additional services (as distinct from co-payments).

There are good grounds for employing front-end deductibles in the NDIS. The Commission considers that an annual front-end deductible of say $500 should apply. This would be consistent with the broad approach adopted in other 'safety net' measures, such as the Medicare Safety Net.

However, there would be many people who already face an 'invisible' front-end deductible. Those people who rely on natural supports to meet many of their care and support needs are already contributing significantly towards the costs of their care. It would be inappropriate for these individuals to be effectively subject to a second payment. The Commission considers that needs assessments should take account of the extent of natural supports, and that the NDIS should waive the front-end deductible where the value of this support exceeds some government

determined level. The Commission would welcome feedback on what that level should be.

The Commission considers that needs assessments should take account of the extent of natural supports, and that the NDIS should waive the front-end deductible where the value of this support exceeds some government determined level. The Commission would welcome feedback on what that level should be.

Co-payments

As with front-end deductibles, co-payments are intended to address problems of moral hazard. The premise is that when individuals have to contribute (even if only partly) to their ongoing care costs they use only essential care and support services. Waste is eliminated and costs reduced with no effect on outcomes.

While true on an individual level, difficulties arise when applying uniform co-payment arrangements to a broad set of services or users. This is because interventions differ in their therapeutic benefits and the value of a specific intervention varies across users. In these circumstances, across-the-board co-payments can discourage the use of even high-value supports. Indeed, studies suggest that more efficient resource allocation occurs when co-payments are a function of the value of a specific service to a targeted group of individuals (box 4.7).

Consistent with international best practice, the Commission considers that the NDIS should fully fund the number of episodes of *therapy* that were appropriate to the person and were supported by clinical evidence, with people choosing further episodes meeting their full costs. This would stem over-servicing, which was a problem in the New Zealand context. (In chapter 11, the Commission proposes that the NDIA build an early intervention evidence base. This would help guide the development of clinical protocols governing the optimal intensity and duration of therapeutic early interventions.)

Contributions post pension age

As discussed in the previous chapter, individuals could elect to remain in the NDIS after reaching pension age. Where that is the case, they would contribute to the costs of their care and support, as if they were in the aged care system (chapter 3).

Box 4.7 The evolution of co-payments in health services

The impact of co-payments on service use and outcomes in the area of health has been a source of academic, government and general interest. Research has provided a number of valuable insights, which are also relevant in the area of disability support.

It is widely accepted, based on considerable evidence accumulated over decades of study, that higher cost sharing will lead to reduced healthcare expenditures. However, the impact of cost sharing on health status has been much more controversial.

The RAND Health Insurance Experiment was consistent with other research, in that it found that patients reduced utilisation of services deemed clinically appropriate by the same amount as they reduced the use of services deemed clinically inappropriate.

Ideally, co-payments should be structured in a way that does not dampen incentives to use high-value services. And as clinical research advances, more sophisticated cost-sharing strategies are possible. Rather than apply across the board co-payments, 'benefit-based' co-payments are now finding favour. The co-payment for a given service is based on its expected clinical benefits to a certain patient population, as determined by evidence-based medicine. The greater the expected clinical benefit, the lower the co-payment.

In contrast, low-value or unproven services are subject to higher co-payments (up to 100 per cent of the cost). In this context, low value goes beyond waste and inappropriate care to include interventions that deliver positive but limited benefits relative to their costs.

Source: Chernew and Newhouse (2008), Fendrick and Chernew (2006) and Fendrick et al (2009).

DRAFT RECOMMENDATION 4.1

The NDIS should cover the current full range of disability supports. The supports would need to be 'reasonable and necessary'. The NDIS should also support the development by the market of innovative support measures (using the approaches set out in draft recommendation 8.3).

DRAFT RECOMMENDATION 4.2

There should be no income or asset tests for obtaining funded NDIS services.

DRAFT RECOMMENDATION 4.3

There should sometimes be a requirement to pay a modest fixed upfront contribution to the NDIS, with free access to services after that point. The NDIS should waive the amount where families have already contributed significantly towards the costs of support through unpaid care.

DRAFT RECOMMENDATION 4.4

People should pay the full costs of services (primarily therapies) for which clinical evidence of benefits are insufficient or inconclusive if they wish to consume those services.

DRAFT RECOMMENDATION 4.5

Services that meet the needs of much wider populations, including people with disabilities not covered by the NDIS, should lie outside the scheme:

- ***health, public housing, public transport and mainstream education and employment services, should remain outside the NDIS, with the NDIS providing referrals to them***
  - ***but specialised employment services, disability-specific school to work programs, taxi subsidies, and specialised accommodation services should be funded and overseen by the NDIS.***

DRAFT RECOMMENDATION 4.6

The Disability Support Pension (DSP) should not be funded or overseen by the NDIS. The Australian Government should reform the DSP to ensure that it does not undermine the NDIS goals of better economic, employment and independence outcomes for people with disabilities. Reforms should aim to:

- ***encourage the view that the norm should not be life long use of the DSP, among:***
  - ***people with non-permanent conditions***
  - ***people with permanent conditions who could have much higher hopes for employment participation***
- ***provide incentives for people to work (even if only for a few hours per week) and for targeted rehabilitation for those with reasonable prospects of employment.***

These reforms should not be limited to new entrants into the DSP.

5 Assessing care and support needs

Key points

- The assessment process would:
  - assess the nature, frequency and intensity of an individual's support needs, regardless of how these might be met. While the process would be person-centred, it would be focused on what was reasonable and necessary
  - consider what willingly and reasonably could be provided by informal carers. Informal carers who met a large share of a person's support needs would receive their own assessment
  - translate identified needs into a person's individualised package to be funded by the NDIS, after taking account of natural supports.
- The NDIS would periodically re-assess people's needs as their circumstances changed, especially at key transition points.
- A coherent package of tools (a 'toolbox') should be employed to determine the support needs and funding for a person covered by the scheme. Different tools would be suited to particular needs for support (for example, the need for aids and appliances compared with attendant care). Any tools used by the NDIS should be rigorous, valid (testing what they purport to), reliable (giving consistent results) and cost-effective. Tools should be open source, rather than privately copyrighted.
- There is no ideal tool to use in the NDIS, but governments should not delay implementation of the scheme in the absence of 'perfect' tools. The NDIS would use the best available tools in its initial stages, with the later development of better tools.
- Excessively tough use of the assessment tool would be unfair, but 'loose' use would threaten scheme sustainability. To guard against both:
  - assessments would be conducted by allied health professionals approved or appointed by the NDIA and trained in the use of the tools. They would be continually assessed for their appropriate use of the assessment tools
  - the assessments would not be 'rubber stamped'. Prior to making budgetary decisions, the NDIA would confirm that the particular assessment followed the appropriate protocol, and was consistent with a 'benchmark' range of assessed needs for other people with similar characteristics. Deviations outside the norm would need to be justified
  - any tools employed would be continually monitored and refined.

5.1 Introduction

One of the primary functions of the NDIS will be to provide individualised, funded supports. A robust process for determining who gets what will be critical for both scheme users and administrators. An assessment tool must provide a reasonably close estimate of a person's support needs and the resource allocation to achieve it. It should avoid being too generous or too tough. The process must be fair, rigorous and safeguard against exaggerated claims of support needs.

At the most general level, the assessment process will be about identifying the supports that would allow a person to fulfil a range of functions, such as participate in their community. However, there are many issues to resolve regarding the design of the assessment tool(s) including:

- what is being assessed, and across what 'domains' or range of life activities (section 5.2)
- the purpose of the assessment process beyond indentifying an individual's support package (section 5.3)
- desirable features of assessment tools, such as validity, reliability and rigour (section 5.4).

Having regard to the intended role of assessment tools in the context of a NDIS, it is useful to then consider:

- the range of tools currently available (section 5.5)
- whether a single tool will be universally appropriate or whether the scheme should employ a 'toolbox' (section 5.6).

The remainder of the chapter considers a range of issues relating to the tools' use, such as:

- who should conduct assessments (section 5.7)
- when, over the course of an individual's life, assessments should take place (section 5.8)
- whether carers should have their own assessment (section 5.9)
- how a 'typical' assessment process might work and the importance of calibration and checking for fairness and scheme sustainability (section 5.10)
- how to ensure that tools are applied rigorously, including safeguards and processes for adapting and refining them over time (5.11)
- the transition to a fully developed toolbox (section 5.12).

5.2 What is being assessed?

Needs, wants and aspirations

An obvious first question to pose with respect to assessment is 'what is being assessed'. The scheme should meet reasonable *needs* (chapter 4). Broadly speaking, Victoria's Transport Accident Commission (TAC) and the NSW Lifetime Care and Support Authority (LTCSA) have this as their objective. In these schemes, the assessment process focuses on needs rather than wants. The TAC for example, states: 'The needs of every person are different, and the TAC looks at each case individually when determining what to pay' (TAC 2011). While the NSW LTCSA notes 'you will get what you need, not things that are simply nice to have' (NSW LTCSA 2011).

But defining and determining 'need' is by no means straight forward. There is a danger that people will ratchet up their claims for support by presenting wants as needs.

The United Nations has noted the complexity involved:

> Defining and determining need is easier said than done. It is not value-free, as who determines it, how it is determined and for what purpose it is done, will all affect the outcome. Neither the methods used to identify needs nor the concepts of social needs have been clearly defined. (ESCAP 2003)

A similar view was put by Anglicare Australia:

> Throughout the social policy and justice histories needs have played an integral role for the planning and development of policy and program responses. However over the course of those histories there has never really been a consensus on what needs are and there is even more contention over the derivation of particular types of needs. (sub. 594, p. 6)

A number of academics such as Maslow (1954), Harvey (1973) and Bradshaw (1972) have attempted to 'unpack' the concept of need. Of those, perhaps Bradshaw's work is the most informative from a social policy perspective. Bradshaw distinguishes between four types of social needs — normative, felt, expressed and comparative (box 5.1). This framework is relevant in disability policy. As Anglicare observed:

> … the needs identified by Bradshaw, particularly perceived [felt] and normative needs resonate most closely with the types of need identified by Anglicare Australia network members. (sub. no 594, p. 6)

Box 5.1 **Unpacking the concept of need**

Bradshaw's framework involves four different ways of thinking about 'need'

Normative need is defined by reference to 'appropriate' standards or required levels of services or outcomes determined by expert opinion. Individuals or groups falling short of these standards are defined as being in need. But normative need is by no means absolute, as Bradshaw observes, normative need 'may be tainted with a charge of paternalism'. Moreover, experts may have different and possibly conflicting standards.

Comparative need is determined by comparing the resources or services available in one area — be it a community, a population group or individual — with those that exist in another. A community, population group or person is considered to be in 'need' if they have say more health or social problems, or less access to services, than others. The main problem with the concept of comparative need are its two underlying assumptions — first, that similarities exist between the areas and second, that the appropriate response to the 'problem' is to align service levels. This need not hold true, for example, when both areas experience chronic shortages for a particular service.

Felt need has a subjective element and is defined in terms of what individuals state their needs to be or say they want. It can be defined easily by asking current or potential service users what they wish to have. But felt need by itself is generally considered to be an inadequate measure of 'real need'. For example felt need can be inflated by users' own high expectations.

Expressed need is defined in terms of the services people use. It is based on what can be inferred about a person or a community by observing their use of services (or waiting lists for services). A community or person who uses a lot of services is assumed to have high needs. While a community or person who does not, is assumed to have low needs. But expressed need is influenced by the availability of services — a person cannot use or put their name down on a waiting list for a service that is not offered.

Source: Bradshaw (1972).

Taking account of aspirations

While the assessment process would primarily be about assessing an individual's needs, it should not disregard their aspirations. The Commission sees merit in the approach employed in the United Kingdom whereby:

> The purpose of a community care assessment is to identify and evaluate an individual's presenting needs and how these impose barriers to that person's independence and/or well being. Once eligible needs are identified, councils should take steps to meet those needs in a way that supports the individual's aspirations and the outcomes that they want to achieve. (UK Department of Health 2010, p. 20, p. 27)

The intention would be to assess 'reasonable and necessary' support needs, but within this objective, the assessment process would consider people's aspirations.

Aspects of life

Individuals lead multi-faceted lives and so a second question to consider is how broad ranging the assessment process should be. Many assessment tools are designed to provide a rounded picture of an individual's needs and related circumstances. The tools themselves are simply a collection of scales and questions, which are often grouped in common or related life areas referred to as 'domains'. Examples of domains that are potentially relevant for assessing care and support needs include, but are not limited to, self-care, mobility and communication.

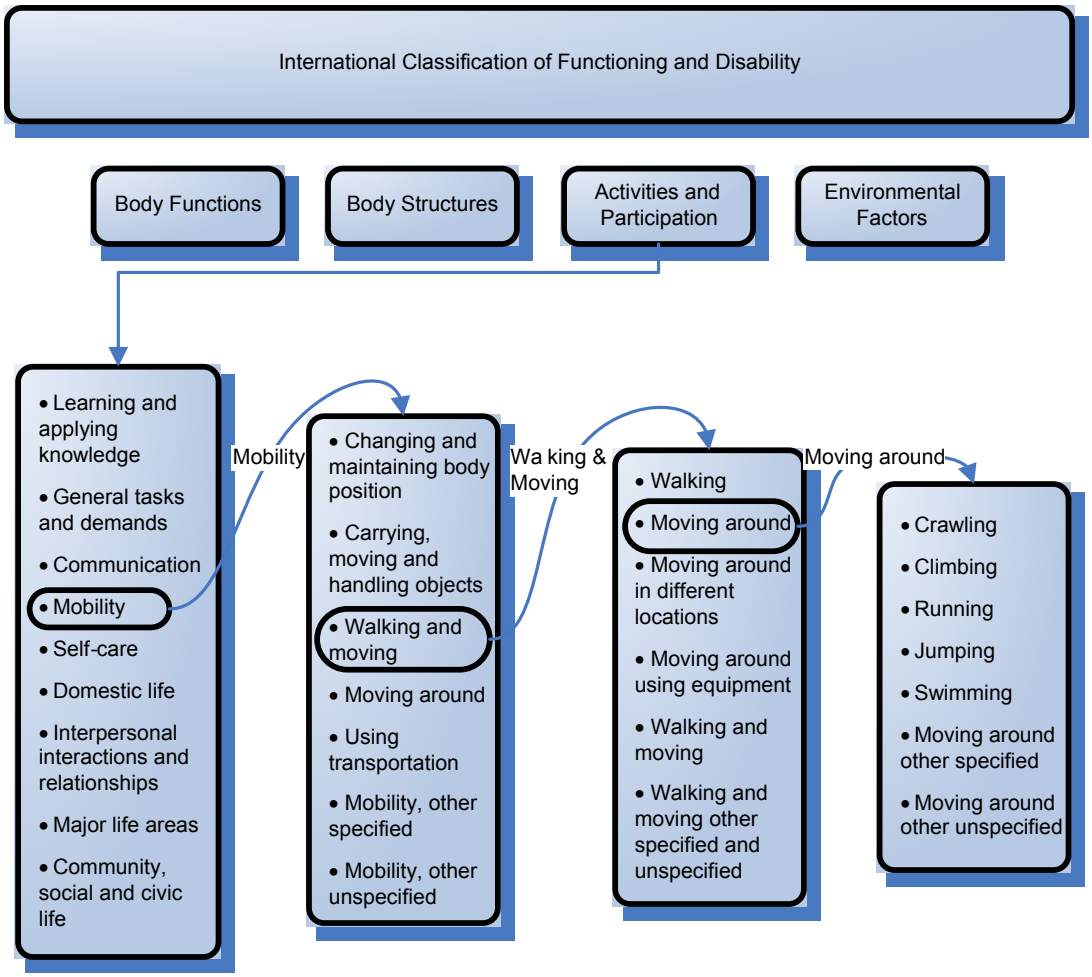
The International Classification of Functioning (ICF) — the World Health Organisation's (WHO) framework for measuring health and disability at both individual and population levels — lists nine 'activities and participation' domains of relevance:

- **communication** communicating by language, signs and symbols, carrying on conversations, and using communication devices and techniques
- **mobility** walking, running or climbing, changing location or body position, carrying, moving or manipulating objects, and using various forms of transportation
- **self-care** attending to one's hygiene, dressing, eating, looking after one's health and staying alone
- **domestic life** carrying out everyday tasks such as acquiring necessities (like a place to live and goods and services), preparing meals, caring for household objects and assisting others
- **interpersonal interactions and relationships** relating with strangers, formal and informal social relationships, family and intimate relationships
- **learning and applying knowledge** learning, applying the knowledge that is learned, thinking, solving problems, and making decisions
- **community, social and civic life** engaging in community, civil and recreational activities
- **general tasks and demands** carrying out single or multiple tasks, organising routines and handling stress
- **major life areas** carrying out responsibilities at home, work or school and conducting economic transactions.

Each of the nine domains (such as mobility) consist of facets or blocks (such as walking and moving) within which are nested groups of second, third and sometimes fourth-level categories (figure 5.1).

Figure 5.1 **The International Classification of Functioning, Disability and Health**

Activity and Participation Domains (showing the details behind one heading 'mobility')



Source: The World Health Organisation, ICF Online, http://apps.who.int/classifications/icfbrowser/.

The ICF is a comprehensive and robust *framework* not an assessment tool itself. The WHO (which developed the ICF) noted that:

> The ICF is impractical for assessing and measuring disability in daily practice; therefore, WHO developed the WHO Disability Assessment Schedule (WHODAS 2.0) to address this need. (Üstün et al., 2010, p. 3)

The implication is that rather than replicate all elements of the ICF framework, an assessment tool would incorporate the best mix of indicators or relevant domains of

need. The preferred assessment tool(s) would still be consistent with the overarching ICF framework. At a minimum, the assessment process should encompass elements of self-care, communication, mobility, learning and applying knowledge, and community and social participation.

5.3 What is the purpose of the assessment process?

As Owen et al. (2005) noted, 'Assessment is a valuable intervention in its own right, and is not just the entry point into service provision' (p. 4). The assessment process can provide an opportunity for individuals to articulate their care and support needs, identify issues that need to be addressed in any personal plan, and be used to collect data. Indeed, in the context of a NDIS, the assessment process will fulfil a number of functions.

Determining whether an individual would receive individualised supports

A short upfront module would establish whether an individual would receive NDIS-funded, individualised supports (figure 5.2). This stage would be waived for some sources of disability that resulted in significant and unambiguous care and support needs such as quadriplegia, Down syndrome and neural tube defects or where the scheme had already identified opportunities for cost-effective early interventions across a group of individuals. Having this initial assessment would reduce overall costs as some people will not be entitled to individualised supports and will not require more extensive assessments.

Determining the service offering

A comprehensive component would consider the supports that would allow a person to fulfil a range of *functions*, such as participate in their community. This component would be supports driven, and so would not solely focus on an individual's diagnosis or what they cannot do.

Assessments would be person-centred, taking account of people's unique circumstances. Consistent with the ICF framework, the assessment process would identify support needs across a range of life activities, and would take into account the interactive effects of an individual's health condition (and impairment), their desired activity and their context (including environmental and personal factors).

The assessment process would identify the type, intensity and frequency of support needed, regardless of how these needs might be met. Moreover, assessments would provide a dynamic account of an individual's support needs, including having regard to fluctuating needs and anticipating changes that can be expected to occur. (For example, as the result of skills development, ageing, or a health condition that is progressive.)

Determining what reasonably and willingly could be provided by unpaid carers and the community

At present, informal care, such as that provided by unpaid family carers and friends, accounts for the overwhelming majority of hours of care provided. Access Economics estimated that the total value of informal care amounted to around $30.5 billion in 2005.[1] No scheme could fund the full cost of this care, so natural supports will remain an important part of the care and support response.

But informal care arrangements need to move to a more equitable and sustainable footing. The pressure on carers should be lessened by more and better services. This approach is consistent with that advocated by the House of Representatives inquiry into better support for carers:

> Importantly, the Committee understands that with adequate levels of appropriate support in place, most carers wish to continue to provide care for as long as they feel able to do so. It is therefore in the best interests of all concerned — carers, care receivers, governments and society — to share the responsibility of providing care more evenly. If realised, this will allow carers and their families to participate more fully in society through engagement with education, employment and social activities. (SCFCHY 2009, p. x)

Under the NDIS, the focus would be on supports that could be *reasonably and willingly* provided by unpaid family carers and the community. For example, it would not be reasonable to expect elderly carers to provide the bulk of the support, but it would be appropriate (in most instances) to expect parents of a young child to provide overnight support and for a reasonable period during the week, as this is what all parents do for their children.

In gauging a person's *appropriate* natural supports, the assessment process should have regard to:

- how much unpaid support is currently being provided or is likely to be provided

[1] This reflects the value of resources that would need to be diverted each year from the formal economy, if all hours of informal care (for people of all ages) were replaced with services purchased from formal care providers and provided in the home.

- the impact on family members, including young carers and other current or potential carers providing support
- the level of care and support (if any) current or potential carers want to provide.

In chapter 4, the Commission proposes that there should sometimes be a requirement to pay a modest fixed upfront contribution to the NDIS (of say $500 per year), with free access to services after that point. The Commission considers that this should be waived where families have contributed significantly towards the costs of support through unpaid care (draft recommendation 4.3). The question of whether carers should receive their own assessment is addressed later in this chapter.

Determining an individual's budget

As self-directed support is to be a feature of the scheme (chapter 6), the assessment process will need to identify a budget associated with meeting the assessed needs of individuals (after taking account of any reasonable natural supports). Crucially, there would be an obligation for the system to deliver the funding determined by the independent assessment. This feature is an essential element of avoiding the chronic underfunding that has beset past allocation systems.

An individual's budget could be *derived* through a 'bottoms-up' approach, by costing all of the support needs identified by the assessment process (after taking account of natural supports). As a very simple example, were a person assessed as needing 10 hours of attendant care per week, but their partner was happy to provide two hours, and the cost of attendant care was say $30 per hour, their budget would be $240 per week (8 hours x $30 per hour).

As budgets will be attached to assessments, it will be important for the scheme to monitor patterns in assessments to test whether these reveal any unwarranted cost pressures (for example, arising from defects in the assessment tool or permissive use of the instruments). (The need for, and benefits of systematic checks are discussed further in section 5.11.)

Determining suitability for self-directed funding

The assessment phase would substantiate the capacity of the person or carer to self-direct funds. This would not be a feature of the assessment tool per se, which would be about identifying needs, but would be part of the interaction with the person with disability during the assessment phase.

Providing a referral to other schemes

Under the current fragmented system, many programs have unique eligibility criteria and assessment systems. But as a number of participants have remarked, this often results in people contacting several agencies or service providers to request a service, providing their personal details, explaining their circumstances and then being assessed multiple times (chapter 2). Bringing *specialist* disability services under a single umbrella, the NDIS, will go a long way to reducing this fragmentation and the consequent need for overlapping assessments.

However, the care and support needs of people with disability are broad-ranging, and the NDIS is not intended to address all of them. There are good reasons for the scheme to focus on disability specific needs, with *mainstream* services such as education and employment remaining outside its scope (chapter 4). But the ongoing distinction between specialist and mainstream services should not make for an overly complex system in which assessment effort is duplicated. Rather, assessments should be portable across the system — subject to protection of privacy — so that people do not have to repeat information for different providers or government agencies.

Where there is extensive overlap in the nature of information being provided, the NDIS should reach agreement with other departments or agencies to either act as the sole assessment point, act as a point of referral or to share information, subject to strict privacy safeguards. The following examples *illustrate* some of the different ways in which this could be put into place:

- *The NDIS acts as the sole assessment point and agent* — say the information collected via the NDIS assessment was sufficient to also establish that an individual was entitled to a disability parking permit, the NDIS could *act as an agent* for state and territory road authorities and *issue* the permit.
- *The NDIS acts as the sole assessment point and provides a referral* — say the information collected via the NDIS assessment was sufficient to establish that an individual was also entitled to a disability parking permit, the NDIS would provide a referral and state and territory road authorities would issue the permit without undertaking an assessment of their own.
- *The NDIS shares information with other departments and or agencies and government-funded service providers subject to strict privacy safeguards* — say the information collected via the NDIS assessment *partly satisfied* the information requirements for a disability parking permit, such that further information was needed. The NDIS would share the relevant information with state and territory road authorities, who would then *add to* it in order to satisfy their own requirements. State and territory road authorities would then issue the permit.

Providing data for program planning and cost management

Administrators of the scheme need to establish whether costs and revenues are in tune and, if not, the best response. They need to know what is safe, what works, for whom, when and how. They need to know whether the benefits of given services and interventions are worth the costs (chapter 10). The assessment process would be an important source of data for program planning, high-level reporting, monitoring and judging the efficacy of interventions. It would also assist in forecasting the likely long-run liabilities for the scheme — a major focus for the management and sustainability of the NDIS.

5.4 Desirable features of assessment tools

There is no universally agreed tool for assessing the care and support needs of individuals. There is however, reasonable consensus about the attributes that any assessment tool must have. These include validity, reliability and rigour.

Validity and reliability

The instruments used for assessing the care and support needs of individuals would belong to the family of 'psychometric' tools. In order for such tools to be generally considered effective, they must be both valid and reliable.

The key aspect of assessing validity is to pose the question: 'what is the tool for?' and ask whether it meets that purpose. For example, in the context of an NDIS, the assessment tool is not intended to measure needs per se, but needs that must be funded by the scheme.

Validity is measured in a number of ways, including by reference to a gold standard measure which has been used and accepted in the field. Another related aspect is the responsiveness of the tool or its capacity to detect change in a person over time. This is an important feature in the disability care and support context, as individuals' needs change.

A reliable measure is one that measures a construct consistently across time, individuals, and situations. A good measure should produce consistent results when the test is repeated within a reasonably short space of time (test-retest reliability) and when different assessors use the instrument to assess the same individual (inter-rater reliability). In order to be valid, a measure must be reliable, but the converse need not be true (box 5.2).

Box 5.2 **Making sense of 'reliability' and 'validity' with examples**

Just because a measure is quite reliable, this does not also make it valid. Take for example a metre long ruler, but assume instead that the ruler is in fact 120 cm long. Every time the ruler is used to determine the height of a person or object, it systematically underestimates height by 20 cm for every metre. A child, for example, who according to this measure is one metre tall, would actually be 120 cm tall.

But this error does not affect the reliability of the ruler. The results would be quite consistent if repeated a number of times (test-retest reliability) or if several different people used the ruler to measure a given person or object (inter-rater reliability) despite being obviously incorrect. In short, this particular ruler would provide a quite reliable but totally invalid indication of height.

Source: Adapted from Carmines and Zeller (1979).

Aside from validity and reliability, there are a number of other factors to take account of in establishing a tool's suitability. Guscia et al. (2006a) identify susceptibility to manipulation, completion time, assessor training requirements and ease of administration more broadly. Owen et al. (2005) also highlight ease of administration, and in addition list applicability and whether the tool is in the public domain (the latter also goes to the ease with which a tool can be administered). Finally, in the context of an NDIS, a tool needs to be nationally consistent.

Rigour

As Harries (2008) notes, a dilemma for funding bodies in the context of individualised funding, is that some individuals will overstate the extent of a disability in order to receive increased levels of funding. (This need not be by the person with disability. Under current arrangements for example, service providers might face an incentive to overstate people's needs to get more funding.) In some cases, people might be conscious of what others receive and may inflate their own claims.

An Australian study conducted by Guscia et al. (2006b) investigated whether assessment tools obtained different results for different purposes. They found that the assessed support needs of individuals were much greater when they were assessed for funding purposes compared to when they were assessed for research purposes.

There are a number of ways to reduce the risk of such 'gaming'. These include the use of professional assessors, careful calibration and gatekeeping and the monitoring of data. But the choice of tool can also affect the scope for gaming.

Harries (2008) notes that the use of objective and auditable measures of need can reduce the risk of gaming. It has been suggested that the use of objective functional measures are potentially less susceptible to manipulation and therefore may be more appropriately suited to funding purposes (Dyson et al. 2000 as reported in Guscia 2006a and Harries 2008).

Where people receive an entitlement to supports rather than a budget to purchase those supports, the incentive to overstate needs is reduced. For example, a person would face little incentive to exaggerate say their need for assistance in showering, if that only resulted in more showers (rather than a bigger budget).

Applicable

Applicability relates to whether the tool can be applied to a particular target group. Some tools for example, target particular disabilities such as intellectual disability, while others target people of certain ages, such as children. Given the target population of the NDIS (chapter 3), the assessment tools will need to be applicable for individuals of different ages and with a wide range of levels, types and combinations of disabilities.

A tool's psychometric performance, in terms of its validity and reliability, should be established across the group in question. It is important that a tool does not unfairly discriminate against people from the Indigenous or ethnic communities.

Practicability

Practicability refers to the ability of a tool to be applied in a given situation or context (Owen et al. 2005). In the case of a NDIS, a tool will be used for both screening prospective users and for determining an individual's package of supports and the budget associated with meeting those supports. In the first instance, a tool that is quick and easy to administer might be preferred. In the second, given the complexity of the task and the need for the outcome to be highly valid and reliable, it would be appropriate for the scheme to invest relatively more time and/or effort in undertaking the assessment. This suggests a role for either a hierarchical tool or multiple tools (section 5.6).

The skills required by staff that implement the tool also affect practicability. A tool that is easier to administer and requires less training of staff, while still producing reliable results, may be preferred to one which requires extensive training of assessors by accredited trainers.

Public domain

Increasingly, the developers of tools are charging license fees for their use. Given the number of people who may receive individualised supports under the NDIS (around 360 000) and the regularity with which assessments will occur, whether a user fee must be paid each time the assessment tool is used, will be a consideration. Moreover, where tools are in the public domain, it facilitates transparency and further research and development (UNESCO 2004).

Efficiency

An efficient tool is one which collects sufficient information to assess support needs in the most economical manner. Assessing need can be time consuming and costly for an agency and the individual and family concerned. It is generally considered best to use the shortest tool available that still meets appropriate standards of reliability and validity.

Nationally consistent

Under existing arrangements it is relatively common to find instances where individuals with similar support needs in different states (and even in the same state) receive quite different care and support packages. (The reasons for this are discussed fully in chapter 2). Not only is this situation inequitable, it hinders people's ability to move between states. Substantially increasing the quantum of disability funding would not resolve these problems.

There are (at least) two options for achieving greater national consistency and enabling portability. The first involves setting national guidelines for a common assessment approach. Guidelines might list criteria for choosing tools, include a requirement that tools be able to produce core summary data or information, or outline a preferred assessment process. This resembles the option employed in the United Kingdom. But it is not clear that this response has resolved their portability and inter-jurisdictional equity concerns:

> People with the same needs receive different levels of care depending on where they live. Local authorities across England use the Fair Access to Care Services (FACS) guidance, issued by the Department of Health, to assess and determine eligibility for services; this aims to make such decisions more transparent. However, different authorities interpret the FACS criteria differently and so they differ in the levels of need they support. Some authorities provide support for care packages for people with moderate or higher levels of need, whereas some only provide support for the higher levels. (UK Green Paper 2009, p. 42)

The second approach builds on the first, but also specifies a 'toolbox' that would be employed nationally. The Commission favours this approach, since it would ensure more equitable access to nationally funded support services and allow portability of funding across borders when people move.

5.5 The current suite of assessment tools

There has been little investment within Australia in the development or refinement of assessment tools that provide a rounded picture of individual's needs. That is because there has been little incentive to do so — the fractured and highly rationed nature of the system means individuals are typically assessed for a narrow subset of services, and assessed need does not translate into entitlement. That said, all governments have agreed to simplifying and improving the consistency of assessment processes and some jurisdictions have recently begun developing and piloting new tools.

The process of starting from scratch to develop a new assessment tool in any field is time-consuming and expensive. As Owen et al. explains:

> A large pool of draft items needs to be written. These need to be tested in a pilot study. The best items are then selected on their psychometric performance, the structure of the tool is analysed to ensure it covers the necessary domains, including reliability, validity and norm development. (2005, p. 21)

Where possible, it makes sense to use existing tools that capture the life areas or domains of interest.

There are well regarded tools that could be employed by the NDIS for assessing certain needs (table 5.1). Though generally, the tools focus on a narrower range of supports than will be offered by the scheme. For example, they do not typically assess home and car modification needs.

Moreover, some tools focus on a narrower subset of disabilities than is relevant for the scheme. The Functional Independence Measure for example, is designed primarily to be used in rehabilitation settings, while the Supports Intensity Scale is targeted at assessing support needs of individuals with intellectual disability. Both I-CAN and D-START are intended to assess the needs of a broader group of individuals, though both are still in the relatively early stages of development and are not yet widely used. More detailed descriptions of the main support need assessment tools can be found in appendix B.

Table 5.1 **Summary of relevant assessment tools**

Tool	*Intended purpose and target population*	*Life areas or 'domains' covered*	*Ease of administration (assessment time)*	*Current use*
D-START	Assess needs, capabilities and aspirations of people; resource allocation Adults with different types, levels and combinations of disability	• medical and health • activities of daily living • behaviour • functional skills • personal risk • environmental factors	Hierarchical model with short and long assessment options Mainly for use by trained assessor (45-90 min)	Being trialled by the South Australian Government
FIM	Assess an injured person's function Adults in rehabilitation settings. (Wee-FIM caters for children)	• self-care • sphincter control • locomotion • transfers • communication • social cognition	Trained assessor with some clinical qualification (medicine, allied health, nursing) (around 30 min)	Used internationally
I-CAN	Assess and report on the support needs of people with intellectual or multiple disabilities (the developers are currently investigating the tool's application to those with traumatic brain or spinal cord injury)	• physical health • mental and emotional health • behaviour • health and support services • applying knowledge • communication • self-care, domestic life • mobility • interpersonal relations • life long learning • community and social life	Trained facilitator guides a semi-structured group self-report process Hierarchical model with short and long assessment options (30-120 min depending on complexity of need)	Currently used by some NGOs and by teams within government in some states
ICAP	Assess adaptive and maladaptive behaviour to determine type and amount of support needs Can be used for determining eligibility, planning and in funding reports	Adaptive and maladaptive behaviour with the former covering: • motor skills • personal living skills • community living skills • social and communication skills	Assessor requires no formal training but should self-study manual (20-30 min)	Widely used in the United States

Continued next page

Table 5.1 **(Continued)**

Tool	*Intended purpose and target population*	*Life areas or 'domains' covered*	*Ease of administration (assessment time)*	*Current use*
SIS	Assess frequency, type and duration of support needed. Adults with intellectual and developmental disabilities	Behavioural, medical, and life activity with the latter covering • home living • community living • lifelong learning • employment • health and safety • social activities • protection & advocacy	Staff resource use is intensive. Trained staff required for reliability (1 hour but can be up to 2.5 hours)	Used by several states in the US and a number of Canadian provinces as well as in around 14 other countries
SNAP	Measure the support needs of individuals with different disability types and levels of severity in receipt of accommodation and day support services	• personal care • physical health • behaviour support • night support • social support	Assessor requires no specialised training but must have good knowledge of the person (10-20 min)	Has been used in NSW to guide funding of residential and day support services, and was trialled by the South Australian Government

The Commission seeks feedback on whether these tools, or any other assessment tools, would be appropriate for assessing the care and support needs of individuals having regard for:

- *the role of the assessment process in the context of an NDIS*
- *the desirable traits as outlined in section 5.4.*

5.6 A single tool or a 'toolbox'

The assessment process will need to be applicable for individuals of different ages and with a wide range of levels, types and combinations of disabilities. However, as noted in the previous section, many current assessment tools tend to be developed on the basis of a single disability type (such as intellectual disability) or service type (such as attendant care or home modifications) and so lack the flexibility or breadth of coverage required by the NDIS. A simple and common response to this problem is to employ a toolbox rather than a single tool.

In order for this model to work effectively, a thorough benchmarking and mapping process would be required. The aim being to ensure that all relevant activities were

covered, that there was no overlap, and that where individuals were assessed for the same support using different tools, the outcome was equitable. The assessment process must be both coherent and equitable if it is to gain broad user-acceptance.

While this approach may appear disjointed, it is preferable to a situation in which the 'tool is made to fit the task' and reliability and validity are sacrificed.

5.7 Who should conduct assessments?

Who conducts needs assessments can have big implications for both the reliability of the results and the extent to which an individual seeking support feels that they are central to the process. Typically, assessments of need have been conducted by trained assessors. Almost all of the tools outlined in section 5.5 are administered this way (though some have self-report elements). The evidence shows that this produces higher rates of reliability.

But self-assessment is increasingly being advocated as a way of actively involving and empowering service users. And a number of participants in this inquiry have called for its use:

> It is essential that a self-assessment tool be developed, to enable people with disabilities to identify the supports they need in order to fulfil their goals and to participate in society. (Madden et al., sub. 493, p. ii)
>
> [The] Level of funding for individual disability support should be determined through a self assessment approach. (Physical Disability Council of Victoria, sub. 534, p. 5)

While self-assessment is widely advocated, it is not clearly defined or understood. In its simplest form it refers to:

> An assessment that is completed by the subject of the assessment without the immediate involvement of professionals, or a professionally employed layperson. (Griffiths et al. 2005, p. 17)

But beyond this, there is little agreement among researchers or practitioners about its precise meaning. Griffith et al. proposed that self-assessment of care needs must have, as a minimum:

- *self report* as distinct from examination or observation
- *self completion* by the individual concerned rather than by a professional, layperson or family member
- *self as the beneficiary* of the assessment as distinct from provision of a survey response for population needs assessment.

Self-assessment has been used in many ways and for many groups of people. Purposes range from targeted screening for specific medical conditions through to approaches designed to help individuals make decisions in relation to major life events. But examples of its use in the area of social care are limited, especially for resource allocation purposes.

How accurate is self-assessment?

The desirability of self-assessment has not been well explored in the area of health and less so in the area of social support. One major study was conducted by Griffith et al. (commissioned by the National Health Service in the United Kingdom). Griffiths' research suggests that the accuracy of self-assessment in social care remains largely untested:

> No evaluations of the accuracy of self-assessments in the domains of comprehensive or life and social skills were found. (2005, p. 92)

While the suitability of self-assessment in social care has not yet been rigorously evaluated, early experience from the UK has revealed problems with its use. A review of the Individual Budgets Pilot Programme found that case managers were not confident that self-assessment alone would adequately capture individual's needs:

> Most IB [Individual Budget] lead officers felt that some degree of professional assessment was necessary in addition to self-assessment. Having both views was believed to produce a more accurate assessment of needs and offered an opportunity for useful dialogue between the service user and care coordinator. Further, a small number of care co-ordinators and team managers had more serious doubts about the value of self-assessments and reported that it was often necessary to assess needs independently of service users, in order to establish 'what people's needs were as well what their own perception of what their needs were'. (Glendinning et al. 2008, p. 147)

As Griffiths et al. observes, self-assessment relies on a single subjective source, and an individual's own perception of their need can vary from that of professionals (this is consistent with the views put by Bradshaw, box 5.1). However, the review of the Individual Budgets Pilot Programme was suggestive of more systematic divergences:

> A number of sites had experience of older people, and people with mental health problems in particular, under-assessing their own needs; in part this was felt to be a consequence of older people having low expectations, or people with mental health problems being in denial about their needs, or not perceiving their actions or behaviours to be anything unusual. In contrast, people with physical disabilities, sensory impairments or learning disabilities were felt to be more likely to over-assess their needs. This may come from a longer history of campaigning for greater rights,

choice and control, particularly among physically disabled people. (Glendinning et al. 2008, p. 149)

Does self-assessment deliver greater user involvement and partnership?

One of the rationales for self-assessment is the view that it provides greater opportunities for self-definition of needs and desired outcomes; and increased opportunities for users to determine for themselves how they want those outcomes to be achieved.

But as Griffith cautioned:

> Benefits should not be assumed and in particular the use of self-assessment should not be equated with user involvement and partnership. Generally more clarity is required when advocating self-assessment … the partnership is embedded in how the assessment is used, not the assessment itself. (2005, p. 12)

The Commission considers that the assessment process should be collaborative, but is cautious of the benefits attributed to self-assessment. In any event, the Commission has identified a number of more effective ways of ensuring that people have greater power over how their needs are met, including the adoption of self-directed funding (chapter 6).

Keeping the person with the disability front and centre

Assessment should be carried out as a collaborative process, and in a way that is understandable for the person seeking support so that they are able to:

- gain a better understanding of the purpose of assessment and its implications for their situation
- actively participate in the process
- identify and articulate the outcomes they wish to achieve (a support plan will also be key here)
- identify the options that are available to meet these outcomes and to support their independence and well being
- understand the basis on which decisions are reached.

Maintaining professional objectivity

In order to promote independent outcomes, assessors should be drawn from an approved pool of allied health professionals. Assessors should also be independent of the person being assessed to reduce the potential for 'sympathy' bias. This means that health professionals — GPs and others — with past treatment and support responsibilities for the person, would not undertake assessments. It is clear from the experiences of VCAT appeals on TAC benefit decisions that treating professionals are often placed in an invidious position when asked by their patients to make an assessment that determines the person's eligibility for benefits.

As in New Zealand, assessors would be mentored in their first six months of assessments, and all assessors would be regularly assessed to ensure comparability of outcomes and to avoid 'sympathetic bracket creep'. Assessors' approaches to assessment would have to be aligned with the objectives of the NDIS (which is another reason why a person's general practitioner would not be a suitable assessor). Assessors would be properly trained in the use of the tools and be approved or appointed by the NDIA for the purpose of conducting NDIS assessments.

5.8 When should assessments occur?

Before being able to access individually tailored supports, new entrants to the scheme would undergo an initial assessment. That process is intended to provide a dynamic account of an individual's support needs, so that the needs of people who have fluctuating and or longer terms conditions are properly taken into account. Even so, it would not be possible to anticipate all changes to an individual's care and support needs over time. These changes would need to be identified through a periodic reassessment of need. Reassessments will be an important way of making sure that people are able to access the right mix of supports at the right time.

The timing of reassessments depends on a number of factors, such as the nature of the disability, the age of the person and any major life transitions. But it is possible to identify some timely opportunities for reassessment.

For children acquiring disabilities at birth (or revealed in early infancy), key assessments points might be:

- at the time the disability is first identified
- at the point of entry into schooling (around 5-7 years of age)
- at the point of entry to high school and puberty (around 11-13 years of age)
- at the point of transition to adult education (between 15 and 18 years of age)

- at the point of transition to adult work (between 15 and 25 years of age)
- at major life transitions, such a marriage, divorce and moving out of home.

These examples are not intended to be exhaustive — reassessments should occur when is has been agreed that an individual's circumstances have changed, or are about to change, such that a review of their care and support needs is warranted. For example, an individual might approach the scheme to have their need reassessed following a period of ill health.

Scope for reassessments was advocated by a number of participants:

> The level of support required should be reassessed regularly to ensure that services and supports provided continue to be appropriate for meeting the person's needs, and also be able to be reassessed, and adjusted as required in response to changing needs or circumstances. (Jewish Care (Victoria) Inc, sub. 355, p. 3)
>
> … reassessment of need should occur regularly enough to ensure responsiveness to changes over the life course. (Down Syndrome Victoria, sub. 492, p. 3)
>
> Where an individual's disability may undergo change – degeneration or improvement, reassessments and reviews should be available as needed. (Youth Disability Advisory Service, sub. 487, p. 10)

While having an up to date picture of care and support needs is important, it should not result in unnecessarily burdensome processes. A number of participants raised concerns about this possibility:

> Assessment for support under the scheme should not be unnecessarily intrusive or repetitive. (Youth Disability Advisory Service, sub. 487, p. 10).
>
> PWD [People with disabilities] and their families want to tell their story once only and not over and over again. (Sally Richards, sub. 26, p. 6)

Much of the information collected at the initial assessment would still be relevant in a reassessment context, where this is the case, it should be used.

Shifting the emphasis towards wellness

One of the major criticisms of the current system is that is not forward looking. It fails to anticipate changes in people's needs over time, with the result that many people are either unsupported or poorly supported through major life transitions. It also fails to systematically explore 'what might be'. Opportunities for improving independence or functioning are not systematically assessed on either an individual or group level.

NDIS supports should be provided in a way that maximises an individual's functioning and independence. That does not mean that people should go without

the support they need, but rather that they should gain a greater sense of control over their lives. It could be as simple as an attendant carer 'doing things with' a person rather than 'doing things for' them.

In some cases, that might mean individuals will need to learn or relearn the skills necessary for daily living. For those individuals where re-skilling is not appropriate the aim would be to minimise functional losses or future dependencies. (As might be the case with some degenerative conditions.) The assessment process would be a way of identifying these opportunities. This should be a primary focus of the assessment process when people first enter the scheme or when they are reassessed following say a period of ill-health.

This approach is similar to that adopted in a number of other jurisdictions. For example, the NSW Attendant Care and Physical Disability Unit (ACPDU) operate a 'transition model' which, is designed to provide clients with an opportunity to build skills. While not aimed exclusively at any particular client group, it is thought that individuals with an Acquired Brain Injury will most likely benefit from this type of intervention. NSW Department of Human Services note:

> The Transition Model is a component of the Attendant Care Program (ACP) where a person may be approved for an interim period (3 or 6 months). During this time they will receive support from an ACP service provider skilled in working with people with their specific needs with the aim of assisting them to improve and reduce the hours required to support them in the community. The service provision will be reviewed for progress, improvements and likely level of ongoing support required. (Department of Human Services NSW 2010, p. 1)

In the United Kingdom, in some cases, a 'skills building' phase precedes an assessment of longer term needs:

> Before proceeding to determine eligible needs, councils should consider whether an individual might benefit from a short period of re-ablement or intermediate care to increase what they are able to do for themselves before an assessment of longer-term need is undertaken. (UK Department of Health 2010, p. 18)

5.9 Should carers have their own assessment

As noted earlier, the current disability system places an unreasonable reliance on family carers and one objective of the NDIS is to change that imbalance. Even so, many people will still want to provide care and support to family members with disability, but may need support to sustain their caring role (or to relieve the isolation and stress that often comes with that role). The question of supporting carers is discussed more fully in chapter 13. But anticipating that chapter, the Commission considers that there should be greater assistance for (unpaid) carers

through properly funded training and counselling services. This chapter deals with how to go about identifying those support needs.

The role of carers will already form part of the assessment process. As noted in section 5.3, the assessment process should gauge a person's *appropriate* natural supports — those which could be reasonably and willingly provided by unpaid family cares and the community. When it becomes apparent, as part of that process, that an informal carer will provide a substantial share of the care package, the Commission considers that carers should receive their own assessment.

The role of a carer assessment would be two-fold — to consider the sustainability of the caring role and whether the carer would benefit from their own supports, such as counselling or training (for example, a carer may request training in relation to safe lifting or dealing with challenging behaviours). (The need for respite services would be fully appraised as part of the individual's, rather than carer's assessment.) The aim would be to support the relationship as well as the carer.

This is not a novel approach. A number of jurisdictions have carer assessments or are working towards them. For example, in the UK, carers who provide, or intend to provide, a substantial amount of care on a regular basis can request an assessment of their needs as carers, independent of the needs of the person they provide care for.

But processes for doing so are not well established. Within the UK for example, processes have differed from council to council. Some jurisdictions incorporated a carer's assessment into the main service user's assessment. While in other areas, carers were assessed separately. In part, because it was considered that informal carers may feel unable to answer questions about their ability to cope honestly given the person they cared for would see their responses.

As Seddon at al (2007) remarked:

> Our research findings consistently demonstrate that carers appreciate being able to talk privately about their caring role and to raise personal issues that may be difficult to discuss in the presence of the cared-for person (p. 1345).

Some called into question the value of a carer assessment conducted in the presence of the person they were caring for. For example, one participant in Seddon's research noted:

> I wouldn't say anything detrimental in front of [cared-for person]. Having a carer assessment in front of the cared-for is a waste of time (p. 1345).

5.10 How assessment might work in practice

It is likely that people who approach the NDIS for funded supports will have a range of questions, which focus on more practical considerations. They will want to know things like, 'what can I expect, what should I bring, how long might it take, whose involved, what happens in the interim and what happens if I don't agree with the outcome'. The aim of this section is to give a sense of how things might work in practice. Figure 5.2 sets out the suggested process.

What to expect

Once it is apparent that a person is seeking, or is a likely candidate for individualised supports, they should be provided with an early planning and information package. The package would provide individuals with a clear idea about what to expect and when, as well as materials to assist in early planning. The idea being that individuals engage early on in the process, in thinking about their care and support needs and how they might best be met. The package would also include information on the option of having a Disability Service Organisation assist the person with disabilities both during and after the assessment process. Material should be provided in a range of accessible formats such as videos and brochures.

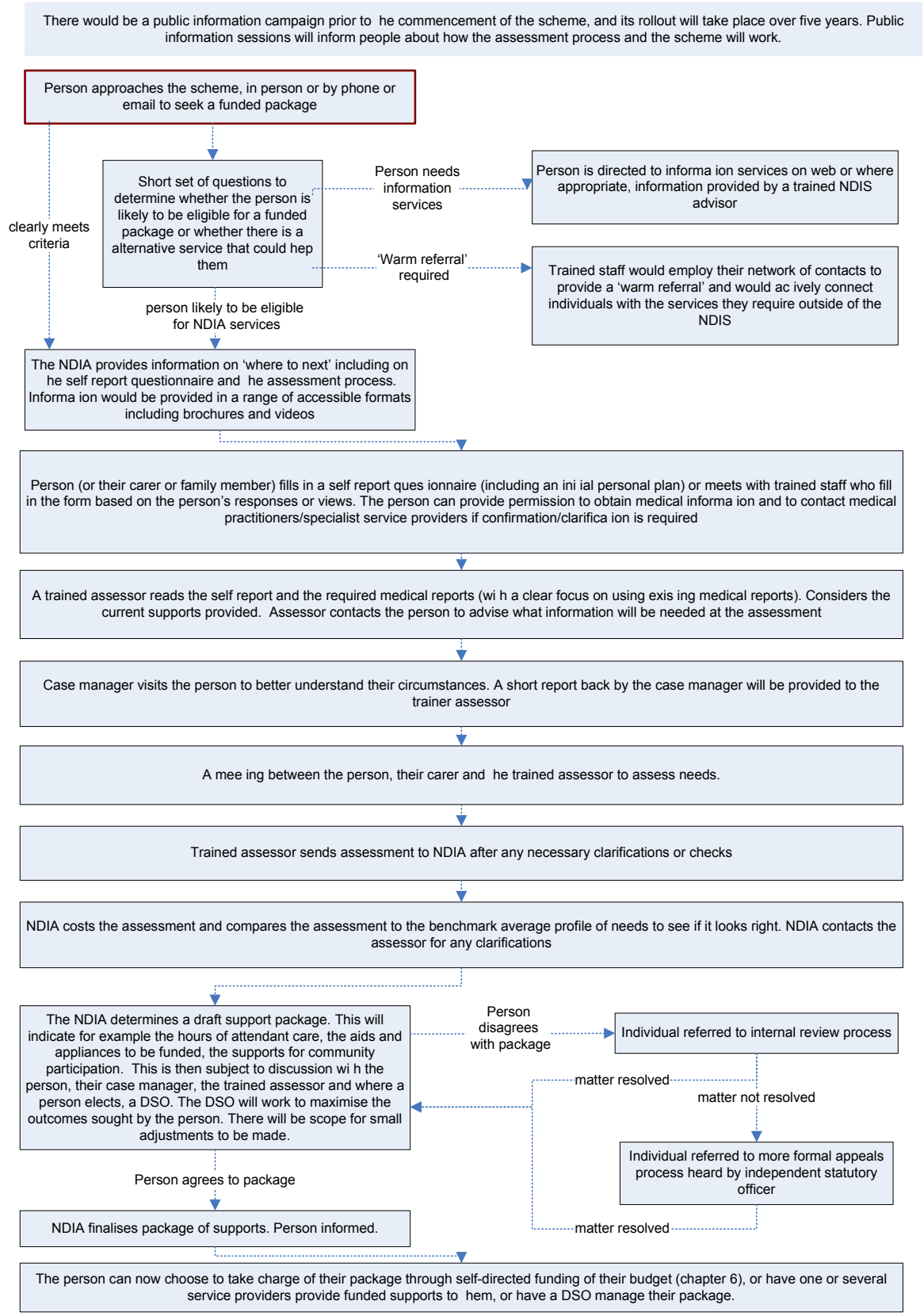
What should I bring

Where possible (and with the individual's permission) the scheme should make use of existing medical reports. Ideally, people seeking individualised supports would make these available at the initial screening stage.

Who is involved

Where individuals seeking services did not feel comfortable being self-advocates, they should have the option of using a Disability Support Organisation (chapter 7). Individuals should also have scope to involve other interested parties (a so called circle of support) in the assessment process. Ideally, these would be people who were familiar with the care and support needs of the individual, they might include family members, carers and direct support professionals.

Figure 5.2 **Suggested assessment process**



How long might it take

Individuals should not have to wait excessive periods for their care and support package to be finalised. Where possible, streamlined processes should apply. The NDIA should report annually on this metric.

What happens if I don't agree with the outcome

Following the assessment of support needs, individuals would be informed of their support package. This step would detail the nature, frequency and intensity of support they had been assessed as needing. In the event that a person disagreed with the outcome, there should be some scope for minor adjustments to be made, without necessitating a full reappraisal. Failing this, individuals could ask for a review from a section of the NDIA independent of the area initially evaluating the assessment. An obvious first step might be that the person has their needs reassessed by another assessor. The role of external review mechanisms is discussed fully in chapter 7.

What happens in the interim

Where it becomes clear that the time required to complete an assessment of care and support needs will substantially exceed the norm, there should be scope for the NDIS to provide services on an interim basis. This might be the case where say an individual with complex needs disagrees with an initial assessment outcome.

5.11 Diligent use of the assessment tool

Any tool that is used to inform decisions that impact on the lives of individuals or is used to guide the allocation of substantial sums of public money must be carefully examined and continually improved.

The increasingly generous use of assessment tools by assessors would risk diluting resourcing, be unfair, undermine community acceptance of adequate public funding and threaten scheme sustainability. But the opposite situation (a progressively more conservative use of the assessment tools by assessors) is equally undesirable. After all, the goal of the NDIS is to properly fund the reasonable assessed needs of people with a disability. The Commission considers that a range of safeguards should be put in place to guard against these two outcomes.

- Assessments should be designed to be as objective as possible and, as noted above, assessors would be assessed themselves for their appropriate use of the assessment tools.

- Assessments would concentrate on the reasonable and necessary supports people require. People would be asked what they had received under the old system. This would focus people on reasonable expectations about the packages they would receive (and in most cases, people would get more). That information would also be useful in modelling the impacts of the new system.
- Data would be collected to assess the reliability and validity of the assessment tools, and the tools would be subject to a regular cycle of evaluation and if necessary recalibration.
- The assessments would not be 'rubber stamped'. Prior to making budgetary decisions, the NDIA would confirm that the particular assessment followed the appropriate protocol, and was consistent with the 'benchmark' range of assessed needs for other people with similar characteristics. Deviations outside the norm would need to be justified. That means that the NDIA would detect and adjust excessively hard or soft assessments before people got their individual package.

5.12 The transition to a fully-fledged assessment toolbox

As noted earlier in this chapter, the process of starting from scratch to develop a new assessment tool in any field is time-consuming and expensive. But as Madden et al. observe:

> The cost of developing disability assessment tools can be considerable, but applying 'ready made' tools to the wrong measurement question is likely to be more costly. It is important to follow the statistical adage that an exact answer to the wrong question is inferior to an approximate answer to the right question. (sub. 493, p. 15)

Madden et al. recommend a staged approach to the identification and implementation of a preferred assessment tool(s), beginning with a process for identifying and evaluating nominated tools against agreed selection criteria. In the event that a suitable tool could not be identified, agreement could be reached for the temporary use of existing tools while further development of an assessment tool takes place. They went on to note:

> The greatest risk in the area of assessment is the speedy adoption of an irrelevant instrument; the financial costs could be considerable, and later re-direction of such a large program very difficult for a range of reasons. (sub. 493, p. 17)

There is no ideal tool to use in the NDIS, reflecting the relatively limited research into generic assessment tools (noting that the imperative for valid and reliable assessment tools across the full spectrum of disabilities are weak in the presently heavily rationed system). Nevertheless, Governments should not delay

implementation of the NDIS in the absence of 'perfect' tools. Accordingly, the NDIS would use the best available tools in its initial implementation phase, with the later development of better tools.

DRAFT RECOMMENDATION 5.1

Working within the International Classification of Functioning, Disability and Health (ICF), the assessment process should identify the supports required to address an individual's reasonable and necessary care and support needs across a broad range of life activities, and should take account of an individual's aspirations and the outcomes they want to achieve.

DRAFT RECOMMENDATION 5.2

The assessment process should be a valuable intervention in its own right, rather than just an entry point to supports. The process should:

- ***draw on multiple sources of information, including:***
  - ***information provided by the individual with a disability, including their aspirations and requirements for supports***
  - ***information provided by unpaid carers***
  - ***current medical information on the person with a disability***
- ***assess the nature, frequency and intensity of an individual's support needs. The process should be person-centred and forward looking and consider the supports that would allow a person to achieve their potential in social and economic participation, rather than only respond to what an individual cannot do***
- ***determine what supports outside the NDIS people should be referred to, including referrals to Job Network providers and mental health services***
- ***consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports')***
- ***translate the reasonable needs determined by the assessment process into a person's individualised support package funded by the NDIS, after taking account of natural supports***
- ***provide efficiently collected data for program planning, high level reporting, monitoring and judging the efficacy of interventions.***

DRAFT RECOMMENDATION 5.3

Any tools employed by the scheme should exhibit validity and reliability when used for assessing the support needs of potential NDIS users. The preferred assessment tools should be relatively easy to administer and exhibit low susceptibility to gaming. The toolbox should be employed nationally to ensure equitable access to nationally funded support services (and allow portability of funding across state and territory borders when people move).

DRAFT RECOMMENDATION 5.4

Trained assessors should undertake assessments. To promote independent outcomes, assessors should not have a longstanding connection to the person. Assessors' performance should be continually monitored and assessed to ensure comparability of outcomes and to avoid 'sympathetic bracket creep'.

DRAFT RECOMMENDATION 5.5

The NDIS should periodically reassess people's need for funded support, with a focus on key transition points in their lives.

DRAFT RECOMMENDATION 5.6

Where an informal carer provides a substantial share of the care package, they should receive their own assessment. This should seek to identify their views on the sustainability of arrangements and the ways in which they could be supported in their role, including through the initiatives recommended in draft recommendation 13.3.

DRAFT RECOMMENDATION 5.7

The NDIS should establish a coherent package of tools (a 'toolbox'), which assessors would employ across a range of disabilities and support needs (attendant care, aids and equipment, home modifications).

DRAFT RECOMMENDATION 5.8

The assessment tool(s) should be subject to ongoing monitoring, as well as a regular cycle of evaluation against best practices, including the ICF framework, and, if necessary, recalibration. The scheme should have systematic internal mechanisms to ensure that anomalies can be analysed and addressed.

DRAFT RECOMMENDATION 5.9

The NDIS should use the best available tools in its initial implementation phase, with the on-going development of best-practice tools.

6 Who has the decision-making power?

Key points

- People should be given much greater power and choice in a new system, with the objective of giving people greater flexibility and control over their lives — with the ultimate goal being greater wellbeing. Consumer choice is one aspect of power.
- There are strong rationales for a consumer choice approach, since people know their needs better than others, it can increase pressures on suppliers to perform, and people value choice in its own right. There are two broad ways of exercising consumer choice:
  - At least over the medium run, the most important would be for consumers to be given an individualised package and to choose one or more service agencies to provide the supports in the package. People could switch providers if they did not meet their needs well. If they wanted, they could get support from intermediaries (Disability Support Organisations — DSOs) in making their choices.
  - For those who wish to and are able to, people would be given the opportunity to manage at the *micro level*, cashing out their package, and allocating their budget to specific supports they assemble themselves ('self-directed funding'). Under self-directed funding people would employ the support workers they want (and when), and could trade off some services against others.
- The evidence strongly suggests a wide range of positive wellbeing outcomes from self-directed funding for people with disabilities and their carers, including higher satisfaction with life, more independent living, better continuity of care and lower levels of abuse and neglect. Self-directed funding appears to cost no more than traditional models of care, and may well cost less.
- The individual budget for self-directed funding should include all goods and services covered by the NDIS, except non-recurrent expenditures and those where specialist knowledge is required for informed choices (such as early intervention therapies).
- Those using self-directed funding should be able to make their own decisions about how to spend the budgets, subject to the approval of a funding proposal that sets out the broad areas of spending. People should be able to hire their own support workers. However, while there is some evidence of benefits, hiring family members should be limited to short-term arrangements or where exceptional circumstances apply until the risks are assessed through a careful trial.
- The NDIA and DSOs would need to provide support to people with disabilities and front-line workers to assist the adoption of self-directed funding.
- A range of safeguarding mechanisms are appropriate, including assessing people for their suitability for self-directed funding, minimum accountability requirements, complaint mechanisms and oversight by local case managers.

In any disability system, someone makes decisions about who gets support, what people get, and when and how they get it. Who has these powers and how they are used, can make a large difference to the quality and efficiency of decisions, and people's sense of value and their participation in society. Historically, the power has been largely exercised by service providers and government officials (the 'service-centred' model), with little real decision-making power given to people with disabilities, their carers or families.

As in many other areas of social policy, governments are tending to move away from traditional service-centred arrangements by modifying disability programs to take account of the preferences of the people in them and to give them greater power. The ideal, if not always the reality, is to shift people from passive 'service recipients' to consumers and citizens.

This chapter is about various ways in which the NDIS could give people the capacity to make many of their own decisions, even if they choose not to do so. Section 6.1 sets out what 'person-centred' approaches mean, and discusses the role of consumer choice as one element of those approaches. Section 6.2 defines the most evolved form of consumer choice (self-directed funding). The chapter then examines the rationales for self-directed funding (section 6.3) and empirical evidence about its effects (section 6.4 and appendix E). The remainder of the chapter considers how to design a workable form of self-directed funding in the NDIS (sections 6.5 to 6.12).

6.1 Person-centred approaches

The concept of so-called 'person-centred' and 'independent living' approaches originated in North America in the late 1980s (O'Brien and Mount 1989; Mount 1992; Garner and Dietz 1996; O'Brien and O'Brien 2000). It is based on the view that people with a disability should be recognised as active participants in the community, needing support to achieve their lifetime goals based on their strengths:

> The person-centered approach creates a team of people who know and care about the individual with a disability, who come together to develop and share a dream for the person's future, and who work together to organize and provide the supports necessary to make that dream a reality. (Garner and Dietz 1996)

One way of distinguishing personalised systems from service-centred approaches is to think about how people ordinarily make decisions. Most people have the chance to live lives that are largely determined by their own decisions, within the limits imposed by their ability, local environment and budgets. They think about what they might want from life and make decisions that help them get there. They decide

where they might like to live, who they would like to live with, and what job and employer they would like. They decide how to spend their leisure time, where to buy things from and the role they will play in the community and as citizens.

That is not so for many people with disabilities (or their carers) because others make and fund so many decisions central to their lives (see Stancliffe and Lakin 2005, p. 204 for relevant studies). In a survey of Australians with disability, the Julia Farr Association found that 51 per cent of people had no choice about who provided personal support and 28 per cent had no choice about where they lived (Julia Farr Association, sub. 494, p. 3). One participant in this inquiry provided a vivid example of her limited choice as a parent of a child with severe autism:

> A respite service which I am offered (for example a five-hour service at a centre for my son in a group) … may fall on a date on which I cannot use the service; its duration may be too long (eg a five hour outing is difficult for my son who is better able to cope with a 2-3 hour outing); I have to spend 2 hours in total driving to and from the centre to drop off and pick up my son; the activities they undertake may be too hard for my son and it is in a group with people with unusual behaviour so my son may be physically harmed by others in the group … These disadvantages sometimes become so great that I refuse even this small service because the costs outweigh the benefits. Due to lack of alternatives, I sometimes accept such a service but pick up my son hours earlier than the scheduled end time in order to mitigate the problems of the service. This causes terrible waste in the system because funds are expended to provide a much longer service than we actually receive. (name withheld, sub. 74, pp. 7–8)

The intention of person-centred approaches is to maximise, as much as reasonably possible, the capacity for people with disabilities to take control of their lives. People with a disability and carers can be given more power in many ways. They include the obligation of providers and others to treat them with respect, genuine opportunities for employment and other forms of social participation, challenging stereotypes and other attitudes that marginalise people, packages of support that suit the person (as for any other consumer), and the appropriate allocation of funding to meet their support needs. As an illustration of the importance of the latter, a person who has to wait months or years for an appropriate wheelchair has little capacity for genuine independence (Samantha Peterson, sub. 581, p. 1). Much of this report is about how to give people genuine control over their lives. However, this chapter focuses on one aspect of power — the capacity of people to have decision-making power as consumers, and in the case of self-directed funding, control of their budgets. As Sally Richards noted:

> Having control over the money is the best way of giving people power. Otherwise, we are forever fitting (or not fitting) into programs and services that might not suit us but which are all that is on offer. We are told things like … 'your son is too old/young; you are out of area; we have no places left; you don't fit the criteria; you must bring your own funding; we have a waiting list; you are not in the priority group' (sub. 26, p. 5)

Giving people choice

The Commission proposes a model that would give people with a disability (or their guardians) more choice under two broad umbrellas. They would:

1) always have power to choose their service providers (SPs), with the support of intermediaries if they wished (disability support organisations or DSOs — chapters 7 and 8). Service providers would be expected to respond to the individual preferences of their clients, with people able to choose the services that meet their needs. People could switch DSOs and SPs if they did not meet their needs well. They might choose one SP for one support need and another SP for another need. They might ask a DSO to bring together the package of supports and the best SPs on their behalf. A DSO or SP would only act for a person with a disability where that person had chosen to assign them that responsibility. The point is that the person with a disability would ultimately be in charge. We use the term 'choice of package' to describe this type of choice

2) have the choice, subject to some conditions, to cash out their individualised package of supports and manage their own budget, allocating it to specific supports they assemble themselves. We use the term '*self-directed funding'* to describe this type of choice (though we note that others use this term to denote a broader model of choice). Under self-directed funding people could employ the support workers they want (and when), and choose to trade off some services against another. They might again get assistance from a DSO, which could help them plan their supports and manage the administrative aspects of self-directed funding (like workcover for employees).

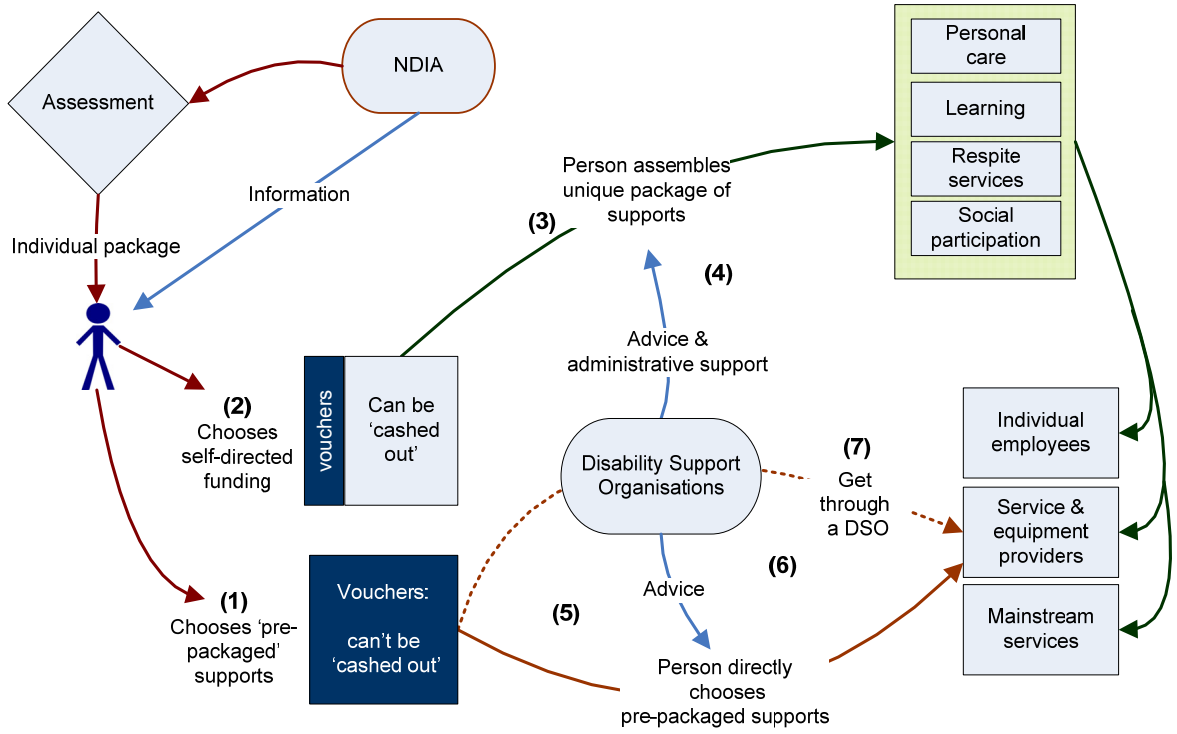
The main difference between the two ways of achieving choice is that the first is like consumers finding a restaurant. They do not cook the food, but they do get to choose the restaurant that suits their preferences. They will not go back if the food or service is poor. The second is like a person buying their preferred ingredients and cooking the meal. He or she would have the freedom to choose when to cook, the exact recipe, cooking methods, and utensils. However, it would involve a lot of work and they could make mistakes.

It is also important to emphasise another difference between the two approaches. At least over the initial stages of the NDIS, 'choice of package' would be effectively a booklet of vouchers, rather than an explicit budget as under self-directed funding. (The reasons for using vouchers are discussed in chapter 7, but one positive advantage is that a person can be certain that they will get their entitled supports under a voucher, but less so with a budget.) So a person might have an entitlement for 10 hours of personal care. They could take their personal care vouchers to any of

a number of specialist providers (or DSOs), who would provide those supports, and which in turn would be reimbursed at a regulated rate by the NDIA. Sometimes, through bargaining, the person might secure, say, 11 hours of personal care with their 10 hour voucher. For example, that might occur if a service provider wished to encourage customer loyalty, as in many other markets, or if a DSO secured a good volume discount by acting on behalf of many consumers. Whether that happened would depend on the degree of competition, the marketing strategies of service providers, and the level of the regulated price. People would also be able to negotiate with the NDIA to enable swaps between one set of vouchers and another — further increasing flexibility. For example, people (if approved) could use more community access and less personal support if that suited them.

Figure 6.1 provides a map of the more detailed options people would have. People would have many ways to choose supports. If they used choice of package (option 1), some would obtain the pre-packaged supports directly from providers — (1) and (5). Others would ask for advice and other support from a DSO — (1), (5) and (6). And others would ask a DSO to do it all for them — (1) and (7).

Figure 6.1 **There are many pathways for choice**



If they chose self-directed funding (option 2), some would take an entirely DIY approach, purchasing the supports that meet their needs — (2) and (3) in the

diagram — 'pure' self-directed funding. Others would get the support of a DSO — (2), (3) and (4).

Choice of package (option 1) is relatively straightforward to implement, but would still have many of the benefits identified later in this chapter for self-directed funding (table 6.1).

Table 6.1 **'Choice of package' and self-directed funding have significant benefits, but different drawbacks**

	Category	*Option 1 Choice of package*	*Option 2 Self-directed funding*
(1)	Gives people sense of control over their lives	●●●●	●●●●●
(2)	Allows choice of specialist service providers and the option to move	●●●●●	●●●●●
(4)	Introduces competitive pressures	●●●	●●●●
(5)	Gives people flexibility	●●	●●●●
(6)	Allows people to trade off items	●	●●●●
(7)	Is easy to use and does not require support from others	●●●●●	●
(8)	Involves low levels of risk to the person and the scheme's probity	●●●●●	●●●
(9)	Imposes low management costs on the NDIA and service providers	●●●●●	●●
(10)	Is cost effective overall	●●●●	●●●●
(11)	Allows easy engagement with mainstream services	●●	●●●●●
(12)	Can work well with limited responsiveness by disability services market	●	●●●

●●●●● Excellent ●●●● very good ●●● good ●● fair ● poor

a The scales are based on judgment and evidence from various studies of self-directed funding. For example, the reason that choice of package is easy to use (item 7) is that it just involves choosing a provider and being able to switch, whereas self-directed funding involves reporting requirements, being confident about managing a budget and employees, and being able to use mainstream services (this is why people may engage DSOs to help them).

These include the value of choice per se, portability across providers, pressures on providers to perform better, and a greater capacity to meet people's preferences. Moreover, it has some advantages over self-directed funding:

- a disability service provider may be able to provide a cheaper or better suite of supports than that obtained by a person assembling their own suite from many suppliers. One aspect of this economy may be a detailed understanding of the needs of people with disabilities, which may not be present with some mainstream suppliers
- the service provider meets all the administrative costs of service provision and provides packages of desired services, so that, for example, a person does not need to hire a cook and a personal attendant separately, but can use a supplier that can provide both.

Its relative simplicity means that this type of consumer choice would probably be the most common way in which people would exercise power, at least initially. Many would find self-directed funding too bothersome or complicated, and would be happy to choose the DSOs and SPs and let them bundle supports for them. Several participants pointed this out:

> Not everyone wants or is able to administer individual funding. Certainly, as you get old you feel the need to let go of the reins. (Meredith Dewar, sub. 317, p. 1)
>
> … [choice] isn't necessarily about that you can't use traditional services, it's about people knowing what support they have got, what the funding is and then choosing a range of management options. So it's not that people who don't want to manage funding would miss out (Ms Jenkinson, trans., p. 982)
>
> While individual support packages may for some provide the best option … this is not necessarily the preferred option for others. Packages can add to the burden of an already over-burdened family and add little value if in reality the services and support required are not available, inadequate or precluded by geography. (JacksonRyan Partners, sub. 30, p. 5)

Self-directed funding (option 2) is more flexible than choice of package and gives people more opportunity to use mainstream services with ease or to engage their own employees. For these reasons, many participants in this inquiry strongly supported the inclusion of self-directed funding as an option in the NDIS.[1]

However, self-directed funding involves many more complexities and practical issues than option 1. Moreover, the experience in the United Kingdom suggests that take-up may be initially slow. In England, just over 10 per cent of people aged less than 65 years completely manage their own budget — such as by hiring their own employees and purchasing mainstream services directly. The share has been growing rapidly and some local councils have much higher rates than this. Under the NDIS, the pace of adoption of self-directed funding can be expected to grow as people gain confidence in the new system, as the market evolves, and as the system provides more support for exercising choice (for example through DSOs).

Given its complexities and the challenges in achieving uptake, self-directed funding is the main concern in this chapter.

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[1] Just a sample includes: the Australian DeafBlind Council (sub. 35, p. 12); Ben Lawson (sub. 103); Susan Harris (sub. 190); John Pini (sub. 96); Action for Community Living (sub. 508); Pave the Way (sub. 528, p. 6); NSW Government (sub. 536, p. 75); the South Australian Government (sub. 496, p. 10); Yooralla (sub. 433); and Leisure Connection Association (sub. 306, p. 3). Community consultations undertaken in South Australia found that all participants were in favour of individualised funding or self-managed care (Disability Advocacy and Complaints Service of South Australia, sub. 267). However, some participants were more cautious about aspects of self-directed funding (for example, the Attendant Care Industry Association, sub. 268).

There should be no obligation to use self-directed funding

In the Commission's consultations, some said they were worried that people would have to use self-directed funding. The Commission emphasises that this would not be the case in the proposed NDIS.

> While individual support packages may for some provide the best option … this is not necessarily the preferred option for others. Packages can add to the burden of an already over-burdened family and add little value if in reality the services and support required are not available, inadequate or precluded by geography. (JacksonRyan Partners, sub. 30, p. 5)

Moreover, some people may only use self-directed funding temporarily. Some people may want one-off payments at certain points in their lives or at a given time of year (for example, to purchase short breaks for the carer, education services or equipment), without having to have ongoing budget holding responsibilities. This arrangement is now common in the UK (Davey et al. 2007, pp. 47ff).

It is against this backdrop that this chapter explores the rationales for self-directed funding, the evidence about its strengths and weaknesses, and its role in the NDIS. The chapter (and appendix E) also discusses the role of person-centred planning, which is an essential aspect of self-directed funding, but has a more general value.

6.2 What is 'self-directed funding'?

Arrangements in which the government gives people with disabilities or their carers the option of getting a budget to spend on goods and services they want come in many forms and have many labels. Among others, these include self-directed funding, individualised funding, self-determination, individual budgets, direct payments, self-managed funding, consumer-directed care, personal budgets, cash for care and vouchers.

The terms do not always mean a precise set of arrangements, which makes it hard to compare studies on their effects and to analyse the extent to which policy really gives people much power. In some contexts, these different terms involve similar, but subtly different arrangements. For example, in the United Kingdom, there are three different types of self-directed funding.[2] Western Australia uses a tiered set of

[2] These are *Direct Payments* (the cashed out value of community care services, with the person having full responsibility for purchasing, hiring and any statutory obligations), *Personal Budgets* (in which people receive a notional budget, but can have administrative and purchasing responsibilities met by local authorities) and *Individual Budgets* (which are like direct payments, but pool more funding sources into the budget, such as equipment services).

funding arrangements, which includes option 1 above as an element of self-directed funding. These tiers entail different administrative responsibilities for people depending on the option they choose. A recent study of the effects of Australian 'individual funding' approaches included many service models that, while providing greater choice, were sometimes far removed from the concept of self-direction common in overseas schemes (Fisher et al. 2010).

In Australia, policymakers and governments have often used the term 'individualised funding' to describe the determination of funding at the individual level (DHCS 2007; Attendant Care Industry Association, sub. 268, pp. 5–6), but without the person necessarily having any control over their package, or even having the package tied to them. This would define individualised funding as the absence of block funding. For example, disability employment services are characterised as 'individualised funding' in Australian national statistics (see below), because individually conducted Job Capacity Assessments determine referrals to different services and entitlements. Disability employment network providers get case-based payments rather than block funding. However, individuals have limited control over what happens to them or how resources are spent once the referrals are made. The same contrast between determination of funding at the individual level and real consumer power was a major criticism in the evaluation of the original Individual Support Packages offered by the ACT Government (Maher 2003). Some participants in this inquiry have made much the same point, arguing that the term 'individualised funding' has become 'emptied of its initial intent', and can relate to arrangements in which people with disabilities have limited say (National Federation of Parents, Families and Carers, sub. 28, p. 5).

Given the ambiguity of the term 'individualised funding' as used in Australia, the Commission has instead used the term 'self-directed' support throughout this report, with its key aspects being:

- resource allocation based on assessment of the individual's needs and aspirations
- the capacity for informed and genuine choice by people with disabilities or/and their family
- access to their own individualised budget (usually with the money in a specified bank account)
- the power for the person to tailor the mixture and type of services they get, subject only to their overall budget and to reasonable administrative constraints on spending options. For example, tailoring would include choice of own carers, the capacity to organise innovative respite and social participation options, and to choose accommodation services that meet their needs. This goes beyond the

capacity for a person to negotiate services with their provider and to choose (and switch between) their service providers, though that remains important.

In this chapter, the term self-directed funding is used to describe all arrangements with these features, but recognises that there are other ways of giving people more choice than giving people the money directly. Indeed, as noted above, it is expected that initially most tier 3 participants in the NDIS will choose individual packages, rather than budgets.

6.3 Reasons for self-directed funding

There are several strong in-principle reasons for giving people with disabilities, or those closely associated with them, power over the funding allocated to them.

Social norms and legal considerations

Australian social norms generally accept that people should be able to run most aspects of their lives. It would be inconsistent with those norms to put them aside for people with disabilities or their families. Moreover, laws now include the principle of self-determination, which means that the presumption is that people with a disability would make (or at a minimum inform) the key decisions about their lives. For instance:

- the first principle of the United Nations Convention on the Rights of Persons with Disabilities (to which Australia is a signatory) is 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons' (UN 2006)
- the Victorian *Disability Act 2006* sets down principles that include people's right to 'exercise control over their own lives' and for disability services to be 'flexible and responsive to the individual needs of persons with a disability [and] maximise the choice and independence of persons with a disability' (s. 5). This right is not an absolute one, as indicated by subsequent specific sections that introduce caveats related to the practicability of achieving full choice (for example, section 52(1))

Information economies

People have different, complex and changing preferences about their lives — their food, clothes, jobs, education, hobbies, friends and partners — that are not cheaply or easily observable by others. This is true for even the most apparently simple

products. A social worker might observe that a person likes tea. But they are less likely to be able to remember what type they like, or whether they like it strong, sugared, with milk, in a mug, very hot, after or before breakfast or both. Nor would an external agent know how, given a finite budget, a person might trade off one preference against another. So, individuals know a lot more than others about how to meet their own preferences, and in turn, this is likely to lead to better outcomes for them (greater economic 'efficiency'). This is why in most cases, a large degree of weight is appropriately given to the power of people to make their own decisions. The same principles hold for people with disabilities or their families.

There are several qualifications to this general proposition, which apply to people generally — not just those with disability:

- some vulnerable people may have preferences that lead to harm for themselves or others. (Examples among the general public would include driving dangerously, illicit drug taking and excessive alcohol consumption.)
- the choices people make to meet a given preference may be based on inadequate or false information, or on faulty cognitions. For instance, people may want to treat a debilitating cancer by using a well-marketed, but ineffective therapy, when a cheaper and more effective one is available. Further, consumer knowledge may be sufficiently limited for some specialised, highly complex services that experts need to act as gatekeepers to ensure that people get the services that genuinely meet their needs ('credence' goods). This may apply to some complex health/early intervention services used in conjunction with disability services. Notably, no health system allows people to choose any therapeutic substance they want without some controls. That said, the bulk of disability services would not require third-party screening
- some people with disabilities are not able to make all of their own decisions (as is the case with profound intellectual disability). In that case, decisions about their well-being will often be made jointly with or by their primary carers, who are usually familiar with the strengths, goals and other preferences of the person with a disability. However, while such carers will usually have the best interests of the person with a disability at heart, that will not always be the case. Like all people, carers (and people with disabilities) are not perfect, and sometimes will act in a way contrary to the interests of the person they are supporting (see later).

These caveats suggest that, just as holds in the community at large, sometimes others may need to provide advice or even override the preferences of people with disabilities or their carers (as, for example, occurs with regulations about drug use in the community as a whole). However, the general presumption is that people with disabilities, their primary carers and others would be able to make better decisions than people removed from their daily lives.

Competitive pressures

In most consumer contexts, absence of genuine choice tends to result in lower quality and more costly services, less product variety and less innovation. In contrast, consumer control of budgets through self-directed funding, or even the *option* of controlling budgets, creates incentives for suppliers to satisfy the needs of consumers, given that they would otherwise lose their business. That in turn typically leads to more complex markets, with suppliers developing differentiated products for different niches, promoting their products and advertising their prices and other relevant characteristics. The point is that competition is not just about achieving the lowest price,[3] but also encouraging the entry of new suppliers, quality service and the creation of new products that match people's preferences. An example in the United Kingdom is shop4support, an online market for a large array of disability services.

As discussed above, the scope for full competition may not always be present when suppliers have market power, consumer knowledge is poor, where services are complex, or where the market context would be likely to lead to distorted consumer decisions. Markets may also take some time to develop, as will the capacities for making informed choices by people with a disability and their families (hence the need for supporting people in implementing self-directed funding). However, choice among specialist disability services may often still produce better outcomes even where markets are imperfect. ('Choice of package' would also be likely to create greater incentives for suppliers to perform better.)

Moreover, choice gives people with disabilities or their families a greater capacity to buy mainstream services (for example, to go to a film, rather than a specially organised event for people with a disability). That has several implications. It:

- provides more pressure for responsive service by specialised agencies because it broadens the scope for competition
- means that people with disabilities get higher quality services. As all people consume mainstream services, it requires only a small number of these to be informed and demanding consumers to elicit responsive services by a supplier to benefit consumers more generally, including those with disability. So, it is better to be in a broad group that includes more of these demanding consumers than a narrow group in which there are smaller numbers. In effect, mainstream services adds the power of other consumers to those of people with disabilities
- expands the type of services people can receive

3 In theory, block funding or regulated prices *might* lead to low prices.

- may reduce social exclusion and marginalisation as people participate in the activities enjoyed by the community as a whole.

However, the role of mainstream services should not be overstated. As argued by JacksonRyan Partners (sub. 30, pp. 4–5) they may play a limited role for many people with disabilities. Many people will mainly acquire services from specialist disability providers.

The value of choice per se

The capacity to exercise choice can represent a valuable 'good' in its own right for many people, as revealed by the efforts people make to secure such freedoms. Many people would prefer to make their own decision on something, even if a benevolent outside party were to make exactly the same decision on their behalf. And, even if people end up asking someone else to choose for them, the option to make a choice remains valuable. The value of having (real) choices per se has been confirmed in a number of empirical analyses of choice in health care (Barnett et al. 2008). However, there is some evidence that people do not always value choice when there are too many options — choice 'overload' (Schwartz 2004) — or when the choices relate to lowly preferred options — 'fake' choices (Botti and Lyengar 2004). Providing support to people with disabilities to form personal plans may help to avoid choice overload, while maximising the scope for people with disabilities to determine how they spend their funding avoids the problem of fake choices.

There are social tradeoffs when someone else pays for a person's choice

The above four factors suggest that for the *given* budget that government allocates to a person under self-directed funding, there are potentially strong ethical and economic arguments for the person with a disability (or their proxies) to control how it is used. However, it does not imply that it is efficient for taxpayers to meet *all* of a person's preferences, regardless of the cost. (Of course, a person could add any of his or her own financial resources to meet needs not satisfied by taxpayers.)

This reflects the fact that the resources allocated to a person with a disability is funded through compulsory taxation of the community, who also have goals that they wish to achieve (buying a house, getting an education, being part of their community). Moreover, governments have to allocate the finite funding they are able to raise among many competing community needs (hospitals, roads, defence, addressing disadvantage and so on), and cannot meet all of them, even were they to increase taxes. Consequently, spending by governments is a zero-sum game — if

someone gets more, someone else gets less. Many families without disability also struggle to meet their aspirations. For example, one participant pointed out that in many other areas of government services, such as education, there are limits to meeting all the preferences of children (D. Holst, trans., p. 255). Another commented that 'the harsh reality is that no matter what the barriers faced by many people with a disability, the same barriers also face many other cohorts in our society' (JacksonRyan Partners, sub. 30, p. 6).

In that context, and as emphasised in chapters 5 and 7, the funding of the NDIS is based on people's reasonable needs, not wants.

6.4 Impacts, benefits and costs

There is now widespread evidence about the impacts of self-directed funding on people, and its costs, risks, and effective implementation, based on its use in many settings (summarised in table 6.2). Self-directed funding has been adopted in countries with otherwise very different frameworks for social welfare provision (Arksey and Kemp 2008; Townsley et al. 2010). There has also been piecemeal and generally small-scale implementation of self-directed funding in Australia, which helps guide the wider application of this funding approach (appendix D).

A detailed analysis of the impacts of self-directed funding is in appendix E, but the key findings are that:

- people with disabilities derive significant benefits from greater control over their budgets and lives, with their needs better met, greater life satisfaction, more interaction with people and the community, higher quality and continuity of care, with positive or no changes in their health status. As one participant remarked in this inquiry, self-directed funding 'was a huge relief; the quality of support workers, and support services increased (name withheld, sub. 209, p. 1)
- family members providing support have greater confidence in care, satisfaction with life, less financial strain and improved health status
- employed support workers generally get better outcomes, though this is not uniform
- self-directed funding is likely to partly alleviate the (current and impending) shortages of workers in specialised disability services by shifting the emphasis to mainstream services and by allowing friends, people in the local neighbourhood (and potentially relatives) to be paid for services

- there is little evidence of major difficulties for service providers from self-directed funding over the long-run, but some evidence of transitional costs associated with new systems
- ongoing costs appear to be generally lower (and at worst no higher) than traditional agency-based disability systems, though there are significant upfront implementation costs.

Table 6.2 **Summary of the impacts of self-directed funding**[a]

	Person with a disability	*Family members*
Consumer and family benefits		
Met individual needs	Improved	..
Satisfaction with care	Improved	Improved
Sense of control over life/ empowerment	Improved	..
Community interaction (circles of friends)	Improved	..
Greater use of mainstream services	Improved	..
Quality of care/ confidence in care	Improved	Improved
Costs of supports	Down or no change	
Personal dignity	Improved	..
More independent living	Improved	
Abuse and neglect	Down	..
Satisfaction with life	Improved	Improved
Culturally and linguistically appropriate care	Improved	..
Providing care during non-business hours	Improved	..
Continuity of care	Improved	..
Employment and productivity gains	Improved	
Use of preventative care	Improved	
Use of hospital, other health services & residential care	Down	
Economic wellbeing	Improved	Improved
Health status	Improved or no change	Improved
More aids & appliances and home/vehicle modifications	Improved	

a These results are derived from the studies cited in appendix E. While they include studies from Canada, the Netherlands and Australia, they mostly relate to the Medicaid waiver self-directed funding programs in the United States and to direct payments in the United Kingdom.

Self-directed funding is now a common feature of international disability systems, and has grown in importance where governments have implemented it. There are few indications of major problems in areas where people perceive significant risks (an issue discussed later in more detail).

Given the strong rationale for self-directed funding and the weight of evidence indicating that it achieves greater benefits for lower or at least, no higher costs, self-directed funding should be an available option throughout Australia for people with

disabilities. However, that still leaves open how any arrangements should be designed.

DRAFT RECOMMENDATION 6.1

Governments should give people with disabilities eligible for benefits under the NDIS, or their nominated proxies, various options for exercising choice, including the power to:

- ***choose directly the service provider/s that best meet their needs***
- ***choose disability support organisations that would act as intermediaries on their behalf when obtaining services from service providers, and/or***
- ***'cash out' all or some of their individual budgets if they wish, with the NDIA making direct payments to their bank accounts, and allowing people to purchase directly the detailed package of supports that best meets their preferences ('self-directed funding'), subject to the constraints set out in draft recommendations 6.2, 6.7 and 6.8.***
  - ***The specific arrangements for self-directed funding should be underpinned by the principle that, subject to the assessed individual budget and appropriate accountability requirements, the arrangements should maximise the capacity for a person to choose the services that meet their needs best and that promote their participation in the community and in employment.***

6.5 Design of self-directed funding

At the broadest level, self-directed funding involves people having significant control over their budgets. However, there are many issues about how to design self-directed funding and how it fits into a coherent disability system, encompassing:

- the division of power between a person with a disability and their families (section 6.6)
- the types of goods and services people may purchase and the ones where other parties still make purchasing decisions (section 6.7)
- whether people could hire their own employees, and in particular whether this could extend to family members — a controversial issue in the Australian context (sections 6.8 and 6.9)
- the capacity of people to know how to use the system and to meet the administrative and legal requirements for employing people, and how

governments and others can lower these costs or provide decision-making support to make self-directed funding a genuine option for people (section 6.10)

- the risks it may pose to people with disabilities, to support workers, to government and to service providers — and the best policy responses to these risks. An associated issue is whether all people should be eligible for self-directed funding (section 6.11)
- how self-directed funding should be implemented, taking account of the considerable transition issues (section 6.12).

6.6 Exercising power at the family level

The principle of self-directed funding is that where possible, decisions should be made as close to the person with a disability as possible, because such decisions are more likely to reflect the specific preferences of the person and their exact circumstances. In many cases, the decision-maker will be the person with a disability (though many will need support to exercise that role in the early stages of the NDIS — section 6.10).

However, where significant intellectual or mental health disabilities are present, people with disabilities may not be able to self-direct their funding by themselves. That does not require that traditional agency-based service provision be the default model for support. As noted by My Place:

> All people, regardless of the nature or severity of their disability, should be able to access the scheme. Where the person is unable to make their own decisions, court-appointed family members or guardians should be appointed to assist them with the decision-making. There is good evidence, accumulated from local practice in WA particularly, that Individualised Funding is well suited to people with significant disability (although there is an uninformed contrary view abroad amongst a number of service providers who do not operate Individualised Funding services). (sub. 217)

There are strong grounds for guardians (such as a parent or partner) familiar with the person with a disability to act as their proxy under self-directed funding. Several participants pointed out the importance of a familiar party or 'trusted other' as the most appropriate guardian where the person with a disability cannot make informed choices (D. Holst, trans., pp. 261–2; C. Quinn, trans., pp. 834–5; Julia Farr Association, sub. 494, p. 19). For example, Ms Quinn noted:

> He can't make any choices about plans, life. … So I'm basically the one that needs to make those kinds of choices in his life. I want to be able to do that and I'm quite capable of doing that but the system frustrates you in being able to exercise that — what everybody else gets to take for granted. So I really want choice about how things happen in my son's life. The other thing that's disturbed me significantly about the way

> disability services have traditionally been provided is that there's almost an assumption that service providers make better choices for people than their families do. I think that's intrinsically false.

It should be emphasised that guardians are obliged to take into account, to the extent practicable, the wishes of the represented person.[4] It should also be noted that while such carers will usually have the best interests of the person with a disability at heart, this will not always be the case. Like all people, carers (and people with disabilities) are not perfect. Some will act in a way contrary to the interests of the person with a disability or to the community, an issue that is relevant to accountability measures.

6.7 What services should be covered?

Tied or untied funding?

Existing international arrangements for individualised funding usually involve earmarking, with people facing restrictions on where and how they spend their funds. In some countries — France, the United Kingdom and the United States — purchases must be in accordance with a care plan, but can otherwise be quite flexible. Existing Australian arrangements are similar. For instance, in Victorian and South Australian self-managed funds, people must keep individualised funding accounts separate from other money and must only spend money on recognised carers, respite services and other goods and services identified as legitimately disability-related. In some countries, such as the Netherlands and Sweden the self-directed funding is largely restricted to personal care. Austria, Germany and Italy appear to be relatively exceptional in providing cash-for-care schemes that are unregulated (Arksey and Kemp 2008). In Germany, people electing direct payment have their package of supports discounted by 50 per cent.[5] While not seen as a form of self-directed funding, the UK Disability Allowance is effectively an unrestricted payment — albeit involving relatively low amounts.

Earmarking is usually inefficient because it entails administrative and compliance costs, and people cannot choose things they value more than items on the list of 'approved' purchases. It also can undermine independence, initiative, innovation and trust. On these grounds, one option is to pay individualised funding as untied income, as with income generally among the community, with the presumption that

4 For example, see Section 28 of the *Guardianship and Administration Act 1986*, Victoria.

5 Nevertheless, a significant number of people take up the direct payment option (Schultz 2010).

people will use it for the purposes best suited to their individual needs. On the other hand, there are difficulties in completely untied payments.

First, some major purchasing decisions are essential to good outcomes for people — such as adequate aids or home modifications. While there should be scope for a person to get choice *within* these areas, it is not clear that governments should give people the opportunity to cash out essential NDIS-funded items for other unrelated non-essential items, unless they have made a strong case. While, in fact, most people would spend their funds on essential aids and services, where someone did not, the government would feel compelled to allocate additional funds to provide them. This would reduce any personal impacts of poor decisions, thereby lowering people's incentives to choose carefully ('moral hazard'), and decreasing the scheme's cost effectiveness.

A major concern is where the benefit is a costly investment needed for the long run welfare of the person (such as an expensive wheelchair or a vehicle or home modification). The high cash-out value, combined with people's common tendency to be short sighted, could increase the risks of the inappropriate use of any cashed out benefits. The experiences with lump sum payments in accident compensation cases illustrates this risk, with people often not putting aside enough funds to meet their lifetime needs (chapter 15). Notably, a pure form of self-directed funding would give people the present value of the future lifetime expected stream of their assessed entitlements — in effect a lump sum — with the problems these have. In that context, the NDIA should pay annual allocations of self-directed funding in monthly instalments paid in advance.

A second major concern about untied funding is that cost-effective choices among some therapies require significant technical knowledge and evidence, which may be absent or limited among many people. For example, while the science is evolving, there are certain clinical protocols for appropriate early interventions for acquired brain injury and autism, which requires expert input. Notably, the *Helping Children with Autism* package from the Australian Government has specific requirements for eligible interventions, practitioner qualifications and program processes based on existing evidence (Roberts and Prior 2006). It would be hard to justify allocating NDIA funds to unproven or even potentially hazardous interventions just because they represented self-directed choices. (The same limits to self-direction apply more generally in the health system. People are not able to use public or private health funding for any-health related therapy they want.) This does not mean that the person with a disability or their agents (such as peak bodies) could not contribute to debates about new therapies through advocacy, or use their own money.

Thirdly, untied funding may undermine the integrity of the assessment process, leading to adverse fiscal and welfare impacts. The tools used to assess people for their needs and the extent of their natural supports are not perfect (chapter 5). To some extent, they rely on information provided by the person with a disability and their family. Once that is the case, it becomes possible for someone to err on the side of greater revealed needs and to err on the side of fewer natural supports, leading to greater payments (with concerns for the fiscal sustainability and fairness of a scheme). The incentives to do that are greater if people can treat the funds like ordinary money, and spend it on anything they want.[6] Moreover, the availability of high levels of untied payments may unwittingly encourage the persistence or exaggeration of an injury or disability — with adverse long run impacts on enablement (an example of so-called compensation 'neurosis' as happens with compensable injuries). This does not imply that people with disabilities are innately untrustworthy, but rather that, as a group, people with disabilities are like everyone else when responding to incentives. (To think otherwise is to adopt an inherently stereotyped view of disability.)

Finally, completely untied payments raise probity risks (perceived and real). The less open to scrutiny and the greater the value of untied payments, the greater is the risk of fraud and the inappropriate use of what is public money. Any significant abuse of funds – with funding sometimes exceeding $150 000 annually for a person with high care needs — would risk alienating public support for any form of self-directed funding and may jeopardise the scheme itself.

Accordingly, *entirely* untied self-directed funding could lead to adverse outcomes for people with disabilities, would fail to meet the usual public accountability standards for public monies, and could risk discrediting self-directed funding generally.

It may seem that this conclusion is inconsistent with the (generally) untied nature of Australian Government income support payments, like the Disability Support Pension (DSP). Historically, welfare payments have been framed in line with the so-called 'inalienability' principle that ensured that where a person qualifies for a payment, the payment is regarded as a legal right and cannot be withheld from that person (Buckmaster et al. 2010, p. 12). However, such payments are intended to be like ordinary income; are means and asset tested; not aimed at purchasing support services, therapies or complex equipment; subject to relatively low ceilings ($17 165 for the DSP in September 2010); and, by virtue of their role as a 'safety net' payment, must mostly be spent on basic needs, like food, clothing and

6 The fact some might do this need not reflect fraud (though that is a risk), but the desire given the uncertainty about actual future needs to have a buffer amount that can be spent on any option.

accommodation. Reflecting this, the biggest probity concerns about such payments have related to fraudulent or erroneous *eligibility*, rather than concerns about where the money is spent. Therefore, there is no inconsistency.[7]

Eligible goods and services

Requiring some constraints does not mean losing much flexibility in self-directed funding. The Commission favours a significant capacity for someone to tailor-make their supports, and envisages that, subject to the exceptions discussed later, the assessed value of services covered by the NDIS (chapter 5) would be bundled into a single individual budget (IB). A single individual budget also has the implication that governments would need to collapse any budgets currently dedicated to specific spending components into a single government budget (an observation made by Joyce Bellchambers, sub. 58, p. 1).

The rationale for an all-inclusive individual budget, rather than choices within spending silos, is that there may well be gains from people shifting resources from one basket to another. For instance, someone might want to use some of the funding earmarked for attendant care to buy a hoist or automatic bed turner to reduce future needs for attendant care. Subject to its cost-effectiveness, this was possible in a self-directed funding arrangement in the United States.[8]

That still leaves unresolved the issue of the appropriate constraints on what people may spend. Few would contest the legitimacy of spending on aids and appliances or traditional respite services. However, some spending categories, especially community access, do not have clear boundaries. For example, could a movie ticket or a gym membership ever be appropriate?

From one perspective, movie tickets are customary goods that most people buy with their own money. The wider the set of permissible goods, the more self-directed funding resembles untied funding, with the problems identified above.

However, looked at from a broader angle, without adequate support, many people with disabilities are unable to participate fully in society in ways that most people take for granted. Even buying ordinary things — movie tickets, attendance at a

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[7] Moreover, in recent years, quarantining for food and clothing *has* been introduced for some welfare payments in Australia following concern about the misdirection of payments away from essential purposes (*Social Security and Other Legislation Amendment (Welfare Reform and Reinstatement of Racial Discrimination Act) Act 2010*, No. 93, 2010). These provisions have not included disability payments.

[8] This was the Home and Community Based Service Physical Disability Medicaid waiver in Kansas in the 2000s (Kim et al. 2006).

class, going to the football, joining a gym or theatre group — can be very effective ways of achieving that goal compared with costly specialist alternatives (and these often could not be afforded through income support payments). One participant noted that a scheme should cover leisure costs:

> … because a person with disability requiring constant or frequent care [is] rarely employed. They have a lot of leisure time to fill and they need to be supported to engage with the community. (name withheld, sub. 74, p. 10)

The Commission knows of one woman with an intellectual disability where going to a movie means learning and maintaining skills (catching public transport), engagement with the public (buying the ticket, sitting with others in the theatre), and the creation of a sense of independence. The money spent on a movie in this case may be much more cost-effective and appropriate than some disability-specific services. In this particular instance, it was a fraction of the cost of the alternative disability services, she enjoyed the activity much more than specialist services and liked that fact that it was not a segregated activity. Notably, a NSW day program (Life Choices), which is *not* run through direct payments, includes many entertainment options (including movies, sporting clubs and concerts). It would be problematic to allow such options when a service provider acts as the intermediary, but not to permit them when a person controls their own budget.

The problem of drawing the boundaries for eligible expenditures under individualised funding reflects the broadness of the goals of contemporary disability policy — achieving independence, community engagement, ordinary life skills and citizenship for people with disabilities. Given these broad goals, and people's diverse needs and preferences, it would not be sensible to be prescriptive about where the money should be spent, but to have other approaches to deal with the risks of unrestrained choice (section 6.11).

The experiences in various self-directed funding programs in Australia and in other countries suggest considerable benefits from an accommodating approach by authorities about flexibility (for example, Laragy, sub. 84, p. 2). One Australian user of self-directed funding gave an illustration of the benefits of creative use of funding:

> Tim turned 21 and like any young man he's entitled to the rite of passage of a 21st birthday. Self-management allowed me to do something that was absolutely inconceivable any other time. I was able to employ [someone] for a small number of hours … to do some social education informally with him in preparation for his 21st birthday. It worked sublimely. He got the issue, even though his cognitive capacity is quite limited … and he had a ball. … But no other place except self-management allows you to do that kind of thing. So the system needs to have that flexibility to deal with that kind of life issue. (C. Quinn, trans., p. 836)

Another submission pointed out that self-directed funding provided personal assistance for a person to regularly visit a cemetery for cultural and faith-based reasons, which would not have been otherwise possible (National Ethnic Disability Alliance, sub. 434, p. 33).

A further aspect of desirable flexibility would be the capacity to save a proportion of an annual entitlement — say 10 per cent — to spend on future needs. The self-directed funding arrangements in Victoria allow this (appendix D). This has the advantage that people can plan for longer-term goals. It would also reduce incentives to spend all of an entitlement, even on lower priority needs, because the funds would otherwise be lost. However, a person should not be able to accumulate significant reserves by adding successive 10 per cent surpluses year after year, since that would bring into question the accuracy of the assessed package of supports. (That suggests a limit to the accumulation of surpluses — say to two years — with any further surpluses returned to the NDIA.) The Victorian model also includes some limits on the accumulation of surpluses.

Notwithstanding the benefits of flexibility, some accountability would be warranted. In particular, any system of direct payments (or arrangements close to these) would need to distinguish well enough between cases where it would be reasonable to spend money on entertainment services, and when that was not appropriate. If the risks were too high, some blanket rules might be appropriate. Nevertheless, completely avoiding risk would undermine the benefits of self-directed funding, and create many administrative and compliance costs. So how can the goals of accountability and flexibility be reasonably met? Probably the best approach would be to adapt the current Victorian model.[9]

Step 1 Assessment and budget determination

The individual budget for self-directed funding would be based on the formal individual assessment of the person's needs and would include the cashed out value of all goods and services covered by the NDIS, except those where specialist knowledge is required for informed choices. The prices for services underlying that budget would be based on efficient supply prices. For example, if an assessment indicated that a person needed 10 hours of attendant care a week, and the efficient supply cost for a typical supplier was $45 an hour in that geographic area, the budget would be $450 per week. (A more complex question is the estimate of the

9 This model was advocated by several participants, for example, Northcott Disability Services, (sub. 376, pp. 11–12). But it was also seen by one expert in self-directed funding as 'cumbersome and resource intensive' because of its detailed planning and review process (Laragy, sub. 84, p. 5).

budget for appropriate accommodation, since different types of accommodation solutions have varying costs).[10] The parallel Commission inquiry into aged care discusses the determination of appropriate prices at length — and the NDIA would need to follow similar processes.[11]

The amount allocated to self-directed funding should be equal to the budget determined by the assessment process. Were a discount factor applied to self-directed funding then this would encourage supply by specialised disability agencies, against the principles of competitive neutrality and economic efficiency.[12] A potential objection to this might be that people using self-directed funding do not face some of the costs experienced by specialised providers — such as an office, the need to administer the funds, supervisors, a computer system and other overheads. However, people with disabilities would still have to undertake some of the functions performed by agencies (like administration), but would take the payment for these tasks in the form of a capacity to access more services. Moreover, to the extent that self-direction involves lower costs than specialist provision (say because a person's home is also their 'office'), then this is an efficiency gain that should not be penalised. Finally, people may choose to pay a DSO to undertake administration tasks on their behalf, and for this to be a realistic option, their budget must include an amount that allows them to do so.

Step 2 Set up a plan and funding proposal

With the help of their family, friends or others strongly connected to them, the person would develop a personal plan and a funding proposal. This would be aimed at meeting the individual's aspirations and the outcomes he or she wanted to achieve, within the budget determined by the assessment.

The funding proposal could be reasonably flexible by specifying a range of spending options to achieve certain goals, rather than an excessively detailed breakdown of spending intentions. For example, where a person could not engage independently with the community, the proposal might say that the goal of community access would be achieved by going to the movies, attendance at a gym

10 Some participants pointed to concerns that self-directed funding would present challenges to creating accommodation infrastructure because suppliers would not be willing to invest without greater certainty about referrals (Disability Trust, sub. 230, p. 1). In other parts of the market, businesses are willing to invest in infrastructure, based on expected demand, *if the price is right*. So an essential aspect to infrastructure is ensuring that the budget amounts allocated to people reflect the prices needed to induce supply.

11 See PC (2011, p. xxxiv, p. xlviii, recommendations 8.2, 9.2, 11.2, 11.5, and chapter 5).

12 However, in some circumstances, a discount may be appropriate, such as when self-directed funding is used to employ family members.

or swimming pool, participating in a community class or similar such activities, with a budgeted average cost of $40 a week. In this instance, the person would be able to choose among these options as they felt appropriate, but would not have to pre-specify which one he or she would use. In general, the goal would be to provide as much flexibility as possible related to the particular needs of the person.

However, for the reasons outlined earlier, there would be a strong presumption that people would not be able to trade-off funding for essential aids and appliances and building and motor vehicle modifications against other spending options. However, people could direct some non-recurrent funding to other purposes if they could provide persuasive reasons for this as part of their funding proposal. The discipline of an approved funding proposal (described below) would prevent the practical dilemmas and risks of completely free choices about these high-cost non-recurrent spending items.

The NDIA would help in the formation of the planning and funding proposal by providing written resources and other guidance, as occurs in Victoria already. If the person wanted further assistance in planning or formulating the funding process, they could engage a DSO, which could provide specialist planners and other support for choice. Some participants specifically requested such a coordinator to assist with self-directed funding (for example, the Australian Leukodystrophy Support Group, sub. 564, p. 3)

Step 3 Getting the funding proposal approved

The funding proposal would allow considerable flexibility, but would also impose some disciplines on spending because the NDIA (or a panel, as suggested by Valued Independent People, sub. 201, p. 4) would have to approve the proposal or any significant alterations in it. The NDIA would pre-specify:

- generally admissible services
- inadmissible goods and services. A sensible criterion identified by the Julia Farr Association (sub. 494, p. 18) is that these would be goods, like gambling and alcohol, that can sometimes be contributory to the incidence of disability or the deepening of disadvantage
- those items where spending flexibility would be typically constrained (such as home modifications).

A plan would get approval if it met some clearly specified criteria relating to outcomes for the person and for appropriateness. The guidelines used in various Australian and overseas jurisdictions could be adapted to create a national approach under the NDIS, such as the guidelines used in the Florida self-directed care program (Hendry 2008).

There would also need to be a reasonable degree of accountability for spending and an ongoing re-assessment of the funding proposal to ensure its continued relevance and appropriateness. The way in which risks could be reduced is discussed in section 6.11, but the emphasis would be on the minimum required. Notably, some accountability can be useful to people. For example, one parent using self-directed funding in Victoria said that she found the accountability requirements 'quite helpful keeping you on track. It gives a little bit of structure ... ' (C. Quinn, trans., p. 842).

That said, another element of a flexible arrangement would be to allow a modest component of the individual budget — such as $30 a week — to be free of any requirements for receipts. This would have the benefit of allowing people to meet expenses that are not readily invoiced (say hiring a canoe) and for irregular and incidental 'employment' arrangements of the kind described later without any documentation. Notably, this kind of incidentals policy is already in place in the United States, with three US states allowing people to receive a small fraction of their allowance in cash for incidentals, providing the purchase plan states the overall amount and the types of goods and services people purchase (Philips and Schneiderm 2007, p. 408).

Step 4 Leveraging the proposal with private funds

People with disabilities, their families or the community generally could add their own funding to the proposal. For instance, that could allow the person to buy a better wheelchair, a longer holiday or a dwelling in a more preferred location.

What goods and services should be outside the individual budget?

Some services covered by the scheme should not be included as items in a person's individual budget, though they would be included in the overall budget allocated to the person through the assessment process. These excluded items would be:

- specialist therapies — where clinical or specialised knowledge would be required to make informed choices as discussed earlier
- specialised job readiness services (for example, the two-year intensive readiness scheme funded and overseen by Disability NSW). This is because employment is such an important goal that such services should be genuinely free, which would only be possible if using these services would not reduce the available individual budget.

Moreover, the individual budget would necessarily exclude some goods and services earmarked for people with disabilities, but funded outside the scheme

(mainstream employment services, health services, educational goods and services and public housing — see chapter 4).

DRAFT RECOMMENDATION 6.2

Self-directed funding should include the following key stages.

- ***It would be informed by any prior planning and aspirations expressed by the person during the assessment phase (draft recommendation 5.2).***
- ***The individual budget for self-directed funding would be based on the formal individual assessment of the person's needs and would include the cashed out value of all goods and services covered by the NDIS, except those where specialist knowledge is required for informed choices.***
- ***The person with a disability — and/or their support network or chosen disability support organisation — would create a personal plan and a concrete funding proposal to the NDIA that outlines the person's goals and the type of support that is necessary and reasonable to achieve these within the allocated budget.***
- ***The resulting funding proposal would require approval by the National Disability Insurance Agency (NDIA).***

There should be a capacity for a person to:

- ***obtain quick approvals for changes to a funding proposal***
- ***add their own private funds to a funding proposal***
- ***allocate the individual budget to any mix of preferred specialist and mainstream goods and services, subject to the requirements that:***
  - ***the person spend the budget in areas related to his or her disability needs and consistent with the funding proposal***
  - ***the scope to cash out funds set aside for large non-recurrent spending items should be limited to the (rare) circumstances where the NDIA has approved this as an appropriate decision.***

DRAFT RECOMMENDATION 6.3

The NDIA should pay annual allocations of self-directed funding in monthly instalments paid in advance, with the capacity for the person to 'bank' up to 10 per cent of the annual allocation to the subsequent year.

What about spending options in regional and remote Australia?

Some think that self-directed funding would be hard to achieve in regional and remote areas because of limited options for purchasing services (for example, the Attendant Care Industry Association, sub. 268, p. 6). This might be true in some cases. However, as discussed earlier, people would not have to take up self-directed funding, so they would not be worse off. Even if there was only one provider, the potential for self-directed funding would at least encourage entry by a new provider or the use of mainstream services as replacements for specialist services.

In many cases, however, people would still be able to use self-directed funding in regional Australia. My Place (sub. 217, p. 8) and Perth Home Care Services (PHCS sub. 520, p. 7) observed that the demands of people using self-directed funding can often be met in the country because:

> … the lion-share of supports that people with disabilities and their families seek are practical, everyday supports. These supports are generally available in most communities. (PHCS, sub. 520, p. 7)

The evidence suggests that many of the patterns of spending by people with access to self-directed funding between country and metropolitan areas were similar in that state, suggesting comparable spending options were available. For example, PHCS notes that the spending shares for aids and appliances, leisure support and personal care were very close between these two areas (sub. 520).

Advocacy Tasmania (sub. 483, p. 15) noted that Tasmania is the least urbanised state in Australia, with many small towns, but that (fledgling) self-directed funding arrangements still appeared to have worked well. A trial of a voucher for buying care in the United States[13] suggested that people in regional areas were still able to buy services, but did so in a different way. People in rural communities were much more likely than urban dwellers to spend their voucher on non-agency workers compared with agency workers (Meng et al. 2010). Some of the reasons for this were shortages of agency workers in rural locations and the preferences of rural people for hiring workers they knew, rather than receiving services through formal agencies.

A potentially important aspect of self-directed funding relevant to regional Australia is the capacity to hire family members. This controversial issue is discussed at greater length in section 6.9 (and appendix G), but it appears that this flexibility can be a further way of reducing shortages of formal support workers in regional areas.

[13] This was the Medicare Primary and Consumer-Directed Care Demonstration in New York State, West Virginia, and Ohio.

The difficulties in accessing specialised or even mainstream, services are accentuated for Indigenous people in remote areas. These problems are compounded further by:

- the high rates of disability in these communities, creating a higher level of incipient need
- the multiple sources of disadvantage that often affect such communities
- weakened informal support networks for people in some communities
- a cultural tendency not to identify disability or to access services when they are needed.

Together, these features present challenges for both traditional agency-based and self-directed funding arrangements for Indigenous people in regional Australia (an issue discussed in detail in chapter 9).

6.8 Employing people directly

A common feature of self-directed funding overseas is the employment of attendant carers or other support workers by a person with a disability (or their agent). Attendant care often comprises the main share of the recurrent costs faced by a person with a disability. An arrangement that allows people to hire people suited to them is a major source of the gains from self-directed funding. Many care services are 'low-tech, non-medical and do not require extensive training or oversight' (Kodner 2003, p. 2), which reduces the need for mandatory qualifications or for third party screening of people's choices.

Moreover, an essential aspect of the quality of support services is the extent to which support workers have an emotional connection and intangible skills specifically suited to the specific person with a disability, which only that person can observe. For instance, in a major UK study of self-directed funding (Adams and Godwin 2008), people with disabilities listed the top three desired attributes of an employee as a friendly attitude (89 per cent of employers), a willingness to work flexible hours (78 per cent) and adapting to the specific needs of the person with a disability (77 per cent). In contrast, having an employee skilled in healthcare tasks or with work experience in social or health care was important to less than 30 per cent of people with disabilities. My Place found similar patterns in the use of self-directed funding in Western Australia, with people with disabilities preferring to hire people suited to their particular needs, often without formal qualifications (sub. 217, p. 6). On these grounds, there are strong arguments for employment arrangements to be an eligible part of self-directed funding.

On the other hand, some people think that direct employment is not appropriate because of the vulnerability of people with disabilities and risks to workers. These concerns are considered in detail in appendices E and G and section 6.11, but the evidence suggests that these perceived risks do not usually eventuate, and can be addressed through appropriate oversights. That said, in some instances, such as where workers require some kinds of specialist knowledge, such as upper bowel care, tracheostomy support and formulation of behaviour management plans, choice should be limited to workers having some credentials in the relevant skill (Attendant Care Industry Association, sub. 268, p. 8; Disability Discrimination Legal Centre, trans., p. 757).

A bigger concern may be that the responsibilities and compliance burdens associated with employing someone are so big that it is not a realistic option for many people with disabilities. One participant in this inquiry noted:

> … if a family carer or the individual endeavours to personally manage their funding they will need a commitment equivalent to a lengthy part-time job to find, engage and supervise care and support, as well as be accountable for income and expenditure. (Lorna Carroll, sub. 106, p. 3)

The administrative and compliance obligations for employment of people under self-directed funding depend on the exact nature of the employment arrangement, which can be complex to determine (appendix F). In many instances, self-directed funding would involve no superannuation, tax withholding or OH&S obligations, which may well suit some of the flexible arrangements people might adopt. Such arrangements would be likely to cover arrangements in which:

- someone gets a neighbour to drive them to a gym class sometimes and pays them for doing so
- an adolescent helps babysit for a child with a disability and gets $15 an hour
- a neighbour helps mow the lawn or clean the house most weeks and gets paid $20 each time
- a support worker provides an average of 10 hours of care a week in the home of the person with a disability, but with the amount of work and the times when it takes place varying with the needs of the person with a disability.

However, the full employer responsibilities would usually apply where people and families receive large funding packages and employ support workers for regular and substantial lengths of time. In those cases, people would either have to learn how to do this themselves (largely a fixed cost that may be low relative to the long-run benefits) or could contract a third party, such as a DSO, to undertake the tasks for them. Either way, it is likely that people with disabilities and their carers would

need help in employing support workers, at least at the start of any employment arrangement. Section 6.10 discusses the supports people may need to self-direct.

An additional question is any needs for the NDIA to have vetted employment arrangements to ensure they meet the various statutory obligations. There are grounds for a two-tiered arrangement, in which the person with a disability would provide the relevant documentation to the NDIA for substantive employment arrangements in large employment packages, but with no or few reporting requirements for other forms of employment. This would be more akin to the situation outside disability, where small, sporadic and informal domestic arrangements like paying for a babysitter are not burdened with compliance or reporting requirements.

Employment of family members raises special issues of risk and benefits.

6.9 Paying relatives for care

Payment of family members has been a controversial element of self-directed funding, with concerns about abuse and unintended impacts on caregivers, people with disabilities and government budgets. In principle, these concerns are sound and some anecdotal cases back them up. However, the systematic evidence suggests that payment of family members is generally beneficial (appendix G).

That said, aside from the (relatively modest) Carer Payment and Carer Allowance, Australia has little experience in administering funding arrangements that permit payments to family carers.[14] This suggests a cautious approach.

- Carer Payment (and to a lesser extent, Carer Allowance) is already a payment to a family member (or others close to the person with a disability). These (or similar) payments should continue, though there are grounds for their inclusion in the overall self-directed funding package.
- The arguments about the risks from paying family carers relate to ongoing employment of resident family members. They apply less clearly to non-resident family carers and even less so to intermittent or one-off employment contracts. Accordingly, there are strong grounds for at least intermittent (rather than just recurrent) payments to non-resident family members, with less stringent accountability, for activities like respite and holiday care. For instance, one parent of a child with a disability, Sally Richards, was able to hire her sister for

[14] An historical exception is the Domiciliary Nursing Care Benefit, a precursor to Carer Allowance, but with little take-up despite its greater generosity (Howe 2007).

two weeks to care for her son and maintain his community participation while Sally went on holiday (trans., p. 400).

Moreover, the NDIS should conduct a trial of payments to resident and non-resident family members to test its risks, advantages, disadvantages and optimal design. The trial should use an appropriately rigorous scientific approach, drawing on the evaluations used in the United States 'Cash and Counseling' programs. The trial should include several safeguards:

- the part of any self-directed funding package relating to payments to family members should be discounted (for instance, by 20 per cent) to reduce cost-padding incentives (appendix E)
- paid family care would initially be limited in duration (say 6 months), with continuation based on assessment of 'burn out' or psychological distress for carers, and the consequences of the arrangements for the independence of the person with a disability
- appropriate management of the risks. The Wisconsin *Guidelines for Paying Family Caregivers*[15] provides a useful template for overseeing payment of family carers. Among other things, the process includes assessment of the competence of the carer, checks to identify any past abuse or neglect, training, education about the pitfalls of paid family care, a mandatory schedule of respite if caring is intense, and assessment of any economic stresses that may indicate the potential for financial abuse. The managed care team can decline authorisation on health and safety grounds if they are not satisfied that appropriate care would be provided.

DRAFT RECOMMENDATION 6.4

There should be a capacity for people to recruit and employ their own support workers, subject to the proviso that these should not be close family members, other than when:

- ***care is intermittent and provided by a non-resident family member***
- ***exceptional circumstances are present and after approval by the NDIA***
- ***the person is in the family employment trial spelt out in draft recommendation 6.5.***

15 http://www.dhs.wisconsin.gov/ltcare/Partners/PDFs/famcaregvrs.pdf.

DRAFT RECOMMENDATION 6.5

There should be a trial of the employment of family members under self-directed funding to assess its risks, advantages, disadvantages and optimal design, with its wider adoption if the evaluation proves positive. The trial should use an appropriately rigorous scientific approach, drawing on the evaluations used in the United States 'Cash and Counseling' programs. For the trial:

- ***the NDIA should determine that there are few risks from hiring relatives for each family in the trial***
- ***the individual budget should be discounted by 20 per cent***
- ***support should be initially limited in duration to six months, with continuation of any arrangement for a given family based on the benefits and costs to that family***
- ***risks should be carefully managed to ensure appropriate use of funds and to safeguard people with disabilities and carers (draft recommendation 6.8).***

6.10 Take-up of self-directed funding and the need for support

The evidence from overseas is that relatively few people initially take up full control of their budgets when it is offered (Vick et al. 2006, p. 2; Laragy, sub. 84, p. 2), with particularly good evidence on this issue from the UK (appendix E). In England, the take-up of self-directed funding, while modest, is still increasing rapidly. Just over 10 per cent of all people receiving disability supports used self-directed funding, but nearly one in five of carers where they were the responsible person. These international experiences suggest that most people will not use self-directed funding initially, especially in those jurisdictions where arrangements for self-directed funding are in their infancy (such as Queensland). Nevertheless, take-up is likely to grow quickly, especially if people are supported in taking control over their budgets.

Some contributors to low take-up are not problematic. The evidence from abroad suggests that low take-up rates sometimes reflect satisfaction with delivery by specialised agencies. Self-directed funding is not an objective in its own right. If people make informed choices in favour of other arrangements then it should not be a policy goal to persuade them otherwise.

However, other reasons for low take-up are appropriately the target of policy. These include different levels of enthusiasm for self-directed funding among local authorities; reticence by frontline disability workers to promote it; lack of awareness

that consumer-directed payments are an option; and perceived concerns about the risks to, and compliance costs for, users (Carr and Robbins 2009, pp. 6–7; Adams and Godwin 2008).

Inertia, uncertainty and lack of confidence may also affect people's willingness to take up self-directed funding. For example, one participant thought that a short-run cultural obstacle was the learned passivity of some people with disabilities, who were too long accustomed to command and control services:

> The disability service system has taught people with disability and their families to be dependent users of services, discouraging initiative and rewarding crisis. The system has often destroyed their dreams for their sons and daughters and until recently, most families have been immobilised in their ability to plan and think about the future because so much of the picture seemed dependent on the whims and changing policies of government. (Joyce Bellchambers, sub. 58, p. 11)

Compliance costs are also a significant issue because users have some responsibilities when they have greater choice and power. If consumers take *full* control of funding, they would be responsible for hiring any staff they want (section 6.8 and appendix F); ensuring that they have adequate public liability or other insurance; overseeing service provision; and accounting for spending.

The costs and uncertainty associated with these responsibilities act as a barrier to take-up of self-directed funding (as noted, for example, by Autism Spectrum Australia, sub. 443, p. 19 and Perth Home Care Services, sub. 520, p. 5). This is especially so when many people with disabilities and their carers are exhausted by their existing responsibilities. Moreover, people's willingness to invest in the upfront costs of self-directed funding (such as learning about obligations to employees) depends on some confidence that they will get funding in later years. This has not been the case in some existing schemes. Wesley Mission Victoria said:

> Through our current evaluation of the ISP Funded Facilitation program, we know that people feel uncertainty and anxiety about the continuity of funding – they worry that what they have in their current allocation may be taken away or diminished in the next allocation. (sub. 541, p. 12).

Moreover, a system with too many compliance costs may result in people still using self-directed funding, but not to its full extent. Adam Johnston, who participated in the NSW Attendant Care program (a trial of self-directed funding) said:

> My case should stand as an example of the inefficiencies in a system, whereby the recipient of funding declines to proceed with available, additional funding. This is because dealing with my own current personal circumstances and arrangements … is currently easier and less emotionally taxing, than engaging with the bureaucrats of the ACP. (sub. 55, p. 3)

A direct way of increasing people's willingness to use self-directed funding is to provide certainty about support entitlements through a transparent and rigorous assessment process (chapter 5) and to reduce compliance burdens where they do not undermine public accountability, or the safety of people with disabilities or support workers. Reducing compliance burdens for people with disabilities using self-directed funding has the likely added advantage that it will lower the administrative costs of the NDIS. Bits of paper in one part of the system need to be read and processed in other parts, so cutting the bits cuts the costs.

A further way of facilitating self-directed funding is through effective support and training.

Effective support and training

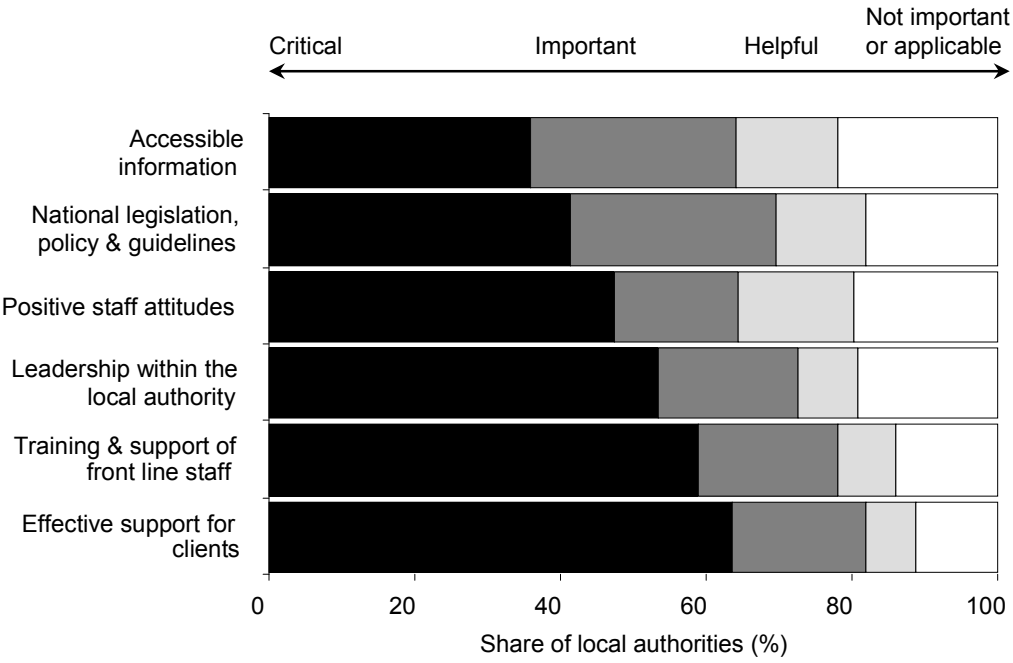
The UK experience suggests that take-up can be improved through better support of people using self-directed funding, and training and commitment by front-line staff in government and other disability agencies (figure 6.2). This was view more generally endorsed by Laragy (sub. 84) in this inquiry.

The Arkansas Department of Human Services (ADHS 2008), responsible for one of the three large experimental trials of self-directed funding in the United States, has argued similarly, observing that offering self-directed funding 'without the necessary counseling and fiscal services is a recipe for a disaster'. This was why the main US scheme for self-directed funding is structured as Cash *and* Counseling. Several participants in this inquiry have voiced similar views about the need for consumer supports to implement self-directed funding in an Australian context.[16] One noted:

> A lot of people with disabilities and families are coming from a background of being disadvantaged, poor, powerless, not used to actually making those decisions. So to expect that people might just jump into a system is, I think, a bit silly. There has to be some of those capacity-building things in place (Ms Jenkinson, trans., p. 982)

16 Among others, these included Carer's NSW (sub. 244, p. 6); S. Jenkinson (trans., p. 982); R. Held (trans., p. 409); Wesley Mission Victoria (sub. 541, pp. 11–12); and M. Ireland (sub. 233, p. 4).

Figure 6.2 **How can take-up of self-directed funding be encouraged?**
Evidence from the UK experience



Data source: Davey et al. (2007, p. 100).

There are two critical elements of an effective support system. The first would be training of local case managers and other front-line government agencies in implementing self-directed funding — why it exists, how a plan is drawn up, knowledge about the supports for people with disabilities, and the risks. Drawing on their evaluation of the ISP Funded Facilitation program in Victoria, Wesley Mission Victoria argued that staff needed to be supported in implementing self-directed funding (sub. 541, p. 12).

A second element would be adequate support of the person using self-directed funding, which would include helping them to draw up a funding proposal and addressing the main compliance burdens of self-directed funding. The overseas evidence shows that many people would like to self-direct the key elements of their budget — such as hiring their own support workers — but prefer to pay a fee for intermediaries to undertake the 'red tape' and administrative aspects of hiring workers or managing and accounting for the funds.

This kind of support would mainly be provided by DSOs (or others) contracted to people with a disability. This already occurs in some jurisdictions, for example, Allowance Incorporated in the ACT and NSW (sub. 130, p. 1) and Western Australia generally. However, it should be an optional feature of an NDIS since some people may not need such guidance. One participant in this inquiry already despaired of being 'smothered' by coordinators (Adam Johnston, sub. 55, p. 7).

However, regardless of whether people use a DSO to provide support during and after the creation of a funding proposal, there are also grounds for the NDIS local case manager to provide 'light touch' guidance and also, since the welfare of vulnerable people and public funding is at stake, to fulfil a safeguarding role.

Self-directed funding in a national disability scheme can draw — with adaptation — on extensive existing practical information and guidelines on how to provide support to all the agents affected by this funding model. Several Australian jurisdictions already applying self-directed funding have released practical guides, including a detailed manual from Perth Home Care Services (2010) and a handbook from the Victorian Department of Human Services (DHSV 2009a). In the United Kingdom, the Social Care Institute for Excellence and In Control has produced many different guides to personalisation geared to certain purchases, clients and service providers. The handbook produced in the United States by Crisp et al. (2010) represents an elaborate and pragmatic guide to setting up the appropriate types of supports, and in providing guidance for users, case managers and service providers.

There are strong grounds to draw from these existing guides in developing support arrangements for users (and any hosting agencies) and in informing them about how self-directed funding works. Equally, there is already a free, open source, software tool (the CDM or Consumer Direction Module from the US National Resource Center for Participant-directed Services) for administering self-directed funding,[17] which could be adapted for Australian use (and which could be made freely available on the NDIA's website).

There should be a continued evidence-based approach to reducing the barriers to the use of self-directed funding, as new research shows how different approaches may be effective. As an illustration, a small-scale pilot of self-directed funding in the UK among young people found that practice budgets helped people understand how to set budgets, and that shared experiences among families about self-directed funding plans helped people to realise what was possible and how to set up practical plans (Crosby and Fulton 2007, p. 35). More broadly, it would be critical for a disability scheme to systematically monitor take-up, determine why there may be variations by area, by the severity or nature of the disability, or by other traits of recipients, and then adjust the scheme design and administration accordingly.

[17] Among other things, the CDM allows the overseeing agency to keep track of participants in a self-directed funding arrangement (brokers/counselors, fiscal agents, employees, medical providers, representatives/guardians); maintain case notes; generate spending plans; track participant expenditures; coordinate approvals, denials and appeals; and communicate with all participants.

The Commission is not proposing the creation of a fund for explicitly fostering creative practices similar to the Direct Payments Development Fund in the United Kingdom (NCiL 2006). This is because the NDIS itself will subsidise the use of DSOs (at least initially) whose role, among other things, would be to help people create innovative plans (if they wish this).

DRAFT RECOMMENDATION 6.6

The NDIA should:

- ***inform people with disabilities and their proxies of the various options for self-directed funding***
- ***provide support for people using self-directed funding, including easy-to-understand guidance about the practical use of self-directed funding, including standard simple-to-follow forms for funding proposals, hiring employees and for acquittal of funds***
- ***promote the use of self-directed funding, with examples of innovative arrangements***
- ***provide training to local case managers and front-line staff about self-directed funding***
- ***encourage the formation of disability support organisations to support people in the practical use of self-directed funding.***

6.11 What about the general risks of self-directed funding?

Quite apart from the special risks (and benefits) associated with employment of family members discussed in appendix E, there are many other perceived risks associated with self-directed funding. Since self-directed funding is public money, there must be at least some mechanism to ensure that people spend the money as intended and that there are no other significant risks to people's safety and wellbeing. Leaving a system without adequate protections against these risks would undermine the integrity of a scheme and threaten its viability and pubic support.

There are many possible sources of general risk from self-directed funding:

- people with disabilities or their families might deliberately or accidentally misuse the funds through theft or by spending on goods and services unrelated to disability needs, an issue raised by several participants (for example, the Centre for Cerebral Palsy, sub. 290, p. 5). Some people with disabilities have to address addictions and substance abuse problems that may make it difficult for them to handle money directly (though other parties could act on their behalf). For

example, there is empirical evidence that 68 per cent of people who experience traumatic brain injury have a history of substance abuse (Headwest Brain Injury Association of Western Australia, sub. 448, p. 6). And, while a small share of people with a disability have come into contact with the justice system, nevertheless some have (Holland et al. 2007; Office of the Public Advocate Queensland 2005; DIG 2009, p. 110). For these self-directed funding would need to be oversighted carefully

- people might exaggerate disability in order to acquire funds. This risk is reduced if funding is limited to disability-related supports identified in people's funding proposals. (Most people do not want unnecessary support, since it is often intrusive, although this would not hold for paid family carers.) Moreover, the strong process of assessment and governance of the NDIS also aims to control inflated claims (chapters 5 and 7). In particular, these risks could be moderated through systematic data analysis. Under the NDIS, people will be asked about their previous package and the supports they require, as well as many other aspects of their circumstances (such as condition, duration of disability, extent of functional limitations, family circumstances and so on). It would then be possible to develop a model that predicted people's budgets using this information. If a person requesting self-directed funding was to obtain a budget that, given their characteristics, lay well outside the range predicted by the model, that would require closer scrutiny of their assessed budget
- people with disabilities and their families are sometimes vulnerable — tired, isolated, poor, and in some cases, unable to complain due to their disability. Overall, rates of abuse of people with disabilities are multiples of those for people without disability (Hayes 2009), indicating their general vulnerability. Data from examination of referrals to the UK Protection of Vulnerable Adults list (POVA) shows that people with a learning disability were more likely to be abused physically or sexually than those with a physical disability (Stevens et al., 2008, p. 45)
- on the other side of the coin, paid carers can also be vulnerable without the support of an agency, and may be exploited by people with disabilities
- some functions of self-directed funding — like hiring one's own carers — involves relatively complex administrative and compliance tasks that if not performed adequately, may leave the employer or the employee at risk (for example, inadequate workers' compensation arrangements) or, if funds are poorly managed, under-payment of providers (Glendinning et al. 2008, p. 205) or under-provision of important services

- people may be left with inadequate or no services if self-directed funding arrangements break down (a carer becomes unreliable or leaves), suggesting a need for backup 'last resort' services, which have to be funded.

As an illustration of their strength, the *perception* of such problems by officials and others — particularly of misuse of funding — held back the passage of legislation that would have allowed direct payments in the United Kingdom for a long period (Pearson et al. 2005). It is still a barrier to the practical expansion of self-directed funding in that country. In 2008, survey evidence suggested that more than one third of the social care workforce in the UK believed that the personalisation agenda was the wrong direction for adult social care (Mickel 2009). More than 90 per cent of local authority social workers were concerned that self-directed funding would make people with disabilities more vulnerable. Similarly, officials in several trials of self-directed funding in the United States were initially anxious that beneficiaries might use the cash benefits to buy alcohol, cigarettes, drugs or gambling products, or that support workers hired under self-directed funding would neglect, exploit or abuse the person with a disability (Doty et al. 2007, p. 383; O'Keefe 2009).

These latter concerns partly reflect the fact that support workers hired under self-directed funding may be subject to little third-party scrutiny, potentially exposing people with disabilities to greater risks. In the UK, some people using direct payments have not been required to request Criminal Records Bureau and POVA checks for people they employ, while this is mandatory for formally employed staff (Stevens et al. 2009). In contrast, specialised services have, *in theory*, a greater capacity for delivering quality because they have accreditation processes, monitoring of staff and a reputation to maintain, which may not be present in transactions between a household and a paid carer in the informal, largely unregulated market. But 'in theory' and 'in practice' outcomes may diverge.

Perceptions aside, what is the evidence?

The evidence about the extent of risks is often anecdotal. In the UK study of individual budgets, there were anecdotes of financial abuse of direct payments (Glendinning et al. 2008, pp. 173–4). The study reported that:

> … examples were cited of financial abuse, financial irregularities, concerns about the criminal record of the carer (fraud), deception regarding levels of need, allegations of rape and personal assistants ignoring court injunctions preventing family visits. (p. 175)

For example, one team manager of disability services indicated three or four cases of financial abuse by attendant carers within a four-month period.

However, while anecdotes indicate that abuse occurs, the systematic evidence suggests that the levels of abuse are low. If anything, the evidence suggests that while people with disabilities are vulnerable, if anything, they are less vulnerable under consumer-directed care arrangements than through those organised by specialised services.

Laragy (sub. 84, p. 5) noted that in the (Australian) individual funding models she had studied, there 'was always a high degree of review and no instances of abuse reported'. A Queensland service provider reiterated this point, indicating that of the 165 families getting access to cash payments, there was just one instance where a family did not meet the accountability requirements (Ward, Mamre Association, trans., p. 402). Perth Home Care Services observed that in Western Australia the evidence suggested fewer risks with self-directed funding than traditional agency approaches (sub. 520, p. 7).

Evidence from annual audits of direct payments over a three year period in one council area in the UK identified one minor case of misuse of funds (relating to taxi receipts). The audit costs to detect this instance were around £165 000 (Poll et al. 2006, p. 85). The third evaluation of self-directed funding in the UK found a significant improvement in the capacity of professionals to manage risks (around 40 per cent of professionals sampled), while less than 5 per cent considered that risks had worsened (Tyson et al. 2010, p. 143).

A more detailed empirical examination of rates and types of abuse experienced by people with disabilities under self-directed and traditional funding arrangements in the United Kingdom found that the rates of any form of financial abuse was 5 per cent under self-directed funding and 9 per cent under traditional care models. The comparable rates of psychological, physical and sexual abuse for the two different forms were 6 and 13 per cent, 1 and 3 per cent, and 0 and 2 per cent (with the first number of each set being for self-directed funding) (Adams and Godwin 2008, p. 34).[18]

Other evidence more generally points to the considerable problems of abuse in specialised institutions compared with informal settings, notwithstanding the quality

[18] A flaw in these statistics is that the questions related to 'ever' experiencing abuse. One reason people may report a higher abuse rate for traditional services is that they had used such services over a longer period than self-directed funding. Nevertheless, survey evidence that asks people to rate their relative vulnerability in the two systems overcomes this bias. That evidence shows that 77 per cent of people with disabilities felt they were *less* vulnerable under self-directed funding than under previous traditional support models (Adams and Godwin 2008, p. 39).

controls that governments put in place in the former.[19] For example, in the UK, a relatively significant number of complaints of abuse (for the elderly disabled) relate to nursing homes and hospitals, and there are similar concerns about abuse in specialised residences for those with an intellectual disability (Poll et al. 2006, pp. 94–95).

In the United States, there was likewise little evidence of any systematic exploitation, neglect or fraud associated with self-directed funding, even though the target populations tended to have lower than average incomes. There were very few instances of reported fraud or abuse (of consumers or workers) in the large US *Cash and Counseling* trials of self-directed funding (Schore et al. 2007, pp. 461–2). Counsellors periodically contacted consumers and their representatives in person and by telephone, and both counsellors and bookkeepers reviewed consumer spending. Only two of 37 New Jersey counsellors reported any incidents and they related to only two people (one of self-neglect and the other for exploitation). Counsellors considered that any agents chosen by consumers acted in the consumers' best interest in all but a few cases. In this trial, people had the right to enrol in the program without any screening for their suitability, which would tend to increase the risks of abuse. For that reason, the program director in each state had the power to revoke the right to use self-directed funding in the event of abuse or exploitation. Very few consumers had this right revoked (Phillips and Schneider 2007, p. 404).

The trials also revealed that informal carers had far fewer concerns about the safety of the person with a disability where that person was enrolled in self-directed funding (compared with outcomes for a control group without access to self-directed funding). The share of caregivers worrying that:

- a care recipient's safety was at risk 'quite a lot' fell from by between 19 and 14 percentage points (depending on the state)
- there was a significant risk that someone will take the care recipient's money or other belongings fell by between 5.5 and 7 percentage points
- a care recipient would face a significant risk of inadequate help fell by between 13 and 18 percentage points (Foster et al. 2005, p. 29).

Cash and Counseling had no adverse (and sometimes positive) effects on objective, care-related outcomes for consumers, such as injuries incurred while receiving care. This is again consistent with higher, or no lower, levels of health and wellbeing outcomes for people with disabilities (Carlson et al. 2007 and appendix E). For

[19] A point made by the Pave the Way Mamre Association (sub. 528, pp. 17–18) and name withheld (sub. 74, p. 11).

example, the incidence of bedsores, urinary tract infections and falls were lower among those using self-directed funding than those in the control group.

A further large US study of the risks associated with consumer-directed care compared with traditional agency services (based on the California In-Home Supportive Services Program) found that self-directed funding was associated with a lower or equal level of risk for people than agency-based care (Matthias and Benjamin 2003).

Risks for support workers

There can also be risks for support workers, such as low pay, failure to meet statutory employment standards and abuse. However, there is little consistent evidence of low wages, but reasonably reliable evidence that wellbeing of employees is typically better, or at least no worse (appendix E). For that reason, there are no grounds for blocking people with disabilities from employing support workers directly or of excessively regulating their employment. However, there are grounds for some protections (discussed below).

What do the risks mean for policy?

The trade-off between the risks of self-directed funding and the benefits it brings suggests the need for prudent oversight.[20] People with disabilities also acknowledge the need for safeguards from misuse and abuse of self-directed funding.[21] Risk mitigation should be achieved by:

- assessing the capacity of people to handle their funds before agreeing to direct payments. Scope (sub. 432, p. 19) recommended that the stability of a person's social situation and health needs should be a condition for eligibility to self-directed funding. In the UK, there is a legislative requirement that people be 'willing and able' to manage direct payments (Frontier Economics 2006, p. 55). Some local authorities have explicitly assessed the risks for individuals using Risk Enablement Panels, and these have generally received strong support by care coordinators (Glendinning et al. 2008, p. 177). If a person is perceived as high risk, then management of the funding could be the responsibility of an intermediary, but the person could still determine the decisions about the

[20] Some participants stressed the need for a balance between risks and benefits, for example, the Councils of Social Service in Australia (sub. 369, p.7); and Scope (sub. 432, p 19).

[21] For example, name withheld (sub. 482, p. 5) and consultations by the Disability Advocacy and Complaints Service of South Australia with up to 50 people with disabilities (sub. 267, p. 11 and attachment).

allocation of funds in accordance with their approved personal plans. DSOs could play such a role in Australia. Local case managers would also assess whether a person was coping with self-directed funding

- providing information, training and support to people using self-directed funding where it is needed, and clear guidance on appropriate usage of funds, including an understanding that penalties may be applied for misuse (as suggested by Melissa Ryan, sub. 251, p. 9)
- providing avenues for people using self-directed funding to complain to the NDIA about any inappropriate behaviour by providers and to have these investigated (chapter 7 describes the complaint mechanisms)
- ensuring reasonable accountability for funding, with acquittal periods determined on a risk basis, with less frequent acquittals by those who demonstrate proficiency in managing their funds and initially greater supervision for those inexperienced with self-directed funding. People would have to account for most of their expenditure with proof of purchase, but as discussed in section 6.7, a small amount of the individual budget should not require acquittal
- ensuring that people with a disability and their carers have easy and cheap access to police checks of employees who provide personal services. Such vetting would be required for would-be employees working alone with particularly vulnerable people,[22] such as children or adults with intellectual disabilities.

Just as self-directed funding (or any support arrangement) poses risks for people with disabilities, they also pose risks for employees. That suggests provision of information to, and support for, employers to help them meet their obligations to employees, particularly in relation to worker's compensation (where that applies). It also suggests that there should be measures for employees that allow for mediation, lodgement of complaints and advice. These could address employee/employer disputes, inappropriate behaviour by employers, and issues relating to concerns about unreasonable expectations. For example, the latter might be requests to an untrained attendant carer for clinical services, where an issue of quality or safety arose (Attendant Care Industry Association, sub. 268, p. 8). Finally, one of the considerations in removing a person's right for self-directed funding would be whether the person had handled any employer responsibilities inappropriately.

[22] Such employees would need to be distinguished from one-off employees. That could be determined by any contract period or where the person was covered by the full employment arrangements described in section 6.8.

DRAFT RECOMMENDATION 6.7

Before offering self-directed funding to a person, the NDIA should:

- ***meet with the person with a disability and their carers, and take account of their experience and skill sets***
- ***use that and any information provided during the assessment phase to determine whether the person and/or their support network are likely to be able to:***
  - ***make reasonably informed choices of services***
  - ***manage the administrative and financial aspects of funding if they wish to oversee these aspects by themselves.***

DRAFT RECOMMENDATION 6.8

In offering self-directed funding, the NDIA should ensure that:

- ***it reduces the risks of neglect or mistreatment of people with a disability by support workers or other service providers hired by users in the informal sector, by:***
  - ***ensuring easy and cheap access to police checks***
  - ***giving users the capacity to complain to the NDIA about inappropriate behaviour of providers, and to have these investigated***
  - ***monitoring by local case managers***
- ***it reduces the risks to support workers employed under self-directed funding by requiring that they are covered by workers' compensation arrangements and have an avenue for lodging complaints***
- ***it adopts a risk-management approach for receipting and other accountability requirements, which:***
  - ***requires less accountability for people with low risks or who have demonstrated a capacity to manage their funds well***
  - ***takes into account the compliance costs of excessive accountability measures***
  - ***allows a small component of the individual budget to be free of any receipting requirements.***

6.12 Implementing individualised funding

The grounds for greater self-directed funding are strong. However, national implementation poses challenges. Western Australia already has a well-developed system and Victoria a rapidly developing one. In other jurisdictions, self-directed funding is still in its infancy. The international experience suggests that it takes time to adapt processes for consumer-directed payments and to build up the capabilities in government, service providers and service users for their adoption (Glasby and Littlechild 2009; University of Minnesota 2009). For example, the United Kingdom Government initiated consumer-directed payments through the Independent Living Fund in the late 1980s and introduced direct payments in early 1997. There was a myriad of changes over the subsequent decade to encourage the adoption of consumer-directed payments and to allow greater flexibility for people. Accordingly, there is a 20 year history of evolving arrangements in the UK, and arrangements are still in flux. It was notable that in the pilot programs for individual budgets in the UK, the evaluators noted:

> The costs and complexities of implementing IBs alongside traditional resource allocation systems and service provision were major challenges in all sites. Even sites that intended using the IB pilot to transform the whole of their adult social care provision recognised the need to operate parallel systems for significant transitional periods. Particular concern was expressed about the capacity to offer IBs while resources were still tied up in relatively long-term block contracts, especially in smaller authorities where overheads were proportionately greater. (Glendinning et al. 2008, p. 23)

Different challenges emerged in the UK with the Independent Living Fund — the UK's first cash-for-care scheme (which continues to exist alongside new self-directed funding arrangements like Individual Budgets and Direct Payments). While the ILF has had beneficial impacts on people with disabilities (for example, Doyle 1995), a recent evaluation found that people did not understand how their cash amounts were calculated, the decision-making processes used in the scheme, or how they could challenge decisions (Henwood and Hudson 2007). These weaknesses reduced the benefits of self-directed funding — suggesting that the administrative processes used in any self-directed funding arrangement should be transparent and carefully explained.

In the United States, the story is much the same, with the same perceived challenges. As one study pointed out:

> … individual budgeting requires a degree of fiscal flexibility, accountability and data management capacity that is unprecedented in developmental disabilities services and present significant challenges to states making the changes from traditional methods of funding and service design. (Moseley et al. 2005, p. 264).

Australia can clearly benefit from the experiences of Western Australia, Victoria, the United Kingdom and other jurisdictions in implementing consumer-directed payments to avoid the same drawn out process.

Nevertheless, it is important not to oversell the capacity for consumer-directed payments to revolutionise care arrangements in the medium run. It is unlikely that take-up will be very high initially:

- people with disabilities and their families will need to become aware that they have scope to be in control of their funding and to understand how the system works. Many families will never want to undertake these tasks, given their existing workloads
- the NDIA overseeing the system would also need to develop accounting systems and other approaches to manage the new system, as would providers. The NDIA would also need to create practical guidance for people to use a system that pushes more administrative costs onto them (for instance, a guide on hiring and firing employees and how to deal with any occupational and health risks). In the early experiences of consumer-directed payments in the UK, there were cases where recipients faced thousands of pounds of debt because they had unwittingly failed to make the appropriate national insurance contributions for carers they employed (Glasby and Littlechild 2009, p. 16). In a major survey of local authorities in England, the single most important factor aiding direct payments was an effective direct payments support scheme (Davey at al. 2007, p. 100)
- service providers will have to adapt to a system that reduces their certainty of funding (chapter 8). Intermediaries that help people manage consumer-directed payments will need to develop
- service coordinators and case managers will need to take different approaches to decision-making about services for their clients. The evidence from the UK is that positive staff attitudes and training can encourage take-up, which will take some time to realise (Davey et al. 2007, p. 97). A survey of local authorities in the UK found that staff training was rated as the second most important factor in implementing direct payments successfully (Vick et al. 2006)
- it will be important to ensure that coordinators and case managers provide consistent advice about people's entitlements and obligations under self-directed funding. Significant inconsistencies emerged in the UK as they implemented self-directed funding. The British Government developed overarching principles and national legislation, and local authorities implemented it in the field, but often at odds with the national rules. Nearly one in five local government policies indicated that people were unable to employ a close relative living in another household when national policy allowed this, and nearly one in ten local

government policies stipulated a maximum amount of direct payments when national guidance stipulated no limit (Tobin and Vick 2004)

- the flexibility that underlies many of the benefits of self-directed funding means that people with disabilities will legitimately make purchases (like attending a football match) that the community may sometimes perceive as inappropriate. Accordingly, there will need to be some reassurance and education of the wider public about self-directed funding (a point made by the City of Playford DDA Community Reference group, sub. 308, p. 4)
- there should be certainty that direct payments to people made under self-directed funding are not treated as income for taxation and welfare purposes, since that would have the unintended impact of reducing the available funding and the incentives for uptake of self-directed funding (appendix F). The Commission recommends legislative change to avoid these problems as self-directed funding is rolled out across Australia. In addition, sometimes people may wish to augment direct payments with private funding, including early release of superannuation. There are reasonable restrictions on obtaining early release, but unnecessarily severe tax treatment of the released funds, which the Australian Government should change.

Accordingly, the 'gradual, step-by-step' approach recommended by the Centre for Cerebral Palsy (sub. 290, p. 5) is appropriate. However, the speed of adoption of self-directed funding should still be as fast as possible, within the constraints of the development of supports, ensuring administrative efficiency, and safeguarding measures. The development of an evidence base from monitoring and evaluation to inform the ultimate form of self-directed funding will be an important component of its long-run effective implementation — a point emphasised by People with Disability Australia (sub. 524, pp. 30–31).

DRAFT RECOMMENDATION 6.9

The NDIA should undertake ongoing monitoring of self-directed funding arrangements, with a quarterly report to the board of the NDIA on issues arising from self-directed funding. There should be a full evaluation three years after their commencement to assess any desired changes in their design.

DRAFT RECOMMENDATION 6.10

The Australian Government should amend the Income Tax Assessment Act 1936 and the Social Security Act 1991 so that the following are not treated as income for assessment of taxes or eligibility for income support or other welfare benefits:

- ***self-directed funding paid by the NDIA and, in the interim, by state and territory governments***

- ***early compassionate release of eligible superannuation amounts for disability expenditures which meet the criteria set down by the Superannuation Industry (Supervision) Act 1993.***

Complementary initiatives

The benefits of self-directed funding can be improved substantially if there are other, complementary policy initiatives to improve the disability system. These are:

- a reasonable number of competing service providers in the local area (or the prospect of their entry), so there is a genuine threat of moving to another supplier (chapter 8)
- information that allows the purchaser to assess the relative quality of competing providers (chapter 8). As one submission noted: 'When you don't know who to turn to or what questions to ask, living across the road from a brilliant service provider would not help' (Kate Evans and Frank Beard, sub. 278, p. 4). A person could also contract with a DSO to help find the best services when assembling a package of supports
- adequate funding so that people receive the budgets determined by their individual assessments. Were funding to be inadequate, a person would be reluctant to move to another supplier for fear of going to the back of a waiting list, and the service variety and infrastructure available under self-directed funding may not meet people's reasonable needs. Several participants made this point (for example, National Foundation for Australian Women, sub. 248, p. 11; Uniting Care Australia, sub. 291, p. 14). Moreover, a highly constrained budget would often mean people could only select the absolute necessities of support (an attendant carer, but no funding for community interaction), and could frustrate innovative aspects of self-directed funding.

7 Governance of the NDIS

Key points

- Measures to underpin good governance will be critical to the ability of the NDIS to provide services to people with disabilities over the long term.
  - a corporate model of governance is needed, with an independent commercial board and independence from day-to-day government control
  - the administrative arrangements for dealings with the relevant minister should be specified in legislation, be on an arm's length basis and clearly defined.
- The board should be supported by an independent advisory council comprising people with disabilities, carers, suppliers of equipment and services, and state and territory service providers and administrators.
- An independent agency, the National Disability Insurance Agency (NDIA), would administer the scheme.
  - key functions of the NDIA would be to assess needs, manage claims, support people with disabilities, determine efficient prices, authorise funding proposals and coordinate services
  - NDIA local case managers would play a key role, and would also be the primary point of contact for people with disabilities and their families.
- Future development of the disability support sector would be heavily influenced by greater use of self-directed funding (chapter 6):
  - intermediaries are expected to play a role in providing personal planning services, assembling packages of supports and undertaking administrative tasks.
- Dispute mechanisms must be designed to give people confidence in the integrity of the process but without unintended effects on the viability of the NDIS (for example, through an unanticipated widening of the scope of the scheme).
- Other critical governance issues discussed elsewhere in this report include the central role of data collection and use to manage efficiency and costs and promote good outcomes (chapter 10), measures to support self-directed funding (chapter 6) and to ensure quality of services (chapter 8).

7.1 Introduction

Much of this report is about the best design of a national disability insurance scheme — who it is for, the services it would provide, and the power people would have. Governments would play a very different role in the NDIS than they do now. Supports would be determined on an individual basis, and people would either manage their own funds, with appropriate safeguards, or choose a package of support services from suppliers of their choice, or through intermediaries.

In that sense, the NDIS would be a much more devolved model than the current centralised approach. Indeed, from day to day, a person with a disability and their family would mostly have direct contact with their preferred support providers or an intermediary, and much of the complex business of managing the NDIS would (and should) be invisible to them (figure 7.1).

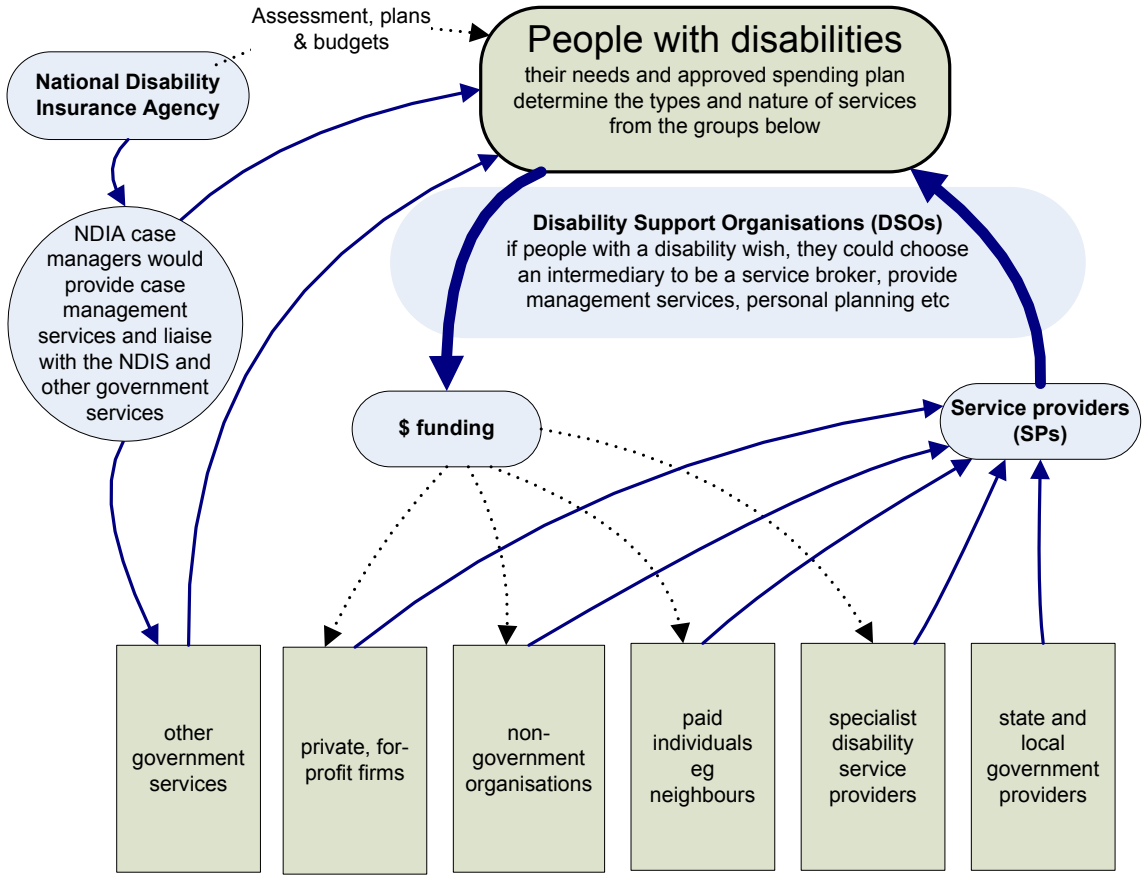
This model is akin to some other insurance products — like Medicare. In that area of insurance, the insurer performs many tasks — negotiating with suppliers, developing billing systems and monitoring fraud — but customers mostly only deal with general practitioners, specialists, hospitals and other service providers funded by the insurer. The wider aspects of the NDIS would be more visible to people than is the case with Medicare because people would be periodically re-assessed, their plans and budgets re-set, they may be given access to new intervention programs, and they would have contacts with their NDIA case manager. However, for most people, those events will be infrequent.

7.2 Defining the scope of governance in the NDIS

'Governance' is how an agency or system manages its functions. In the case of the agency overseeing the scheme (hereafter referred to as the National Disability Insurance Agency or NDIA), it includes the processes and internal culture that gives different people power in the organisation; monitors the utilisation of support services and outcomes; creates incentives for its performance; provides information for good decisions and verification of performance; maintains probity and accountability; and manages its finances.

It also includes how an organisation chooses to structure itself: what it chooses to do itself and what it might contract to other parties, and the basis for these boundaries. At the scheme level, it also includes how government might limit the NDIA's choices about what it does. For instance, that might cover whether government would allow the NDIA to exclude competition in some of its functions or whether government would permit the NDIA to undertake some functions at all.

Figure 7.1 **From a consumer's perspective, supports are mainly provided from outside the National Disability Insurance Agency**



This chapter examines governance from several perspectives, including:

- the roles of the NDIA and of other organisations and parties in the NDIS
- the statutes and guidelines the NDIA would have to meet
- the links between the NDIA and people with disabilities, carers, suppliers and other parts of government, including the relationship between the NDIA as an operational entity and departments that might develop policies for the NDIS (or for disability more broadly)
- the processes and structures that would hold the NDIA accountable to the community: the relevant minister, a 'regulator', and appeal mechanisms, external auditing, and open reporting generally
- the processes and structures that would allow the NDIA to operate as an independent manager, free of covert or explicit interference by interest groups (including politicians) that would be inconsistent with its central charter

- incentives for the NDIA to run an efficient and effective scheme, and to manage long-term risks to financial sustainability. For example, these could include the capacity of the board to hire and fire the CEO, a clear culture for high performance; public disclosure of good and bad performance; and the threat of competition from other parties
- any management features and capabilities needed to realise those efficiency and effectiveness goals (such as reliable measures of performance and outcomes for people with disability, financial management systems, data collection and analysis, internal expertise, research functions)
- how it manages funds (delegated or otherwise)
- provide dispute resolution and complaint processes covering the NDIA and suppliers
- monitoring and feedback
- liability estimation and management — the relationship between individual plans and budgets and aggregate funding availability.

The NDIA would have responsibility for billions of dollars of annual expenditure, and process claims from hundreds of thousands of people. It would have to employ a diverse workforce to oversee its key functions (management and strategy, case management, assessment, quality oversight, actuarial services, financial and data management). It would have to coordinate supports for people in all parts of Australia. It would deal with hundreds of specialist providers and with scheme brokers. Any significant failures in governance by the NDIA in any of these areas would rebound on some of the most vulnerable Australians, on taxpayers, and ultimately could threaten the long-term sustainability of the NDIS.

Based on its experiences of governance in insurance and management, the Insurance Council of Australia (ICA) identified four significant sources of managerial risk for a scheme — ignorance, self-interest, ideology and political interference. It drew attention to the failure of some CTP schemes in the 1980s and early 1990s, where poor claims management, inadequate financial discipline, cost blow-outs and the vagaries of government interventions quickly led to a breakdown in governance and prevented the schemes from operating viably (sub. 238, p. 10).

The overarching goal of the NDIA's internal processes and external rules must be to avoid these risks and, instead, to encourage the hard-nosed, focused pursuit of the sustainable and cost-effective provision of support services for people with disability.

While this chapter covers most of the above issues, some are the subject of other chapters in this report:

- The NDIA would need clear agreements with key government agencies — health, housing, education, employment, transport — so that people with disabilities get a coordinated suite of supports, and to ensure that services are not duplicated or accidentally omitted (chapters 3 and 4). There will also need to be data agreements so that the NDIA can model the broad outcomes for people (for example, getting a job or hospitalisation) and the inputs beyond those provided by the NDIS that might be important in achieving those outcomes. This recognises the value of considering all the 'inputs' that lead to wellbeing and other outcomes for people with disability (and their carers and families), as well as interventions by different parts of government that are complementary to this.
- The NDIA would be an empty shell without good information. As in many insurance schemes, the continual collection and reporting of data, and the analysis of that data, is essential for managing long-term costs, achieving outcomes for people, and in uncovering better intervention and prevention strategies (chapter 10).
- There are governance issues arising for particular topics discussed in this report (for example, concerning how assessments are to be made, how consistency can be obtained across assessors and in the rules that would apply to self-directed funding). In the main, we discuss those issues in the relevant chapters.

7.3 The role of the NDIA and others within the NDIS

The NDIS has many functions (table 7.1), many of which have been discussed in other chapters or in more detail later in this chapter.

What functions should lie outside the NDIA?

Some functions *must* lie outside the NDIA. Establishing driver education programs or spending on roads to help reduce accidents would be an example. Another would be the normal right of appeal to the courts when an NDIA decision is disputed.

Others would *appropriately* belong outside the NDIA. These would include measures to ensure that the NDIA reports are timely, accurate, and provide adequate reporting of the performance of the organisation.

Table 7.1 **Functions of the National Disability Insurance Agency**

	Relationships with people with disability, their families and the community
(1)	Assess needs of people
(2)	Refer people to supports outside the NDIS where needed
(3)	Facilitate personal planning
(4)	Authorise individuals' funding proposals and provide them with individual plans or budgets to self-manage for eligible expenditures. Where people want to use a traditional service model, or appropriate spending items are outside the self-directed funding budget, the client's preferred supplier/s would be directly reimbursed. People will need to deal with intermediaries, nominate service providers, or create and manage their own support through self-directed funding. Direct funding of individuals will be rare initially.
(5)	Ensure that people get appropriate supports and services (eg attendant care, aids)
(6)	Oversight supports funded by the NDIS, coordinate informal local community supports and facilitate other government services through NDIA case managers
(7)	Provide people with disability with a way of complaining about suppliers or the NDIA and to have decisions reviewed.
(8)	Collect information from the client about the performance of funded support providers, and about their NDIA local case manager
(9)	Provide people with information (web, publications, call centres, and ratings of suppliers) and provide a single point of contact
(10)	Address the social contributors to disability (stereotyping, prejudice and stigma, inappropriate public infrastructure)
(11)	Encourage and inform, but not necessarily undertake, programs that address the physical causes of disability (eg accidents) – noting the link to (10) above.
	Arrangements with providers and intermediaries
(12)	Oversee regulation of specialist providers (for example, ensuring police checks are undertaken and suppliers are solvent). The objective would be to give consumers the information and capacity to move their demand away from poor performers. The quality of suppliers would be rated using consumer feedback, with the information made public.
(13)	Use purchasing arrangements for some supports, appliances and aids to get lower prices
(14)	Set up data collection and billing agreements with providers
(15)	Direct reimbursement of services not purchased under self-controlled budgets; set prices payable to suppliers for provision of services of agreed quality on receipt of vouchers from consumers
(16)	Where cost-effective, fund the supply of best practice and cost-effective therapies, aids, appliances and treatment regimes (including early interventions)
(17)	Provide complaint investigation and review processes for suppliers
(18)	During the early stages of the scheme, mentor providers in developing person-centred approaches to support, which should lead to a wider offering of services
(19)	Establish innovation fund for suppliers
	System functions of the NDIS
(20)	Governance structures that ensure the objectives of the NDIS are met efficiently and accountably (regulator, independent auditing, an independent board)
(21)	Manage revenue inflows and outflows, investments and future liabilities
(22)	Collect and analyse data, including for financial reporting, risk management, evaluation and research, and produce reports which are also made available to government. These reports will include regular monitoring of the scheme's experiences, and will feed into actuarial analysis
(23)	Research and analysis (for example, development of appropriate assessment tools, new developments in therapies, interventions, equipment and service provision; better risk management)
(24)	Coordinate NDIS services with complementary services, such as health, education, housing, employment and transport
(24)	Other general operational matters (computing, personnel, contracting, legal, liaison)

In particular, the Commission does not envisage that the NDIA would be a supplier of services for people with disability and carers. There are several reasons for this.

External suppliers often have cost and efficiency advantages over governments

When supplying goods and services, private for-profit and not-for-profit agencies are often less costly and more nimble than government. These agencies are often less bound by the, sometimes rigid, rules that governments require. Over time, Australian governments have divested themselves of directly producing many goods and services, and instead purchased services from external providers. (Australian governments used to directly supply employment services; banking, most utility services, aircraft manufacture, airlines, printing, abattoirs, brickworks and even bakeries.)

That trend does not mean that governments should not run some services — and they continue to play an important role as suppliers in some areas. However, generally, government would have to make the case that they were likely to be more, or at least as, efficient as non-government suppliers, or that social or other goals of services could not be met through contracts or subsidies to non-government agencies.

The case for government supply is weakest where private provision can occur in workably competitive markets. Disability services fit into this category. They do not involve complex technologies, and it is relatively easy to set up an agency to provide services. Currently, the main constraint on competition and responsiveness to people with disability and carers is that consumers do not have choice and do not hold the purse strings (chapter 6), with government often a bulk purchaser through block funding (chapter 8).

Putting the fox in charge of the henhouse — conflicts of interest?

Direct provision of services by the NDIA could create conflicts of interest. Were the NDIA to be a supplier, it could subtly favour its own supply services over competing external ones, especially if a key performance indicator for the organisation was its market share and output levels. For instance:

- NDIA case managers might advise people to use NDIA services or 'market' them more strongly than alternatives
- payment of external parties for services not covered by self-directed funding might be slower than funding of the competing services provided internally by the NDIA

- the price charged internally by the NDIA might appear lower than external competitors — justifying internal provision — but may not properly reflect the full costs of services (for example, in the treatment of fixed and overhead costs of the NDIA). It can sometimes be quite hard to find out whether a government agency has breached requirements for the neutral treatment of external versus internal provision ('competitive neutrality' principles).

The history of large vertically-integrated agencies that hold a monopoly over functions[1] that are inputs into the supply of services by external providers, is that the agencies often find ways of favouring the arms of their own businesses. This is why governments often insist on separating the arms of such agencies ('structural separation').

Any favouritism would not just risk inefficiency, but would work against the principle of self-determination for people with disability. One of the departures of the NDIS from current practice in most states would be that the NDIS would give people with a disability and carers the ability to control their agreed individual packages or budgets. This would allow them to choose providers and, for those who wish to and are able to, have much greater control over the elements of the package. That can only work fully if the 'market' from which people purchase is a fair one.

Government-owned agencies are often given less freedom and flexibility

There are often strong constraints on the behaviour of government-run enterprises. In part, these reflect the political vulnerability of ministers when a government agency does something that might appear to breach the public's expectations (the 'radio-talk-back' test). It seems that governments are less vulnerable when an external party — even one contracted to it — makes such decisions. For instance, under the Job Network arrangements, some providers occasionally gave job seekers second-hand bicycles or even skateboards for transport to jobs — a strategy that would have been impossible for the former Commonwealth Employment Service (PC 2002, pp. 3.3–3.4).

There might be exceptions

The NDIA might supply services in cases where it found it too difficult to reach efficient purchasing agreements with outside suppliers. That would probably be uncommon, but it might occur where:

1 In this case, this would include approval of people's funding proposals and case management.

- there were large difficulties in verifying that external providers were genuinely achieving good quality and cost-effective outcomes for people with disability and carers[2]
- there were significant economies from combining several services together and where government has advantages in supplying that package of services ('economies of scope'). Such economies might sometimes apply to the provision of Indigenous disability services, where governments have to deal with multiple levels of disadvantage (housing, health, education, urban amenity, employment, transport *and* disability). In such cases, governments would need to provide 'last resort' services where no adequate ones were available (see chapter 9)
- government may also need to be a 'last-resort' provider in other cases where it proves impossible at reasonable prices to get non-government provision of some supports. For instance, that might be true for people with very challenging behaviours (chapter 8).

What does this mean for state and territory-owned service providers?

While the NDIA would generally not supply services, that would not prevent current state-owned and run suppliers from competing for business with non-government agencies as service providers. Such state-owned suppliers would operate at arms' length from the NDIA, which would have no incentives to treat them differently from other providers. People with disabilities would decide which supplier to deal with. The advantage of arms' length arrangements between the NDIA and suppliers, and the capacity for people with disabilities to make their own choices, is that it identifies those suppliers who best meet people's preferences. The issue of their ownership would be irrelevant.

2 The key to this issue are the difficulties that a purchaser (the 'principal') may sometimes have in ensuring the quality and quantity of services provided under contract by an outside supplier (the 'agent'). For example, in residential support of aged people with disability (aged care), the funder is not readily able to measure the quality of the services, especially for the most vulnerable people, who cannot complain when services fail to meet the appropriate standards (Ergas 2009, p. 29). Similarly, the Australian Government experienced this problem when contracting with Job Network providers. For example, some providers created temporary 'artificial' jobs to secure outcome payments from the government (Productivity Commission 2002, p. 3.13). That said, such 'principal-agent' problems may not be sufficient to justify government provision, especially as they can persist in different forms in large government organisations anyway, and as there are other problems associated with government supply.

What would the National Disability Insurance Agency do?

Drawing on the analysis in other chapters, the key functions of the NDIA are those of many insurers generally, such as assessing needs, funding, coordinating services, collecting and using data to manage efficiency and costs, and it would also recommend to government on the setting of future levies (figure 7.2).

The Commission does not assume that the NDIA would necessarily undertake all of these functions internally. Rather it would have responsibility for them, and would decide whether to undertake the functions internally or to contract them out, depending on the relative cost effectiveness and any economies of scope. For instance, while the NDIA would need an internal research capacity, it would also provide grants or contracts for external research and analysis. That is because the NDIA often would not have specialised research and analytical capabilities in many areas. Similarly, various IT, data analysis, auditing, and web design and maintenance functions might well be contracted out. Assessments would often (but not always) be contracted out to independent assessors, but with their accuracy and reliability subject to constant monitoring (see later and chapter 5).

In some cases, the NDIA may choose to contract out a proportion of its activity in specific areas to test its internal efficiency and to pressure those inside the organisation to behave efficiently.

In many instances, the motivation for the NDIA to control a function is obvious (such as collection and use of data; cost controls; monitoring of, and advice to, the funds manager and internal complaints processes). However, some may be less obvious:

- *assessment of needs* (including both the assessment 'toolbox' and the professionals applying that toolbox). There are several major motivations for the NDIA to control this (though not necessarily through direct provision).

  First, systematically high assessments of required supports would pose a risk for the sustainability of the scheme, while systematically low assessments or unreliable ones, would be unfair to people with disability. (It would create another lottery for people with disability since they might get less than they needed if the assessor was a 'hard marker' or if the assessor was simply sloppy that day.) Therefore, the NDIA must be able to monitor assessors' accuracy and reliability — and advise (or even fire) them if they lie outside the appropriate performance bands.

  Second, the NDIA would need to monitor the performance of the assessment tools to ensure that they gave accurate and reliable measures of people's reasonable needs for funded support. Parties other than the NDIA do not have

these incentives. Indeed, some parties — such as those also supplying services — would have incentives to overlook soft assessment, and certainly not to zealously suppress it

- *case management*. The Commission envisages that locally-based case managers, operating at a 'grass roots' level, would perform many functions in the NDIS (box 7.1). Their primary role would be to oversight the interaction between clients and the NDIS and the delivery of services to them. But they would also assist in monitoring other aspects of the scheme — for example, by helping to independently assess the quality of service providers (through feedback from people with disabilities and carers).

  While case managers would generally be employed by the NDIA, some may be employed under contract. To avoid any conflict of interest, case managers could not be employed by a provider that is also providing supports to the client. And as case managers would serve a regulatory function for the NDIS, concerns about potential conflict of interest suggest that people with disability should not hire case managers.

  There are many difficult issues associated with increasing the disability workforce for all staff levels, including getting sufficient case managers. Those dilemmas and some strategies and recommendations to overcome them are the subject of chapter 13.

- *authorisation of funding proposals*. The arguments about the need for NDIA control in this area are the same as those applying to case managers.

  For many clients of the NDIA, funding for assessed needs would be provided by way of entitlements to specific forms of supports, such as a number of hours of attendant care of a particular kind per week, certain aids and appliances, and so on. At least in the initial stages of the scheme, while both clients and providers are becoming accustomed to a new way of operating, such entitlements should be given effect by the use of vouchers that clients would take to providers of their choice. This would allow consumers scope to try new providers as they learn about the new system and find ways to take advantage of the new arrangements while operating within a broadly similar and familiar framework.

  A voucher model will also give them the certainty, at a time when the implementation path for the NDIS is being bedded down and early problems are being ironed out, that they will get the supports and services they have been allocated. This would be a simpler approach than self-directed funding (chapter 6), where consumers choose to have direct control over their budgets and they, or an intermediary, will need to enter into negotiations with providers over price and services. A voucher model therefore involves more certainty but less flexibility and less responsibility. Nevertheless, it should still lead to a

reshuffling of service provision arrangements during the early stages of the NDIS.

Well-designed voucher arrangements in the early years might also act to temper the early expectations of both consumers and providers as to what the scheme can and should deliver. Indeed, the early availability of cashable budgets under self-directed funding across the board, while potentially providing many benefits to consumers, might initially create undue expectations about what can be delivered under the scheme, which could undermine its phased implementation and threaten its long-term financial sustainability.

- *determining the 'prices' of the vouchers* that the NDIA would provide to people with disabilities to enable them to obtain services and supports.

  An important early task for the NDIA would be to set appropriate 'prices' for each support to be purchasable by voucher. Use of vouchers means that the NDIA needs to determine the 'price' it will pay for each form of supports provided under the NDIS — for example, for an hour of a particular category of attendant care. Once the service had been provided, the provider would cash the vouchers in to the NDIA at the pre-agreed price. This is not the same as block funding, as the consumer would be able to choose which provider to purchase supports from.

  The NDIA could negotiate prices with suppliers, or set what it judges to be 'efficient' prices based on a theoretical model of costs (as the ACCC does in respect of telecommunications). In both cases, the NDIA would need to take account of the very wide range of supports of different levels of quality that need to be provided to the population of people with disabilities, all of which would need to be individually priced. Moreover, these prices would need to be amended periodically, as costs and market circumstances changed, and made transparent. This is the same approach as taken in the Commission's parallel inquiry into aged care, which discusses the determination of appropriate prices at length (PC 2011, p. xxxiv).

  It would be important when setting prices administratively to avoid setting prices too high, which would mean over-compensating providers, or too low, which would be a disincentive to providers to supply those supports (and which would reduce the returns from future innovation).

  At times, and for specific supports, the NDIA might issue tenders and form contracts for particular providers for the supply of services at a given per-unit price for a given tender period. The NDIA would also have to specify quality for bids to be clearcut, so there would need to be regulated quality guidelines for all supports. Again, this would not be the same as block funding. The producer

would not be given a guaranteed market because consumers might not choose to go to them.

Under either approach, there will be scope for some price competition. For example, an efficient provider may well offer 'deals' to consumers, such as an extra hour of attendant care to what is allowed for by their vouchers if they 'sign up' to that provider for sufficient paid hours (the commonly-observed 'coffee club' approach, whereby the tenth coffee is free). This would effectively lower the average price of that service, directly benefiting the consumer. Equally, consumers may be able to 'trade' vouchers when they need some short-term flexibility additional to that already provided for in their packages. For example, in order to attend a special occasion such as a family wedding held during the evening, they may wish to swap some hours of 'ordinary' day-time attendant care for a smaller number of higher quality hours of active late night or overnight care. And over time, it may be possible to open up price competition in at least the competitive parts of the market, a point also made in the Commission's parallel inquiry into aged care.

What would others do in the NDIS?

In most instances, the roles of other organisations and parties in the NDIS are spelt out above (or elsewhere in this chapter), or are obvious. However, one important aspect of the NDIS not covered elsewhere is the likely role of intermediaries — Disability Support Organisations (DSOs) — which might perform several potential functions.

Their principal role would be to act as an agent for a person with a disability on matters concerning the NDIS. It is a role separate to that of the NDIA case manager (see above), but in some ways complementary to it. For example, once the NDIA has undertaken an assessment and agreed to a funding plan, people with disabilities have several options. They may choose to nominate particular service providers to meet their needs, or they may or create and manage their own support services by contracting with a range of different suppliers in a variety of ways. They may undertake the organisation of this themselves, or they may prefer to employ the services of an intermediary for all or part of this task.

Box 7.1 **The role of NDIA case managers**

Case managers in the NDIA would play a critical role in the operation of the NDIS. They would:

- provide a single point of contact for people with disabilities in their dealings with the NDIS
- operate locally, at a 'grass roots' level (although some would have a regional focus)
- provide advice, and oversight and monitor the interaction between clients and the NDIS and the delivery of services to them
- liaise with other government services on their behalf
- assess the capacity of a person to use self-directed funding, help them draw up spending plans or to pay family members under the pilot arrangements
- negotiate, if requested, with service providers in the event of a dispute or complaint
- be the point of contact for clients to provide confidential views about the performance of suppliers, for analysis by the NDIA.

Case managers would either be directly employed by or contracted to the NDIA.

There is a range of tasks that an intermediary might undertake for people with disabilities. Some are already provided now by some agencies.

Providing brokerage services

The intermediary may, for example, act as advisors to people with disabilities on the quality and choice of support services available from specialist and mainstream providers, and act as brokers by assembling 'packages' of supports for them. It could try to get the best deal for a person from among a variety of providers, given the person's preferences and the constraints of his or her individualised plan. (An example of the sort of question a broker might ask of competing suppliers is 'My client needs someone to take them to church on Sundays at 7 am — can you do that reliably?')

Intermediaries may also advocate on behalf of people with disabilities, including in relation to complaints or disputes with support providers (section 7.8).

Providing personal planning services

Intermediaries could help people form appropriate long-term life plans and help them to realistically meet their goals. They could also act as mentors or

'motivators', explaining to people how they can get much greater control over their lives in the new system and how to plan for their economic and social participation.

Undertaking administrative tasks

This would involve helping people meet the administrative tasks associated with self-directed funding, such as record keeping, and tax and workers compensation matters. Some agencies already undertake this function as an adjunct to their main activities (for example, My Place, sub. 217).

Box 7.2 The role of DSOs (intermediaries)

People could choose to use DSOs to:

- provide them with personal planning services
- help them get the best value from their self-directed funding
- give them the skills and confidence to practically exercise choice
- provide them with information of the quality and choice of support services available from specialist and mainstream providers
- assemble 'packages' of supports from specialist and mainstream providers
- undertakes administrative tasks such as record-keeping and tax returns.

Such a role may facilitate greater innovation in the provision and coordination of services to people with disabilities.

When first dealing with the NDIA, people would be informed by their case manager about the services that a DSO might offer them. They could choose a DSO to deal with from a list, or if they preferred, the case manager may recommend one to them.

Conflicts of interest?

To avoid conflicts of interest, there would need to be some constraints on the extent to which a DSO could also provide services. In particular, it would not be appropriate for a DSO to act as a service provider. But in other areas — such as assisting with the administrative burdens of self-directed funding — it could also be a provider.

Paying for DSOs?

During the implementation phase of the NDIS, there are grounds for subsidies to create a market for intermediaries — at least for the first three functions described

above. Such a temporary subsidy would be justified by the fact that many people have become used to being passive in the current system, and that inertia would be likely to persist unless the market changed.

Thus, the NDIA could, as part of its public education strategy, fund DSOs to provide early information sessions for people with disabilities and support providers, to explain how the scheme will operate and the DSO's role in it. This would help build a knowledge base and greater self-support capacity among people with disabilities, by informing them about the options available to them. Such 'capacity building' should be an important focus of the NDIA, particularly in the early years of the scheme. Similarly, initial interactions with the DSO could also be paid for by the NDIA. However, for subsequent services, the Commission proposes that people would in effect pay a fee to DSOs out of their allocated funding plans, if they choose to use their services.

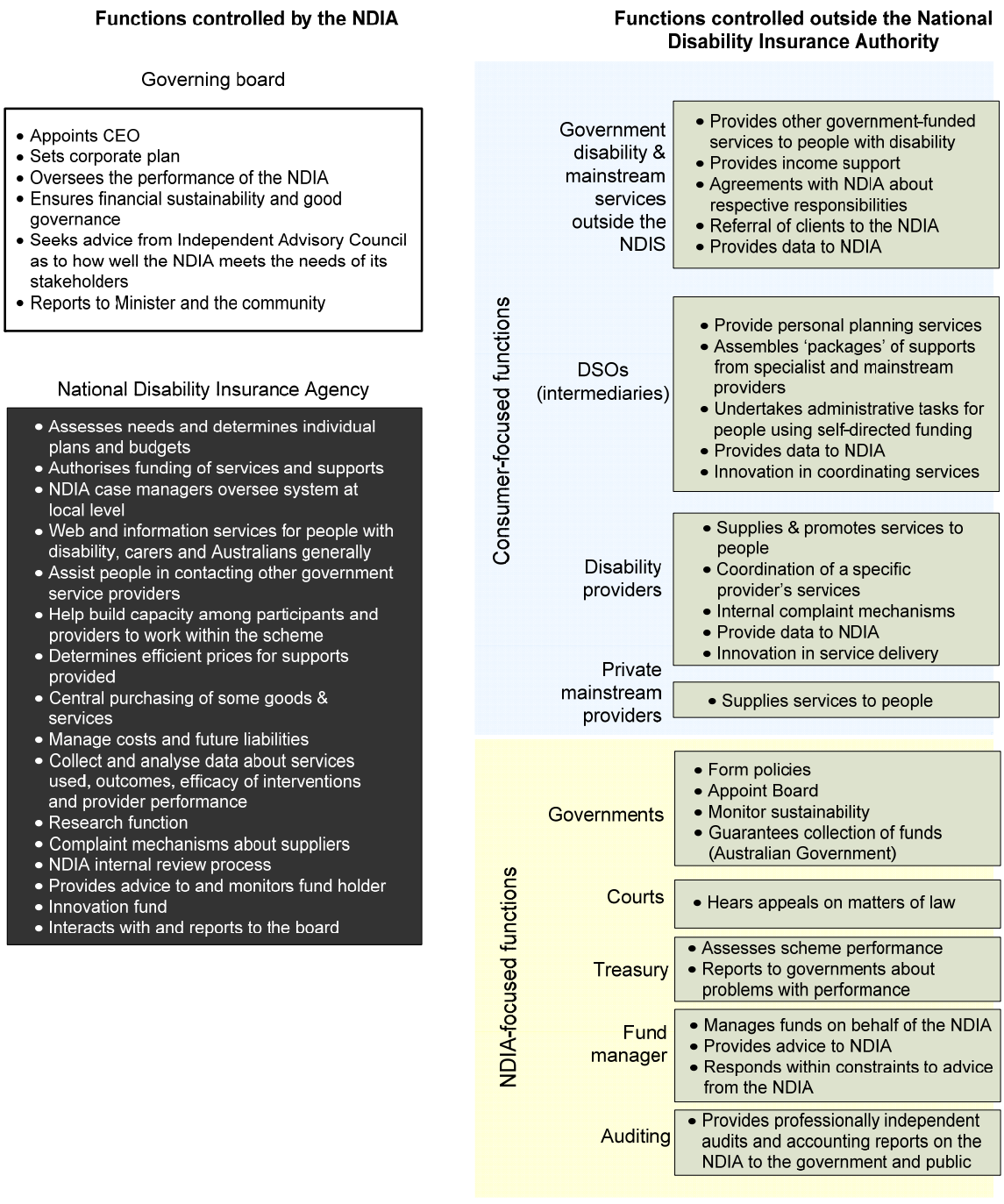
7.4 Why have just one agency?

Currently nine governments fund, organise and, to a varying extent, directly supply supports to people with disability and their carers. The Commission is proposing a simpler approach with one national organising agency. Legislation would define the roles of the NDIA and some of its processes. All Australian Governments would have a role in appointing its board, which would be a commercial rather than a representative board, independent from day-to-day supervision by governments (see below). Individual jurisdictions would still decide whether they wanted to retain a role in directly providing services and supports to people with disability. In addition, the Commission proposes that governments of all levels would still provide many broader supports — education, public housing, transport, most employment services and income support — through their existing agencies. No scheme could efficiently encompass all functions. The NDIA and NDIS would draw on the existing federal model for disability services, but into a more coherent national framework and with a clear single organising agency.

There are alternative models that would preserve a significant degree of control by states and territories.

Figure 7.2 **Who does what?**

Long-run structure of the NDIS



Maintaining state disability agencies as organisers

Each jurisdiction has a department(s) or agency that oversees disability — developing policies, regulating and in some cases, supplying services. In principle,

an alternative to the model described above could involve agreement by all parties on certain broad features of disability support throughout Australia.

To maintain the core aspects of the NDIS, this would need to include:

(a) genuine implementation of self-directed funding

(b) a common national assessment toolbox, with individual plans and funding budgets being no less than the amount determined through the assessment process

(c) a protocol for monitoring the performance of assessors

(d) the competitively neutral provision of services

(e) data sharing.

Funding could then be allocated to each jurisdiction — based on summing people's individual budgets following the assessment.

Within the confines of the overarching rules described above, state and territory governments could then have considerable latitude about how their system ran. As illustrations, jurisdictions could choose:

- different approaches to acceptable expenditures under self-directed funding. Some might accept paying family members under self-directed funding or be more open about what would be an 'appropriate' choice (for example, some might say yes to the use of the funding to allow an uncle to take a child with an intellectual disability to a football match as family respite; others not)
- whether to employ assessors directly or to contract out this function
- what were permissible or non-permissible therapies under the NDIS (such as acupuncture)
- what boundaries to set around the use of personal plans
- whether to supplement the funding provided under the NDIS to improve supports further, depending on state budgets and on the preferences of the community. (Given a common assessment tool and an entitlement to the budget determined by the assessment process, they could not *reduce* funding.). Augmented funding might be directed to areas like more dwellings for independent living; rates relief; cheaper or greater access to transport
- the extent to which the role of the case manager extended to helping people administer self-directed funding or in trying to engage the community to support people with disability

- how to measure and regulate the performance of providers. Some might maintain highly detailed regulatory approaches — others more light-handed ones
- different ways of informing people with disability about how the system works and their opportunities
- the way in which various supports outside the NDIS would interact with other government services — like education, housing or transport. For instance, some might closely tie access to public housing to the NDIS assessment of needs; others might use separate processes.

Would this approach be appropriate? It depends on why different jurisdictions would adopt different positions on the micro-design of the disability system. The differences could reflect:

(i) the underlying preferences of citizens in each jurisdiction. If true, that would be both more democratic and more efficient

(ii) differences in the capacity of lobbying groups to achieve outcomes. For example, in one state, lobby groups might strongly resist paying anyone other than workers employed by an agency through self-directed funding because of concerns that broadening the labour market might reduce workplace bargaining. In another state, regulation of service providers may be much more onerous because of embarrassing media-highlighted abuse by one provider

(iii) leadership and circumstance — some states will forge ahead undertaking experiments in policy which, whether they fail or succeed, are useful for other states to learn from. For example, Western Australia has been a leader in self-directed funding and NSW a leader in transition to work programs

(iv) whimsical variations that arise from 'accidents' of politics, history, fads, the desire to differentiate, or the style of policy making in each jurisdiction, rather than variations that are carefully thought-out matters of design.

If interstate differences mainly reflected (i), then that would be an important balancing consideration in deciding how much national uniformity would be appropriate. But it is hard to see the current differences in jurisdictions' design and funding of disability as genuinely reflecting intrinsic differences in the attitudes of Australians in different states. For example, is the historically lower funding of disability supports in Queensland really a reflection of a lesser need than in other states? Moreover, neither the political process nor mobility really give people a nuanced way of achieving their preferences in any given state. Variations between states in disability service offerings can make relocating difficult. People living near state borders often find such variations illogical and inequitable. And there are so

many tradeoffs when voting for a particular political party that means that the package of policies that emerges will often not best match people's preferences.

Consideration (ii) might reflect some of the differences that we see now or that could arise in a system in which the NDIS was implemented in this way. However, would such variations be a good thing?

All other things being equal, consideration (iii) is a virtue of a federal system. However, Australia is a small player in a large world — and there are many more and bolder experiments conducted all around the world all the time. For example, elaborate models of self-directed funding have been in place for years in the United States and the United Kingdom. And meta-studies of programs that attempt to help carers show that most operate overseas. Accordingly, the gains from federal experimentation should not be overstated. This is all the more so since experiments do not always have to have a federal flavour, but can involve regional or community experiments by national governments (for example, as in Indigenous policy or the Disability Support Pension employment trial). In particular, the strong motivation for the NDIS and NDIA to control future liabilities and to measure outcomes — and associated with this, the much more structured use of data — suggest that a single NDIA may increase *considered* experimentation.

In many, but not all cases, (iv) is likely to be the major source of jurisdictional variations. It is hard to see these as the virtuous outcomes of the revealed preferences of different states.

In that context, it is far from certain that this approach to governance of the NDIA would be appropriate. This is especially so as the Commission's proposed arrangements gives a voice to all governments, and preserves their roles in many important areas.

Moreover, it ignores one of the central benefits of the proposed NDIS. The capacity of people with disability to choose their service providers or to manage their own supports leapfrogs the controls exerted by *all* levels of governments. Under such an approach, governments would not be irrelevant, but their relevance would be much less than is currently the case. Consequently, any additional gains could not be large.

That said, were the above model for the NDIS to be used, it should occur under the umbrella of the points (a) to (e) above. If this were not done, it is doubtful that the way the disability 'system' worked for people would be much improved, apart from having more money. That would leave intact many of its flaws.

7.5 Creating a National Disability Insurance Agency

The Commission proposes that the Australian Government constitute the NDIA as a new independent Commonwealth statutory authority. While the NDIA would be a new government body, it would replace significant functions in existing state and territory bureaucracies, rather than merely adding to, or attempting to coordinate them. Moreover, as discussed in chapter 17, ultimately the NDIA would replace the existing plethora of agencies that pay for and oversee disability services at the state and territory level. As one participant cautioned, the problem of an unwieldy bureaucratic structure would not be fixed by creating 'yet another box' on that structure (Jackson, sub. 30, p. 7).

The increased Australian Government role reflects its much greater funding commitment and above all, the desire to remove the striking inequities in service entitlements and access to self-determination across different jurisdictions.

A corporate model of governance is needed

While the NDIA would be a government entity, there are strong arguments that it be independent and use a corporate model of governance. This is usual in commercial insurance arrangements and government long-term care schemes such as Victoria's TAC, the NSW LTCS scheme and New Zealand's ACC.

Broadly, the Commission proposes that the NDIA:

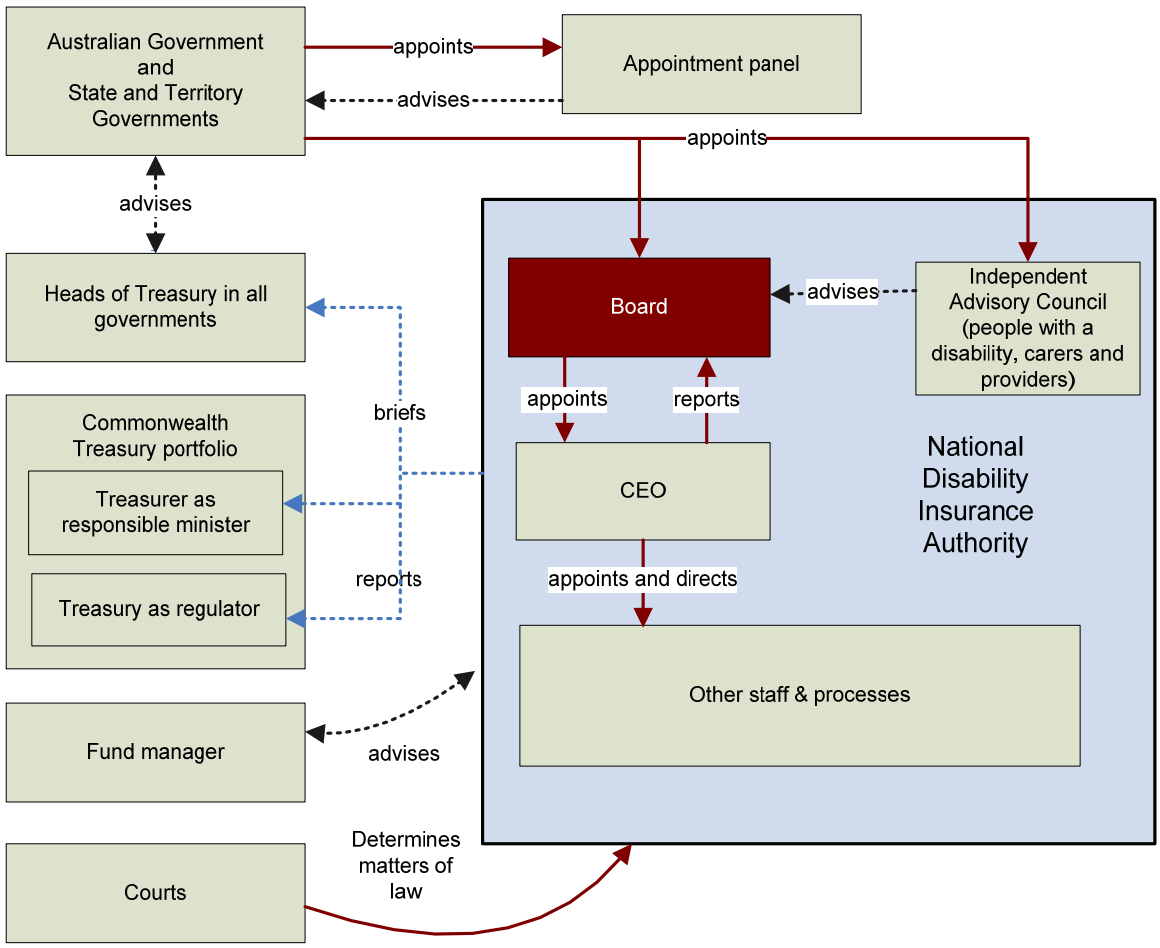
- be an independent Commonwealth statutory authority
- be overseen by a governing board that would be skill-based, not representational
- have an advisory panel of key stakeholders to advise the governing board
- be independent from day-to-day government control
- have its own legislation that specifies its roles and objectives.

Figure 7.3 sets out the broad framework — with its main features described in more detail in the remainder of this section.

Given these proposed governance arrangements, the NDIA should operate under the *Commonwealth Authorities and Companies Act 1997* (CAC Act) and not under the *Financial Management and Accountability Act 1997* (FMA Act). The latter would not usually be suitable for agencies that require a governing board. FMA organisations face much more direction from the responsible minister, the Finance Minister has primary control over their financial arrangements (which are in any case not appropriate for an organisation that will need to incur and hold long-term

contingent liabilities), and employees would typically be employed under the Public Service Act. The CAC Act is much more suited to 'commercial-like' agencies, such as the NDIA (box 7.3).

Figure 7.3 **Accountability arrangements and the NDIA**



The approach summarised above has several advantages. The agency's roles and responsibilities would be clearly defined, including mandatory performance reporting. It would avoid the risks of political interference in operational matters (ICA, sub. 238, p. 14). It will require a long-term funding agreement so that its finances would be quarantined from the uncertainties of the annual budget process, which would otherwise undermine the goal of the NDIS to provide future surety of services (South Australian Government, sub. 496, p. 19). Finally, it would recognise that the body would have long-term commitments and complex financial dynamics (Victorian Government, sub. 537, p. 24).

The Victorian Government further noted that:

> The governance model adopted must enable strong management of all aspects of the scheme. An understanding of the very long-term nature of the liabilities and the financial implications of strategies and decisions are essential if the scheme is to be sustainable. (sub. 537, p. 24)

The Victorian Government, citing TAC as a model, proposed that the NDIS be constituted as a statutory authority, to operate in a corporate manner with a commercial board.

Box 7.3 Aspects of CAC Act supervision of government agencies

While there is 'a policy preference' not to create new government agencies, where new agencies are created, they need to be made subject to the *Financial Management and Accountability Act 1997* (FMA) or the *Commonwealth Authorities and Companies Act 1997* (CAC Act).

Broadly, the FMA applies to budget-funded bodies, regulators and bodies that raise public money under a Commonwealth law — examples include government departments, Medicare, APRA, Comsuper and the courts.

But for agencies for which a governing board will be essential for its effective governance, the appropriate supervisory structure is the CAC Act. The Reserve Bank and CSIRO are CAC Act bodies.

In discussing governance arrangements for CAC Act bodies, the department noted:

- where the CAC Act is appropriate, it is preferable to establish the body as a Commonwealth authority, rather than a Commonwealth company
- the governing board sets strategy and oversights management:
  - board appointments should be skills-based, rather than representational
  - directors and officers must exercise their powers and duties in the best interests of the body and for a proper purpose
- the CAC Act allows the Government to rely on the directors to properly govern the relevant body, in line with their directors' duties
  - directors have legal duties under the CAC Act and Corporations Act 2001, with penalties attaching to breaches of these duties
- a CAC Act body could also have an advisory board to advise the governing board
- the CAC Act does not give Ministers a general power of direction in relation to a body's functions (this is left to the enabling legislation if required)
- but it does give the responsible Minister and the Finance Minister broad powers to require the authority to provide information about its activities.

Source: Department of Finance and Administration (2005).

DRAFT RECOMMENDATION 7.1

The Australian Government should establish a new independent Commonwealth statutory authority, the National Disability Insurance Agency (NDIA), to administer the National Disability Insurance Scheme.

The NDIA should be subject to the requirements of the Commonwealth Authorities and Companies Act 1997 (CAC Act), not the Financial Management and Accountability Act 1997.

An independent commercial board

As noted by the ICA, an essential aspect of a corporate governance model for the NDIA would be an independent commercial board, which is given genuine responsibility for actively managing the balance of costs and benefits of the NDIS over time (sub. 238, p. 8). The New South Wales LTCSA, the TAC in Victoria and the ACC of New Zealand all have such independent boards.

Primary roles of the board would be to appoint the CEO, provide strategic direction and oversight of the scheme's success in meeting the objectives laid down in its Act, to ensure financial sustainability and to manage the relationship with governments. The board would need to ensure that the scheme, and the NDIA, was run professionally and efficiently, and that structures and procedures were in place to ensure that costs and the associated future liabilities were monitored and controlled. The board would seek external advice, such as regular actuarial assessments, as it saw fit.

As with these and corporate boards generally, NDIA board members would need to be chosen for their commercial skills and experience. The scheme would also benefit from having some board members who have experience with long-term care or insurance schemes. Maurice Blackburn et al. said board members should be chosen based on their expertise and skills in managing large insurance funds (sub. 392, p. 74). The DIG report emphasised the need for:

> … acumen and experience in a range of disciplines necessary in managing a personal disability care and support service delivery system operated within a prudential insurance framework (DIG 2009a, p. 166).

The Commission sees a highly skilled and genuinely independent board as essential to the successful operation of the NDIS. While the CAC Act quite clearly provides for this, the issue of independence — and the public perception of the board's independence — is so important that it raises the question of *how* board members would be selected, especially given the importance of guarding against 'politically

friendly' appointments' as one participant noted (ICA, sub. 238, p. 10). Historically, some have criticised the processes used to appoint the boards of Australian public sector agencies (Edwards 2006).

One avenue would be to:

- set up clear merit-based criteria for the appointment of board members in the legislation. These could include the requirement that, across the board, there was a mix of skills and commercial expertise in areas such as understanding of the issues confronting people with disabilities; finance; management; knowledge about the prudential management of a large and complex commercial corporation with long-term liabilities of the kind envisaged here; and board members from a variety of locations around Australia (that is, not just Sydney and Melbourne)
- establish an independent appointment panel,[3] with agreement by all Australian governments that this group has their confidence. The panel would comprise people with skills and experience in the same areas, including people with a clear interest in disability policy issues. It would provide a recommendation about the appointment of the chair of the board, which would need to be agreed by the majority of Australian governments (similar to the process used for appointing the chairman of the ACCC). The panel would nominate two candidates per vacancy for other board positions, reflecting the broad range of skill sets and experience required. The final appointments would be based on the majority decision of all jurisdictions, with a responsible minister in the Australian Government (the Treasurer, in the Commission's view — see later) making the ultimate decision if the votes were tied. Appointment for a five-year term may well be appropriate.

This sharing of the responsibility for the initial nomination process and appointment of the board chair highlights that the NDIA would be a cooperative federal venture. The goal is to create a new federal social and economic institution that would be independent from all governments in operational matters.

Were the board or its chair to perform badly, the Australian Government could dissolve the board, or seek to replace its chair, re-triggering the appointment process

3 A somewhat similar approach was taken to make additional appointments to the ABC and SBS boards in 2009, with the panel nominating at least three candidates per vacancy, with the Australian Government making the final choice. It may be necessary to nominate a smaller number of candidates per board member for a full board. Governments in the United Kingdom and some Canadian provinces (like British Columbia) and have also reformed appointment processes for all public sector boards so that independent appointment panels/agencies make recommendations to the relevant minister (Edwards 2006).

described above. (The Government would not be able to sack the CEO, as this would be a matter for the board.)

Once put in place, the board would appoint a CEO, who would appoint a senior management team to help implement the scheme. On good governance principles it would be preferred that the board alone appoints the CEO, without the need for additional authorisation from a relevant minister (shareholders usually do not authorise the appointment of CEOs in commercial entities). As the Department of Finance and Administration noted:

> Boards of directors are an effective governance structure where they have been delegated the full power to act … Such powers would usefully include the appointment and removal of the CEO (2005, p. 36)

What about the decision-making power of people with disability?

Several advocacy groups argued that the board of the NDIS should comprise 'a majority of people with disabilities' (Disability Advocacy Network Australia, sub. 490, p. 18), or be representative of peak disability groups (see also People with Disability Australia, sub. 524, p. 43). The Julia Farr Association said:

> … our view (based on the principle of 'nothing about us without us') is that the membership of the body of governance for the scheme should include people living with disability. This should not be limited to advisory functions but should extend to authentic participation in the formal leadership of the scheme, including the range of decisions that any board of directors might be expected to consider. (sub. 494, p. 59)

Some participants quoted the United Nations Convention on the Rights of Persons with Disabilities to the effect that people with disabilities and their representatives should be involved in and participate fully in 'the monitoring process'. (Article 33.3 of the UN Convention states that '... persons with disabilities and their representative organisations shall be involved and participate fully in the monitoring process' (In Control Australia, sub. 570, p. 110).) People with Disabilities ACT argued that this should extend to:

> The making of higher policy level funding distribution decisions and the resourcing of local/regional disability resource centres that would play a key role in providing independent advice and could support development of initiatives at the local level that would enhance effectiveness of individualised funding allocation. (sub. 488, p. 7)

In Control Australia took the same view (sub. 570, p. 110), emphasising the importance of people with disabilities being at the centre of decision-making about their lives.

The Commission strongly agrees that any new disability system must give people much more power over their lives, and the design of the NDIS intends to do that. However, the issue of who governs the scheme is not just about who uses its services. The responsibility for the operation of the scheme needs to be at arm's length from the main users, in the same way that Medicare is independent of the chronically ill and medical practitioners who are the biggest users and producers of its services. Equally, the board would not be constituted to represent the interests of the Australian and state and territory governments, disability service providers or other interested parties. As the DIG report put it, the NDIS needs 'a business board rather than a stakeholder board' (DIG 2009a, p. 166).

Keeping the scheme on track and within funding limits needs a single-minded commercial focus to avoid loss of strategic direction, indecision, and cost overruns — a particular risk for schemes such as this. The risk otherwise is that decisions about assessment tools, local resourcing and many other aspects of the NDIS would be determined without a mind to the financial sustainability of the scheme and without the objectivity needed for fair and efficient allocation of services.

This approach is not peculiar to disability, but the principles generally adopted in corporate governance. Notably, in its directions on governance arrangements for Australian Government bodies, the Department of Finance and Administration indicates that for government entities under the CAC Act, 'appointees to governing boards should not be there in a representational capacity' (2005, p. xv).

An independent advisory group

However, while the governing board should be an expert board, there are very strong grounds for mechanisms that give stakeholders the capacity to advise the board. The South Australian Government said that stakeholders should have input into decisions:

> An Advisory Board for key stakeholders would be one option to enable ongoing stakeholder engagement — representing interests of clients, service providers, taxpayers/premium payers, Federal and State governments and disability specialists. (sub. 496, p. 20)

Ros Madden and others saw an 'essential' role for an advisory body that included people with disabilities, their families and NGOs, noting that such groups:

> … have been significant drivers of innovation and expansion in the field … National management structures should draw more formally on this well of expertise' (sub. 493, p. 21).

In their view, such a body could advise on the early development of the scheme, and promote integration with other services, better outcomes for people with disabilities and carers, adequate, equitable and consistent access to services across the country, and the development and sharing of data for use in improving outcomes for people and services (pp. 21–22).

In light of these points, the Commission considers that there are strong grounds for an independent disability advisory council to advise the board on the scope and activities of the NDIS, from the perspectives of people with disabilities, carers, suppliers of equipment and services, state and territory service providers, and government officials. Such an approach has proven successful in other areas such as consumer policy administration and development. For example, the Consumer Consultative Committee advises the Australian Competition and Consumer Commission on issues or market developments affecting consumers, and emerging issues that may be of concern to particular groups of consumers. Similarly, the Consumer Advisory Panel provides advice to the Australian Securities & Investments Commission.

An advisory council would help identify problems at the coal face on how the NDIS was operating. As hypothetical examples, it might reveal faults in the way self-directed funding was working, inadequate training of case managers, excessive compliance burdens, or poor IT links between suppliers and the NDIA. The Board and the CEO would then consider this advice when determining how they ran the NDIA. The advisory council would provide an annual public report on their principal advice.

DRAFT RECOMMENDATION 7.2

An independent board should oversee the NDIA. The board should comprise people chosen for their commercial and strategic skills and expertise in insurance, finance and management.

- ***As specified in the CAC Act, the board should not be constituted to be representative of particular interest groups, including governments, disability client or service provider groups.***

The Australian Government and the state and territory governments should together establish an appointment panel comprising people with skills and experience in these areas, including people with a clear interest in disability policy issues.

- ***The panel should nominate candidates for each board vacancy against tightly specified selection criteria set down in the Act governing the NDIA. Appointments should be based on the majority decision of governments.***

The Australian Government, with the agreement of the majority of state and territory governments, should have the power to remove the chair or dissolve the board as a whole.

The board would have the sole power to appoint the CEO and to sack him or her if necessary, without authorisation from governments.

DRAFT RECOMMENDATION 7.3

The Australian Government, together with state and territory governments, should establish an advisory council. The council should provide the board of the NDIA with ongoing advice on its activities and effectiveness in meeting its objectives, from the perspectives of people with disabilities, carers, suppliers of equipment and services and state and territory service providers and administrators.

- ***The council should comprise representatives of each of these groups.***

Independence from day-to-day government control

Governments (as agents of taxpayers) are the implicit shareholders of the NDIA, and consequently, the NDIA would ultimately be accountable to government. However, unlike line departments and existing disability services, the NDIA would be a more commercially-oriented body, with a need for long run stable funding and independence in its operational decisions. Consistent with the CAC Act, this implies a more limited role for government in the management of the NDIS. The ICA also took this view, noting that, while a level of government scrutiny is a necessary and helpful part of the governance framework, 'micro decision making' by responsible ministers and 'micro management' by a government department should be minimised (sub. 238, p. 11). The DIG report also made this point. For example, it would be problematic were governments to interfere in particular cases — such as the assessed amount of services, whether the NDIA might contest an appeal, or decisions about what would constitute 'reasonable' goods or services. New Zealand's experiences provides a warning. The ACC has made decisions — led by directives and subtle persuasion by the government — that have at times undermined the scheme's sustainability.

For these reasons, the Commission considers that the administrative arrangements for the dealings by the board and the CEO with the relevant minister should be specified in legislation, be on an arm's length basis and clearly defined. The provisions would stipulate the:

- frequency of meetings (for example, monthly meetings might be appropriate) The key concern would be to avoid a close day-to-day relationship with the

minister or the government of the day, while providing appropriate reporting about the performance of the scheme

- transparency of requests made by the minister or his/her advisors for action by the NDIA (for example, the need for an 'extraordinary' meeting or encouragement for investment in a given measure). These should be in writing and recorded in the annual report
- requirement that the minister receive copies of any significant reports made to the board
- the government should seek in writing the advice of the board on policy changes that would substantially affect the NDIA, given that such changes may have unexpected impacts on solvency. However, in general, policy would be determined by the government and be achieved through statutory changes, rather than through 'advice' to the board.

The Commission also recommends that the Australian Government minister with responsibility for the NDIS should be the Treasurer, reflecting the commercial focus of the NDIA and the critical need to ensure strong cost controls, long-run sustainability and appropriate management of funds set aside for the NDIA. Other ministers — such as in health, community care, disability or social services — would play a prominent role in developing new disability policies, which might affect the precise specification of the various requirements of the Act governing the NDIA.

DRAFT RECOMMENDATION 7.4

The arrangements between the NDIA and governments should be at arm's length, and subject to strict transparency arrangements.

The federal Treasurer should have responsibility for the NDIA.

The NDIS should have its own legislation

The NDIS legislation should specify the roles, objectives and powers of NDIA and the NDIS, and the critical features that would affect the costs and operation of the scheme. It is important that the legislation be tightly specified to provide a clear indication to the community about issues such as entitlements, coverage and service provision, and to permit the management team and board to plan with assurance.

As there is a need for a single, overarching national Act, and the funding is intended to come from the Australian Government, it should be Commonwealth legislation, but constructed with the agreement of the states and territories. Its design should

also take into account advice from experts, including existing state government injury insurance schemes (such as the Victorian TAC, NSW LTCS scheme and the Tasmanian MAIB), New Zealand's ACC, actuaries and commercial insurers.

The legislation should include a list of functions of the scheme, one of which should be financial sustainability, to be made an obligation on NDIA, its board and the Australian Government, through the responsible Commonwealth minister (as the South Australian Government said, 'a fiduciary duty to maintain a viable scheme' sub. 496, p. 20). The legislation should also specify that recipients are eligible for benefits only as nominated in that legislation. Both of these inclusions may also allow the NDIA to more readily deflect claims that in effect 'widen' the scope of the scheme. As Yooralla observed, managing expectations will be an issue for the scheme (discussed elsewhere in this chapter), while National Disability Services argued that:

> A stable scheme requires stable rules — projecting costs into the future is difficult without these. (sub. 454, p. 20)

And in the case of the NSW LTCSA:

> … the Authority has had a number of internal audits … which have stressed the risk to the Scheme of over-servicing and participants receiving inappropriate or unnecessary services. … The Authority must … ensure that the Scheme is affordable (NSW LTCSA 2009, p. 9)

There would also be merit in specifying 'entitlement to support' as an objective that should be enshrined in this legislation. As Jackson observed:

> Unless service entitlement is included in Disability legislation, the current rationing of services based on a nebulous relative needs approach will continue to promulgate the existing broken system (sub. 30, p. 12)

However, that should be tempered by a statutory provision that support services provided by the NDIS should be 'reasonable' (an issue discussed further in section 7.8 and in chapter 4).

Future changes to the scheme should be made transparently

Future changes to the legislation should be implemented in accordance with a protocol to ensure good governance and transparency, in consultation with the states and territories, and with full parliamentary scrutiny. Such changes would be independently assessed and audited for their financial implications. Periodical widening and narrowing of eligibility and generosity, such as happened in New Zealand with successive changes of government, exemplifies the problems that can happen. In that case, the financial sustainability of the ACC was put at risk.

The legislation should also enshrine the requirement for independent external reviews of the NDIS to be undertaken at regular intervals (draft recommendation 7.8).

DRAFT RECOMMENDATION 7.5

The Australian Government, with the agreement of state and territory governments, should provide the NDIA with its own legislation that specifies its objectives and functions, and its governance arrangements.

- ***Financial sustainability should be a specific obligation of the board, the management and the minister, and this obligation should be enshrined in legislation. It should specifically guide any external review body (draft recommendation 7.8).***
- ***An entitlement to reasonable support should be enshrined in legislation, together with details about people's eligibility for services and the range of services to be offered.***

Future changes to the legislative framework should be undertaken only by explicit changes to the Act itself, made transparently, and subject to the usual processes of community and Parliamentary scrutiny, and in consultation with all state and territory governments.

- ***Such proposed legislative changes should be accompanied by an independent assessment of the impact of the changes on the sustainability of the scheme.***

7.6 Measures to encourage high performance

Markets provide some disciplines for private corporations to manage efficiently and prudently. Such pressures include risks of reduced market share, takeover or insolvency and visible performance indicators (like dividends, share prices, debt/equity ratios, credit ratings). While in recent years, there have been massive failures in corporate governance and reporting that have not provided proper commercial disciplines (Enron, HIH, Freddie Mac), markets generally provide strong incentives for efficient management when combined with appropriate regulatory oversights.

The NDIA would not be subject to these competitive forces, so other means need to ensure good management and cost control.

The Commission proposes several approaches, under several broad banners.

External ongoing monitoring and prudential requirements

Auditing

Accurate, timely and public reporting provides a major discipline. New Zealand provides a lesson in the problems of timely and complete disclosure. In the 2009 Annual Report of the ACC, the responsible minister made the following comments:

> My first glimpse of ACC's financial difficulties came from an urgent briefing before I received my Ministerial warrant last November. I was advised that the Non-Earners' Account required an immediate injection from the new Government of $300 million and similar amounts for future years. These requirements caused considerable angst as the new Government in opposition prudently budgeted commitments to the electorate and this single item exceeded the sum of our new spending. A subsequent Ministerial Inquiry found that this problem should have been disclosed in the Pre-Election Fiscal Update … under the Public Finance Act. Nor was it acceptable that this problem was not disclosed in the Briefing to the Incoming Minister. This annual report discloses similar problems in all six of ACC's accounts. These financial problems have been driven by years of significant increases in costs, increasing numbers of claims, Scheme extensions and declining rehabilitation rates. The underlying cause has been a shift from ACC being a public insurance scheme to it becoming an extension of the welfare state. (ACC 2009, p. 3)

The Chair of the ACC gave a similar picture indicating that the 'Scheme's very existence could be under threat' unless its financial position improved (ibid., p. 4).

The reporting and monitoring arrangements for the NDIA must ensure against similar difficulties.

The Commission considers that, as is usual, the annual financial statements of the NDIA would be audited annually for accuracy and compliance with appropriate accounting standards.

In addition, given the insurance nature of the NDIA, there should be tiered levels of actuarial monitoring. This would include regular (monthly) reporting of trends in usage and costs — and 'red flags' for significant departures from expected outcomes.

More importantly, it would also involve independent professional actuarial assessment of the NDIA on a quarterly and annual basis, with the obligations of the assessments defined in the NDIA Act. While it would not be feasible to fully fund the NDIS, the reporting framework for the NDIA and its independent actuary should cover both its quarterly/annual costs and its notional future liabilities (acting *as if* it were fully-funded). Among other things, the actuarial assessments would:

- monitor and report on outcomes for scheme participants
- identify the likely capacity of NDIA funding arrangements (chapter 12) to meet the future expected liabilities of the scheme
- identify the main factors leading to the costs of the scheme and service utilisation, with that analysis undertaken for different groups of people with disability, by location and by support type
- consider the magnitude and sources of any emerging risks for the scheme, including risks to solvency. A major objective of the report would be to separately consider the impacts on long term liabilities of:
  - internal factors under the control of the NDIA (such as improved or declining rehabilitation rates, changes in the patterns of assessment and service use, over-servicing in allied professional services)
  - external factors, such as the impacts of changes in input costs (like wage increases) on overall costs, and the effects of asset rates of return on the NDIA reserve
- examine the quality of the strategies being used by the management of the NDIA to address those risks, and any recommendations for improved processes
- make recommendations about the suitability of data collected to monitor the scheme
- recommend any additional (or changes to) performance measures that could usefully indicate the performance of the NDIA. Notably, the Victorian Auditor-General found that performance reporting by public financial corporations was flawed, 'with the result that the effort and cost of producing performance indicator data [was] therefore largely wasted' (VAGO 2008, p. 2). It made specific criticisms of the reporting by the Transport Accident Commission (p. 38).

These actuarial reports would be provided to the board, the minister and the external 'regulator' (see later), and in line with agreed standards, highlight any emerging difficulties. The Secretary of the federal Treasury would report regularly to Heads of Treasury meetings on the actuarial performance of the scheme.

The Australian National Audit Office could also conduct periodic performance audits of the processes used by the NDIA, including its reporting functions, but with a clear focus on appropriate, cost effective risk management and scheme accountability.

An external monitor

A small specialist unit in Treasury should provide external monitoring of the activities of the NDIS.[4] It would receive the NDIA reports made to the board. As well as covering the matters addressed in the independent actuarial report, the unit would:

- consider the performance of the NDIA across a range of other indicators (for example, client satisfaction and benchmarked performance against other insurers in areas such as claims processing efficiency and overheads)
- analyse the reports made to the board and the annual actuarial report (seeking the advice of the Government Actuary if necessary), seek clarification if needed and provide advice to the relevant minister if the scheme's performance was falling below expectations
- assess whether the NDIA was managing costs and claims efficiently, and had the right processes for doing so.

The Treasury should be required to prepare an annual statement on the performance of the NDIS and the NDIA, to be provided to all governments and made public.

DRAFT RECOMMENDATION 7.6

An independent actuarial report on the NDIA's management of the NDIS should be prepared quarterly and annually, and provided to the board, the regulator, the federal Treasurer, and to all state and territory governments. It should assess risks, particularly in regards to the capacity of the expected funding stream to meet expected liabilities within its funding framework, the source of the risks and the adequacy of strategies to address those risks.

DRAFT RECOMMENDATION 7.7

A specialist unit should be established within the federal Treasury to monitor the performance of the NDIA against a range of cost and performance indicators, and report its findings annually to its minister, state and territory governments and the public.

4 APRA adopts a supervisory role for private insurers, but as noted by the ICA, the nature of the NDIA is different, and alternative approaches would be justified for that reason (sub. 238, p. 6). (Notably, the NDIA would have far less control over its financial assets, and government is its funder.)

Periodic independent reviews

Periodic evaluation is required for large government-funded programs (and this need should be reflected in the enabling legislation for the NDIS). Accordingly, the NDIS and NDIA should be independently reviewed after its first three years of operation, and every five years thereafter, with the outcomes publicly and promptly released.

DRAFT RECOMMENDATION 7.8

The NDIA should be independently reviewed, initially after its first three years of operation, and every five years thereafter, with the outcomes publicly and promptly released.

Other incentives for efficiency

The transparency and reporting requirements discussed above provide the government, the public and the media with information to hold the NDIA accountable. In itself, these are quite powerful forces for performance. An embarrassed government can sack a poorly performing board or an embarrassed board can fire a CEO.

An important measure that can encourage greater performance is benchmarking against comparable agencies. The NDIA will undertake activities similar to many other corporations and insurers in Australia and elsewhere — claims processing, research, IT and data management, accounts and personnel departments and so on. There are several metrics that could be used to assess whether the NDIA was performing adequately. For example, are its administrative costs to be significantly higher than New Zealand's ACC, or its case management cost for complex cases greater than the TAC? If other agencies outsource certain functions, and appear to reap gains from doing so, why is the NDIA not doing so? (There may be good reasons, but the point is to place pressure on management to look for more efficient solutions, as the ACC was required to after disclosure of its recent financial difficulties.) In its early years, the NDIA could also be benchmarked against aspects of the National Injury Insurance Scheme (NIIS — chapter 16). The external monitor would periodically fund benchmarking studies for these purposes.

DRAFT RECOMMENDATION 7.9

The NDIA should be subject to benchmarking with other comparable corporate entities to assess its relative efficiency in its various functions, with the federal Treasury initiating benchmarking studies.

7.7 Managing the funding pool

The NDIS will be largely structured as a 'pay as you go' scheme. That is, unlike the NSW LTCS scheme or the Victorian TAC it is not 'fully funded' for its future expected liabilities. Nevertheless, the NDIA would need to have a funding reserve because the pattern of claims and their costs are not fully predictable. A reserve acts as a buffer against this unpredictability, and avoids the situation in which the Australian Government would need to inject additional funds from general revenue when there were higher than expected claim costs in any given period (or worse still, if they did not supplement funding, to avoid rationing each time there was a shortfall).

In view of the expected size of the NDIS, the reserve of investment funds would be significant. The management of the NDIA will be most familiar with the patterns of claims and their likely risk profile. Given this, they would need to play an ongoing role in managing the scheme's cash flows and reserves to reduce the likelihood of threats to the sustainability of the scheme.

The way the reserve funds are managed and invested, including the level of acceptable portfolio risk and the net rate of return, will affect the capacity to avoid increases in, or volatility of, funding. Such funds management is a specialised activity and careful investment management over time will be crucial. Also crucial will be the governance arrangements that permit this activity to be pursued efficiently without changes of direction being imposed externally. The ICA, referring to the adverse impact of 'WA Inc.' on the assets of that state's State Government Insurance Commission in the early 1990s, cautioned that:

> Investment risk is material, and government funds are not immune from it. (sub. 238, p. 12)[5]

Possible ways of handling this include the use of a dedicated investment department within the NDIA, or by outsourcing investment management, which could be done on a competitive tendering basis, to a single or multiple managers from the private or public sectors, perhaps with conditions such as incentives based on a benchmark rate of return (DIG, p. 159). The DIG report noted that all of these approaches have precedents in Australian accident compensation schemes. For example, South Australia's Motor Accident Commission manages its own funds, while a government agency, the Victorian Funds Management Corporation, manages the TAC's reserves.

5 citing National Competition Policy Legislative Reviews, *Understanding Scheme Failures*, 1998.

As the NDIS would be a creature of the Commonwealth Government, one possibility would be for funds management to be integrated with existing Australian Government arrangements for investing in long-term assets. The Future Fund Board of Guardians, with the support of the Future Fund Management Agency (a Commonwealth agency), is already performing the role of investing the assets of the Future Fund. The fund meets future public sector superannuation liabilities — and holds assets for the three Nation-building Funds — the Building Australia Fund, the Education Investment Fund and the Health and Hospitals Fund. The Board is responsible for the investment decisions of the Future Fund and is accountable to the Government for the safekeeping and performance of the assets of the Future Fund. They see themselves as having a very commercial focus:

> We are a funds management business focused on delivering high, risk-adjusted returns over the long term on contributions to special purpose public funds. Operating independently from the Government, we will tailor the management of each Fund to its unique mandate while delivering efficiency through common infrastructure. (Future Fund 2010, p. 3)

Of the investment options, the Future Fund appears to be the most appropriate. The Future Fund Board of Guardians operates within the constraints of Investment Mandates set for each fund by the Treasurer and the Minister for Finance, which limits the risks to the Australian Government. Since any overspending by the NDIA would represent liabilities for the Australian Government, they would reasonably have a stake in ensuring the prudent management of those funds.

That said, the NDIA Board would still have a role within the broad framework the Australian Government sets for the Future Fund. The board would need to set guidelines for acceptable levels of risk and return on the NDIA's investment funds, and specify such matters as the required mix of investment types (cash, classes of shares and securities). This may well change over time, as the NDIA learns more about the expected pattern of its future expenditures (and therefore likely demands on short-term cash etc, some of which it may have to hold on its own account for day-to-day use). Beyond the need for managing the funds to meet expected liabilities, the involvement of the NDIA board in these matters would have two other desirable effects:

- Since the responsibilities of the board would be greater, the calibre of directors would be higher.
- It would tend to strongly focus the minds of the board on the NDIA's liabilities, while the changing value of the reserve would provide a very clear indication of threats to the scheme's sustainability.

The NDIA would need to establish internal processes and reporting arrangements, including a small investment advisory and monitoring function within the NDIA itself, and reporting arrangements between it and the board.

7.8 Complaints and dispute resolution

The NDIS will require a tiered set of informal and formal complaint and dispute resolution arrangements to hear complaints about the decisions and conduct of the NDIA (Maurice Blackburn et al., sub. 392, p. ii; New South Wales Ombudsman, sub. 596, p. 2) and about service providers (National Disability Services sub. 454, p. 18). These arrangements will need to take account of the various kinds of problems that people with disability perceive when dealing with the NDIS. The various Australasian accident insurance schemes have detailed complaints and dispute resolution processes, which provide lessons for the NDIS (box 7.4).

Handling complaints and disputes within the NDIS

The primary objective should be to give well-founded confidence to people reliant on the scheme that they will be treated fairly and that reasonable complaints will be investigated.

Service charters are needed

To underpin this, the Commission proposes that the NDIA should establish two charters — one for the NDIA and the other for specialist providers and DSOs. The TAC and MAIB service charters and the ACC code provide good templates.

DRAFT RECOMMENDATION 7.10

The NDIA should establish two service charters that specify respectively the appropriate conduct of the (i) NDIA and (ii) specialist service providers and disability support organisations.

Complaints about the NDIA

The NDIA would need well-developed and rigorous internal processes for reviewing disputes over its own activities, as they affect people with disabilities. This would encompass:

- complaints about the conduct of the NDIA, its employees and contract staff (that is, breaches of its own charter)

- disputes about such matters as assessments and plan and funding proposals.

There should be layered options within the NDIA for handling such disputes, with the objective of first trying to resolve them quickly and informally, at low cost. Some examples of the approaches that might be taken are given in box 7.4. So, for example, a client would first approach their case manager, and if unhappy with the result, would be offered further layers of complaint or review processes within the NDIA, involving higher level managers and, where relevant, independent assessors who have had no involvement in the matter under dispute. And as is the case with many dispute resolution processes, this should be undertaken without legal representation for appellants and not be bound by rules of evidence.

To support these arrangements, the NDIA should have an internal complaints office that would hear complaints about the NDIA or disputes about its decisions (draft recommendation 7.12). This would operate separately from the other parts of the NDIA. The office would be headed by an independent statutory officer, who would be responsible for reviewing complaints and appeals made by people with disabilities and support providers. The NDIA legislation should create this role and specify that the officer appointed would be independent, would act fairly and impartially, basing their decisions on the available evidence, and could not be directed in their decision-making.

Complaints about providers

Similarly, people could also complain to the NDIA about any breach of the service charter by a provider (for example, rude staff or erroneous records). The NDIA has strong incentives to act impartially, and would attempt to resolve these matters in a similar way to the TAC. If the NDIA corroborated a complaint against a provider, then the NDIA should make a determination and would reflect the complaint in ratings of provider quality. (A service provider or consumer could appeal this determination, but only on judicial grounds.)

Of course, a person with a complaint about a service provider would generally complain first to that provider — which would have its own internal complaints processes. The provider would have a reasonable incentive to retain their 'star rating', and this would be weighted in their deliberations. But where people feel too vulnerable or uncomfortable with this, their NDIA case manager or DSO could act on their behalf.

Box 7.4 How do accident schemes structure their complaints arrangements?

The NSW Lifetime Care & Support scheme uses a independent assessor (a doctor or other health professional unconnected with the matter under appeal) or a panel of assessors to settle disputes that cannot be resolved informally by LTCSA coordinators or assessment managers. Their decisions are binding, with limited recourse to appeals (the next step being the courts).

The Motor Accidents Compensation Tribunal (a division of the Magistrates Court) hears appeals against decisions made the Tasmanian Motor Accidents Insurance Board (MAIB). It also has a customer service charter that sets out MAIB's obligations and which helps guide people about when complaints about MAIB's conduct might be justified.

The New Zealand ACC has a more elaborate system of complaints and appeals processes, reflecting the large size of that scheme.

- It has several informal processes for dealing with initial complaints, initially a manager and then the Customer Support Service.
- It has codified the rights of its clients through the Injury Prevention, Rehabilitation, and Compensation (Code of ACC Claimants' Rights) Notice 2002. The overarching goal of the code 'is to meet the reasonable expectations of claimants (including the highest practicable standard of service and fairness) about how ACC should deal with them'. The code specifies the rights of the ACC's clients and the obligations of the ACC, such as the right to be treated fairly and with dignity and respect and to be communicated with openly, honestly and effectively. The code does not relate to disputes about assessed benefits. A person wanting to complain about a breach of the code can take it up directly with the ACC or refer the matter formally to Office of the Complaints Investigator, who hears formal disputes relating to the code. Decisions by the Office are not appealable.
- A separate body, Dispute Resolution Services Ltd (DRSL), which is funded by the ACC but operates independently of it, offers a specialist review service for people who are unhappy about decisions made by the ACC concerning entitlements to goods and services. It also offers alternative dispute resolution processes, such as mediation and facilitation. It has its own board of directors and a separate management structure. If a person appeals the decision of DRSL, then the matter goes to the New Zealand District Court, which can also conduct a merit review. Where there is a legal point at issue, a person can appeal the District Court's decision in the High Court with the permission of the District Court.

The Victorian Transport Accident Commission has similar processes. Where the complaint relates to a perceived breach of the TAC Service Charter, the person complains initially to the staff member, and if responses are unsatisfactory to the (internal) TAC Complaints Office, and ultimately Ombudsman Victoria.

If the matter relates to a claim (for example, a dispute over an appropriate home modification), a person has several options. They can refer the matter to an 'Informal Review', which involves a thorough review of a decision by the TAC Review Manager (who works independently of the claims area where the original decision was made). If the person is not satisfied, then:

- those that are not legally represented may immediately appeal to the Victorian Civil and Administrative Tribunal (VCAT). There is a small filing fee
- those that are legally represented are (generally) required to attempt to resolve disputes utilising Dispute Resolution Protocols before resorting to the VCAT. This involves the TAC, the claimant and their lawyer adhering to protocols that have been agreed by the TAC and the legal profession, to speed up the resolution of cases and avoid the high costs of legal action. If this process does not lead to agreement, the person can then apply to VCAT.

Risks to the scheme from merit review processes

It is important that appeals processes be carefully designed to resolve disputes in a manner that is fair and transparent, but in ways that also limit any adverse effects on the financial sustainability of the scheme as a whole.

The key concern here is that appeals processes that are unduly 'soft' can create costly precedents, leading to an unplanned and problematical redrawing of the rules and boundaries of the scheme. This can lead to additional unanticipated costs, and demands on revenue, over the long-term. Such outcomes may also undermine the motivation for assessors or other NDIA staff to continue to make hard-headed objective decisions.

Moreover, appeals and complaints processes can be very costly to provide, and there is the reality that not all people make well-founded complaints. As noted in the review of the New Zealand code:

> There is a small core of claimants who do not like the ACC and whose expectations will never be met. These people can be extremely litigious and openly discuss future complaints they may lodge. (Litmus 2004, p. 4)

All of these factors would have the capacity to threaten the sustainability of the scheme, and undermine public support for it.

Appeals processes can widen the scope of the NDIS and threaten its sustainability

In its visits and submissions, the Commission heard strong concerns about the risks to the scheme from excessive expectations about the scope of the NDIS. For example, Yooralla cautioned that there would be a serious risk in managing the expectations of some clients (and providers) under a well-funded scheme that was no longer subject to tight rationing. It expressed concern that, were unusual expectations from a few clients to be upheld at review and appeal, this could compromise scheme viability for everyone:

> … schemes such as the ACC and TAC have experience of some people coming to expect that the insurer will pay for ordinary life expenses and supports that go well beyond what is needed to respond to the disability, provide support and facilitate participation. In some instances, these views have been upheld by review authorities and in court. … explicit boundaries on what can be funded and review/appeal mechanisms must require that review bodies cannot make a decision that would result in the scheme funding ordinary life expenses or compromise the viability of the scheme via flow on effects. (sub. 433, pp. 24–25)

More broadly, the NDIA has to clearly define what it might mean by 'entitlement' to support. The Commission envisages that entitlement means that people get the

supports determined by an objective independent assessment (after considering a person's natural supports). But Yooralla warned that some people see entitlement in more ambitious terms:

> Requests for in ground swimming pools, home gymnasiums, ordinary transport costs, computer systems not related to the disability, GPS systems and funding for ordinary child care are sadly common. The notion of an 'entitlement' scheme also becomes problematic when entitlement is taken to mean 'person A' had a computer/gym program/new bathroom funded so I am entitled to have that computer/gym program/new bathroom. (sub. 433, pp. 24–25)

An area of clear risk is self-directed funding. The intention of this model of delivery is for people to fashion funding proposals suited to their own specific circumstances. However, once the NDIA accepts a particular purchase in one plan, there would be a need to avoid that creating a precedent for its acceptability in plans for other people in quite different circumstances.

Particular decisions create precedents that widen the scope of the scheme, and that once entrenched, could only be restrained through new legislation. Such ripple effects could damage the sustainability of the scheme.

Given the experiences of the TAC and the ACC, these concerns are not contrived. Yooralla cited a decision on appeal in Victoria that found the TAC liable for ordinary living expenses, such as rent. The Victorian Government needed to make a legislative amendment so that the ruling did not extend to all people living in shared supported accommodation.[6] Another case illustrating the difficulties is from New Zealand about what might be a reasonable home modification (box 7.5).

The impact of such judgments on the public perception of the scheme is an equally serious concern. The scheme's public support (and therefore its political sustainability) is underpinned by the need for benefits to be reasonable.

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6 Among other changes introduced at the time, this resulted in amendment of s. 60 of the Act (*Transport Accident and Accident Compensation Acts Amendment Act 2007, No. 60 of 2007)*. The amendment allowed limits to be set in respect of contributions to be made by a person towards the cost of supported accommodation.

Box 7.5 **What is reasonable?**

The case of *Witten-Evans v Accident Compensation Corporation [2003] NZACC 5 (22 January 2003)* has acquired the status of a cause célèbre among those concerned about what might be a person's reasonable expectations. The Commission heard about the case from several participants in meetings and it was cited by Yooralla (sub. 433). The circumstances were as follows.

A child had suffered from cerebral palsy and spastic quadriplegia because of medical misadventure. After the breakdown of the marriage of his parents, the original family home (which the ACC had modified) was sold and the proceeds split. The mother purchased and moved to an old two-story villa, which required installation of a lift and other modifications. The historical significance of the building meant that the costs of modifications would be high.

The ACC was advised of the impending purchase, undertook inspections, and according to the District Court, while the ACC's nominated occupational therapist expressed certain misgivings, the mother 'went ahead with the purchase, possibly in the belief of having [the therapist's] tacit approval.'

The ACC agreed to make home modifications, initially up to $25 000, a figure it subsequently amended to $60 000. This figure would fully meet the costs of modifying the building up to the ground floor (including a lift from the carport level to the ground floor), but would not cover additional modifications wanted by the mother, including a lift to the first floor of the dwelling. An original appeal for more money by the mother through the ACC review process found in favour of the ACC. However, the ACC lost its case in the District Court. The Court argued:

> The responsibility on the [ACC] is to pay for the modifications necessary and [so] I find that it is not appropriate for the [ACC] to simply pick on a sum which it may consider to represent an appropriate or reasonable contribution to the cost of those necessary and appropriate modifications. In that regard I find that it is not appropriate for the [ACC] to include any supposed discount factors [in relation to the extra costs of modifying a building of historical significance], particularly when such discount factors are outside the control of the appellant. … the [ACC] cannot expect any contribution from the appellant to his own rehabilitation, such as to the choice of residence or type of residence. … This Court is not in a position to indicate what it finds to be the proper costs of modifications, but as I have noted, it is the [ACC's] obligation to provide for the modifications which are deemed to be necessary and I have found what is deemed to be necessary.

The determination is revealing in that it seems to weaken the importance of 'appropriate or reasonable' as the basis for providing supports, that it disregards that the higher costs of modifying a heritage building were the result of a choice by the boy's mother, and that it is possible to be unclear regarding the proper costs of modifications, but certain about their appropriateness.

An addition concern is the cost of contesting claims and their slowness. For example, it appears that the median time to finalise a case concerning the TAC before the VCAT is around six months (VCAT 2010, p. 42).[7]

In what ways can these risks be limited?

The question is how to address these concerns. There are several complementary approaches.

It will be important for review mechanisms to have not only a broad 'reasonable person' criterion, but to be supported by legislative requirements to:

- have thorough and robust formal initial assessments and processes for calibrating them
- assess reasonableness by balancing the costs of some support against the benefits that these supports have for the person
- assess the appropriateness of the service and of its provider
- take account of any threats to the long run sustainability of the scheme from the review outcome and
- take into account the obligation of people with disability or their families to avoid decisions that unreasonably impose costs on the scheme (such as moving to a dwelling that is very costly to modify).

Notably, the Hon. Justice O'Connor, President of the AAT at the time, referred to the need:

> … to exercise discretionary power in accordance with the terms and purpose of the relevant legislation and with due regard for government policy. In some jurisdictions, this obligation is made clearer by the imposition of a legislative requirement to have regard to ministerial or departmental directions or guidelines. (O'Connor 2000)

The scheme's legislation, as much as possible, should attempt to provide clarity about specific entitlements. For instance, in one appeal, a woman claimed that she should have her childcare costs paid while she attended various health care appointments.[8] The VCAT found for the TAC because of the clarity of the

7 This is the median period for the 'general list'. While TAC disputes form the majority of such cases, there are several other types, like FOI cases. It is likely that the median would be higher were these other types of cases removed from the statistics.

8 Dawson v Transport Accident Commission (General) [2010] VCAT 644 (13 May 2010).

legislation on this matter. Chapter 4 sets out how 'reasonable' services might be defined.

There will also be a need to amend the legislation defensively, as loopholes and problems emerge and also, in some cases because more not less supports should be provided. However, it is not always possible to pass amendments to legislation, or to do so quickly.

Scheme design should seek to avoid large increases in benefits that are associated with small changes in context or circumstances, especially where there is ambiguity about the severity of a person's functional limitation. For instance, one reason why there are concerns about the Disability Support Pension is that someone just passing the threshold work test gets paid significantly more than unemployment benefits and is not required to look for a job, fill in a job search diary or meet other commitments. People face strong incentives to get across the threshold. Similarly, the receipt of ongoing loss of earnings capacity benefits under the TAC's no-fault motor vehicle accident scheme in Victoria is dependent on a person having a 50 per cent impairment rating. Many appeals to VCAT relate to whether a person falls over this decisive threshold.[9]

Similar benefits should be provided, regardless of the cause of a disability. Without this, the inevitable ambiguities about causes of disability and injury lead to complex judgments and the likelihood of appeal. This dilemma particularly affects accident schemes. For example, in the TAC scheme, they arise when there is doubt about whether an accident is a transport accident, when there are pre-existing injuries, and when a person acquires an additional injury that might be linked to the original accident. For example, in one case, a woman had a transport accident that left her dizzy, light-headed and uncertain on her feet. The next day she fell while changing the sheets on a bed, and struck her head on the wall of her bedroom, suffering catastrophic injuries resulting in quadriplegia. On appeal to the VCAT, the TAC provided compensation.[10] In other cases, decisions about coverage have gone the other way. Either way, these cases are the reflection of the fact that people get significant supports under one system of insurance and poor supports under the alternative. However, because of its general coverage, the NDIS will tend to reduce such disputed cases.

9 For example: Hexter v Transport Accident Commission (General) [2007] VCAT 674 (3 May 2007); Moldovan v Transport Accident Commission (General) [2005] VCAT 1436 (19 July 2005); Kennedy v Transport Accident Commission [2003] VCAT 2035 (19 December 2003); Zagar v Transport Accident Commission (General) [2005] VCAT 820 (4 May 2005).

10 Ng v Transport Accident Commission (General) [2006] VCAT 9 (19 January 2006).

The wording of the NDIA Act should limit the capacity of merits review processes to widen eligibility or entitlement. It should require that any claims by NDIA clients would need to:

- ***meet a 'reasonable person' test***
- ***balance the benefits to the person with a disability against the costs to the scheme, including any adverse implications for the long run sustainability of the scheme from the review outcome***
- ***take into account the obligation of people with disabilities or their families to avoid decisions that unreasonably impose costs on the scheme.***

Is there also a need for an external merits-based review body?

A difficult question is whether there also needs to be an external review process to review the merits of particular disputes. An external merit review process would have the power to review the merits of a decision, and, if need be, to substitute a new and binding decision on the original decision-maker.

There are already legal obligations on the original decision-maker, and the right of the affected party to seek judicial review on the matters of law raised by an administrative decision. However, there is no legal requirement for external *merit-based* review. But despite this, there are some arguments for such an external mechanism to promote impartial judgments where a person disputes the NDIA's decision, given that the consequences may have large impacts on the person (for example, about whether they get what they perceive to be an adequate home modification). It would also reflect public perceptions about natural justice.

This approach is the norm for many other government functions, and is true for MAIB, TAC and the ACC.

On the other hand, an internal independent assessment process, with tightly defined criteria, and with appeals on its decisions only on judicial grounds, can also deliver high quality appeals processes. This would:

- be less costly, while still providing reasonable protection for people using the NDIS
- leave the scheme and its clients less exposed to the risks that a single decision would create a precedent that affected scheme costs and sustainability.

While some might see such an approach as denying people natural justice, it would provide a genuine avenue for merit review, and would help safeguard the scheme as a whole. The experience of successful long-term care and support agencies such as the NSW LTCSA have shown that internal appeals processes can work very effectively. They would still be subject to appeals to the courts in the usual way.

The Commission is very mindful of the importance to people with disabilities and their families of the NDIS being financially sustainable over the long term, and of the difficulty of this task even in ideal conditions. In its view, the risks to the scheme that could arise from external review should be constrained to the maximum extent possible.

DRAFT RECOMMENDATION 7.12

The NDIA should include an internal complaints office that would:

- ***be separate from the other parts of the NDIA dealing with clients and service providers***
- ***hear complaints about breaches of the service charters (draft recommendation 7.10)***
- ***reassess contested NDIA decisions on a merit basis.***

The office would be headed by an independent statutory officer who would review appeals made by people with disabilities and support providers against the decisions of the NDIA.

- ***The NDIA legislation should create this role and specify that the officer would be independent, would act fairly and impartially, basing their decisions on the available evidence, and could not be directed in their decision-making.***
- ***A person or support provider should only be able to appeal the decisions of the office on matters of law, rather than on merit, to the courts.***

The NDIA should publish the number, types and outcomes of complaints and appeals (subject to privacy protections).

An alternative approach

Were governments not to accept this recommendation and instead prefer to establish an external merits-based review process, this could take several forms (box 7.6).

Merit reviews of decisions made by the NDIA would need to involve some detailed specialist knowledge about the assessment tools used and their accuracy, past determinations and their precedent value; the guidelines issued by the NDIA; and detailed familiarity with the NDIA Act, which is likely to be a complex and long

statute. (The *Transport Accident Act 1986*, which governs Victoria's transport accident scheme, is 333 pages long.)

Box 7.6 **Appeals processes (Commonwealth)**

Federal tribunals and other bodies have been established to review administrative decisions and actions taken by government officials. The states and territories also have bodies that review decisions made by their officials. Some are specialised and deal with a limited range of decisions, while others have a more general jurisdiction.

There are several major Commonwealth merits review tribunals:

- The Administrative Appeals Tribunal (AAT) has a broad jurisdiction to review decisions made under about 400 federal laws. Family assistance and social security, taxation, veterans affairs and workers compensation constitute the largest part of its workload. (The AAT is unique in the world for the breadth of its jurisdiction and the comprehensive nature of its powers (Walker 2009, p. 5).)
- The Migration Review Tribunal and the Refugee Review Tribunal review decisions made under the *Migration Act 1958*, particularly decisions to refuse or cancel visas or refuse applications for refugee status.
- The Social Security Appeals Tribunal reviews decisions made by Centrelink under social security and similar laws and decisions made by the Child Support Agency.
- The Veterans Review Board reviews certain decisions made by the Repatriation Commission under veterans' entitlements legislation

While the latter two tribunals are independent bodies, their decisions may be appealed to the AAT, albeit not in respect of all matters. This is not generally the case for the decisions of the Migration Review Tribunal and the Refugee Review Tribunal.

It is also possible to appeal from decisions made by administrative tribunals to the *Federal Court*, but only in respect of whether a decision was made lawfully within the statutory powers of the decision-maker.

The *Commonwealth Ombudsman* has a different role again — it will seek to resolve disputes through consultation and negotiation but cannot override an agency's decision.

A person may also complain to the federal *Privacy Commissioner* if they are concerned about how the government collects and handles their personal information. Information privacy principles set out how government is to treat this information and the circumstances in which agencies can pass it to someone else.

Source: Attorney-General's Department 2006 and ARC 2006.

For such reasons, an arrangement that permitted the building over time up of specialist subject matter knowledge within the appeal body would be an important consideration. This could be achieved by establishing:

- a specialist division of the Administrative Appeals Tribunal (AAT) relating to reviews of NDIA decisions, along the lines of its taxation appeals division
- an entirely new independent tribunal along the lines of the Migration Review Tribunal and the Refugee Review.

In general, Australian governments have tended to amalgamate tribunals. For instance, the Victorian and NSW Governments amalgamated several smaller specialist tribunals into larger, more generalist bodies, creating the VTAC and the Administrative Decisions Tribunal respectively. Given the tendency to avoid further review bodies, this suggests that the AAT could be used as the external merit review body, were the Commission's recommendation of a statutory complaints and appeals officer within the NDIA not to be accepted. But it is important to note that the AAT, through its decisions, can problematically redraw the rules and boundaries of the scheme.

There would remain the capacity to appeal a decision by the AAT to a court on judicial grounds. A judicial review would look at whether the merit review body used the correct legal reasoning and followed the proper legal processes, but generally would not review the merits of the case.

Box 7.7 **Administrative Appeals Tribunal**

At the Australian Government level, the AAT is the most common avenue for undertaking merit reviews. In reviewing a decision, the AAT stands 'in the shoes' of the original decision-maker (AAT speech, April 2007), has the same powers as that party, and may substitute its own decision for the original decision. The AAT can also refer parties to alternative dispute resolution, and conferencing to try to achieve settlements prior to proceeding to tribunal.

An important aspect of the AAT's process is that it has some discretion in its judgments. While there are many instances where the law clearly points to only one legally available option, the AAT has the power to make a 'preferred' decision when it is able to choose from a range of equally acceptable outcomes (Walker 2009, pp. 4–5). The quality of those decisions is critical to the financial sustainability of the NDIS because they create 'new rules' that act as precedents for other decisions. As noted by the Hon. Justice Garry Downes (2006), while no formal doctrine of precedent exists in administrative law, members of the Administrative Appeals Tribunal will follow earlier decisions of the Tribunal unless they are satisfied that the earlier decision is manifestly wrong.

If the proposal in draft recommendation 7.12 for appeal processes supported by an independent statutory officer are not adopted, then the Australian Government should create a specialist arm of the Administrative Appeals Tribunal to hear appeals on merit about the NDIA's decisions subject to the constraints of draft recommendation 7.11. The Australian Government should set aside significant additional resources to fund this specialist arm and should include a larger reserve for the NDIS, calculated to take account of the higher risks of this approach.

Costs of an external appeal body

The costs of these arrangements is uncertain, depending on the number of reviews and their complexity. Many VCAT decisions regarding TAC matters involve the testimony of many doctors, the examination of past records, as well as oral evidence from the TAC and others. Judgments can run for 30 pages. Data from existing Australian Government tribunals suggest very different unit costs.

Appeals to VCAT about TAC's decisions provide one source of evidence about possible overall costs. There were 661 appeals to VCAT about decisions by the TAC in 2008-09 (TAC 2009, p. 30). To put that in context, there were around 40 400 people receiving benefits from TAC in that year and 19 200 new claims lodged (p. 12). Appeals can be in relation to claims or to TAC's decisions about existing clients (for example, eligibility for a specific service, or about how impairment may have changed over time). Supposing, for illustrative purposes only, that in any given year, the NDIS had to assess around 500 000 people, then using the TAC appeal rate as a guide would imply around 8000 appeals to the external review body per year. Were each finalised cost to be $4700 — roughly the current average for cases before the AAT — then that implies appeal costs of about $40 million (roughly doubling the cost of the AAT). In fact, the number of appeals would be likely to be lower, as many of the sources of disputes for the TAC would not be present for the NDIS (for example, in relation to matters affecting income replacement or disputes about the source of a disability/injury). The rate of appeals in the Tasmanian motor vehicle scheme are less than half that of the TAC, further suggesting lower likely appeal costs.[11]

[11] While the Commission did not get data on the number of people receiving benefits through MAIB, there were 3367 new claims received for the Tasmanian scheme (MAIB 2009) and 45 appeals made to the Motor Accidents Compensation Tribunal (Magistrates Courts, Annual Reports 2008-2009, Tasmania). This is 1.3 per cent of new claims. Calculated on the same basis, the comparable rate in Victoria is 3.4 per cent of new claims. (This measure is not

Table 7.2 **Costs of tribunals**

Size, approximate cost[a] and workload as at 30 June 2010

	Members	*Staff*	*Expenses*	*Reviews finalised*	*Cost per case finalised*
Administrative Appeals Tribunal	91	162	$35m	7 447	4700
Migration Review Tribunal & Refugee Review Tribunal	94	272	$40m	9 737	4100
Social Security Appeals Tribunal	211	113	$27m	14 706	1858
Veterans Review Board	39	31	$5.5m	3 742	1450

[a] The estimates of costs per case finalised are very approximate and not strictly comparable. Only a rough estimate of total expenses has been used, without, for example, taking into account how the agency is structured (for example, if it pays lease/rent costs) or the extent of fees charged to the applicant. Similarly, a measure of cases finalised in a particular year does not give a clearcut indication of a tribunal's workload, as considerable work may go into cases in progress but not finalised in the same year. Also, some tribunals hold public hearings in a wide range of locations, or require extensive use of interpreters, thereby raising costs. But for the purposes of planning a new appeals body, having a rough indication of aggregate and per case costs can shed some light on the quantum of funds that would be needed to provide an external appeals mechanism.

Source: Annual Reports for 2009-10, websites.

The way forward

As noted above, the Commission is so mindful of the risks of scheme sustainability — and the wider injustice to people with disability that this would involve — that it favours an internal review process with a statutory officer to guarantee impartiality, with external review limited to matters of law. However, in the event that governments prefer external merits review, this could be undertaken by a specialist division of the AAT. Either way, the risks of review processes should be curtailed through clear legislative guidance.

7.9 Other functions

The NDIA will have several other functions critical to the success of the NDIS:

necessarily the best measure of the incidence of appeals since people can make complaints without lodging a new claim, but it provides a picture of the relative appeal risks of MAIB and TAC.)

Quality assessment

The question of how to ensure the quality of support services provided to people with disabilities and their families is a fundamental issue for this inquiry, and a key responsibility of the NDIA. Chapter 8 canvasses this issue in detail, and proposes a range of measures by which this might be achieved.

In view of the greater role that the NDIS would give people with disabilities to make most choices about support services themselves, a major discipline on the performance of disability service suppliers and any intermediaries would be competition. People with disability could:

- assemble their own supports, including through mainstream services
- shift from one specialist supplier to another if they were unhappy with their services. Clearly such mobility would need to balance the reasonable commercial certainty for suppliers writing any longer-term contracts with people with disability and the need to avoid onerous exit terms if services were inadequate (noting that the Australian Government has introduced unfair contract legislation that would address this risk — *Trade Practices Amendment (Australian Consumer Law) Act (No. 2) 2010*))

In addition, the NDIA's case managers would collect assessments from consumers on a confidential basis about the performance of suppliers, and the NDIA would also have information on direct outcomes achieved from its own data management systems (chapter 10). This would allow consumers to make more informed choices when selecting providers — and would penalise poor providers. This would lead to a publicly disclosed rating for all specialist disability providers akin to the 'star rating' systems used in the Job Network. As in the Job Network system, the ratings could be adapted for the difficulty of achieving outcomes for clients with different characteristics. If a supplier was rated consistently poorly, the NDIA could remove them from a list of registered specialist providers.

Chapter 8 addresses these issues.

Data functions

Data collection and management is essential for managing day to day cost pressures and long-term liabilities, testing the efficacy of interventions for people with disability, putting pressure on suppliers to be efficient, adapting assessment processes, and generally assessing risks to the scheme.

As the Insurance Council of Australia observed:

> Commercial insurance by its very nature focuses on "total cost" over the life of the claim and not just individual cost elements. As such it promotes the use of measures which aid the recovery of injured persons to reduce those costs. … To best manage total costs and achieve optimal health outcomes, insurers utilise various strategies including: early medical and rehabilitation intervention; management of external service providers; continually scanning the medical and allied health environment for the latest evidence based programs. (sub. 553, p. 10)

We discuss data collection and management functions separately in chapter 10.

The implication of this data handling and management feature is that the NDIA will need very significant competencies in IT, data management and analysis — encompassing hardware, software and people — with many more resources than currently allocated to this function among the current disability system. The disability sector will also need to have complementary IT and software. The experience with the Job Network was that IT issues dealing with the employment department were a major source of dissatisfaction among providers (PC 2002). Developing the above capabilities will take some time, and would be one of the important initial steps in the implementation of the NDIS. Existing large scale schemes, such as the New Zealand ACC (a large scheme), the TAC, some workers' compensation schemes (and for that matter, Centrelink, Medicare and the Job Network) would provide practical guidance.

The Commission does not presume that the NDIA would necessarily undertake all of these functions in-house. It would be up to management to determine whether it was more efficient to outsource some of these functions.

Research

The NDIA would need to have research capabilities to, among other things:

- use the data described above to achieve the goals of the scheme
- to assess innovative therapies or new aids and appliances proposed by suppliers
- develop new preventative, early intervention and any other approaches improving outcomes for people with disability and their families.

Chapter 10 discusses this issue in detail.

8 Delivering disability services

Key points

- Consumers experience profound difficulties in finding out what disability services are available and how to access them. This is because large parts of the disability sector (government and service providers) are fragmented, with inefficient lines of communication. In part, these difficulties arise because disability services tend to be centrally government controlled rather than consumer-oriented, as in a normal commercial market for goods and services.
- Features of the NDIS — specifically, a single point of entry and assessment, increased resourcing and consumer choice — would ameliorate many of these problems. However, there are further steps that should be taken in order to assist consumers by minimising transaction costs. These include:
  - a national internet database featuring information about service providers and indicators of service quality
  - a strong role for local case managers to assist decision-making and to monitor clients' wellbeing. Their role should be graduated in terms of the needs of the client and concentrated at key transitions, such as when people first enter the disability system or between school and work
  - a confidential and longitudinal database containing client information, for the purposes of reducing administrative requirements for both service providers, government and consumers, as well as client outcomes, which can be used by the NDIS to monitor quality of service provision and evaluate the effectiveness of different types of services, rehabilitation, appliances etc.
- The use of individualised packages and greater consumer choice will increase competition in the provision of high quality services. Nevertheless, there is a strong argument for a continued role for regulatory oversight in protecting vulnerable consumers from harm and ensuring providers adhere to a basic standard of service. In addition, both consumer decision-making and the market incentives for providers to deliver quality service products can be bolstered by making performance information (such as outcomes of audits or annual reports by community visitors) and other standardised indicators available to the public.
- While consumer payments to providers (or through DSOs) should become the industry norm over time, there may still be a role for some limited block funding where markets would otherwise not support key services, to enable a timely response to crisis, and to support innovation.
- Government-run service providers would continue on the same basis as not-for-profit and private service providers.

There is a large and specialised market for providing disability support services and equipment to people with a disability in Australia with more than 2200 disability support agencies (AIHW 2011). The current market gives prominence to relationships between government and service providers and less to those between people with a disability and providers. Governments contract providers directly through 'block funding' to deliver services and undertake quality assurance. The person with a disability is often a passive recipient of (rationed) supports from a local block-funded provider, and has little input into the services they get. The providers themselves are given funds well short of the needs of the groups they serve and have little freedom to adopt innovative practices.

The performance of this market has major effects on the lives of people with disability and on governments' purse strings. Under a NDIS, the sector will face significant structural changes over the medium run — in particular, increased funding, changes in the design of disability system, the adoption of consumer choice (including self-directed funding) and new governance arrangements.

Change itself is not new to the disability sector — over the last 30 years the disability system and social attitudes to disability have changed considerably (box 8.1), mostly for the better (Clear 2000, p. 68; Ward 2006, p. 254). Governments have closed most institutions, and expectations of social and economic participation have risen. Through this period of change, the basic themes of social inclusion and citizenship, empowerment and the need for diverse, responsive and personalised support services, have increasingly been emphasised. However, the reflection of these themes in adequate resourcing and actual service delivery has, at best, been mixed. Clear (2000) observed:

> … the discourse of state policy pronouncements does not match up with their personal experiences, and community care has not presented a reliable and secure opportunity for citizenship for many parents or their sons and daughters.(p. 71)

In short, the broad aspiration of creating a disability system centred around people with disability themselves, and equipped to meet their needs through the provision of high quality services, is very much an unfinished project. In addition to increasing the resources available to people with a disability, the proposed NDIS will provide people with a disability much greater power about how their needs are met (figure 8.1).

Box 8.1 **Changes in the disability system in Australia**

The disability system in Australia has changed considerably over the last 30 years. Historically, supports for people with a disability were limited (beyond that provided by their families) and tended to be charity based and reliant on large scale institutions. This began to change in the mid 1970s with the movement towards 'de-institutionalisation', whereby residents of large scale institutions were gradually released into the community (Ashman 1989). In turn this was accompanied by a growing recognition of the social responsibility to build a more inclusive society through offering greater (and more appropriate) support to people with a disability, as exemplified by the International Year of Disabled People in 1981 and the growth in capacity and variety of disability services throughout the 1980s (Clear 2000).

This culminated in the Commonwealth *Disability Services Act 1986*, which recognised the broad range of services needed to facilitate community (rather than institutional) care and provided a legislative basis for funding disability services. This Act changed the dynamic between government and service providers and set out a framework aimed at linking funding with specific outcomes (such as independence, employment opportunities and integration in the community). The development of Disability Service Standards in 1992, and the increasingly explicit contractual obligations and greater reporting requirements that emerged throughout the 1990s were both geared towards facilitating this in practice.

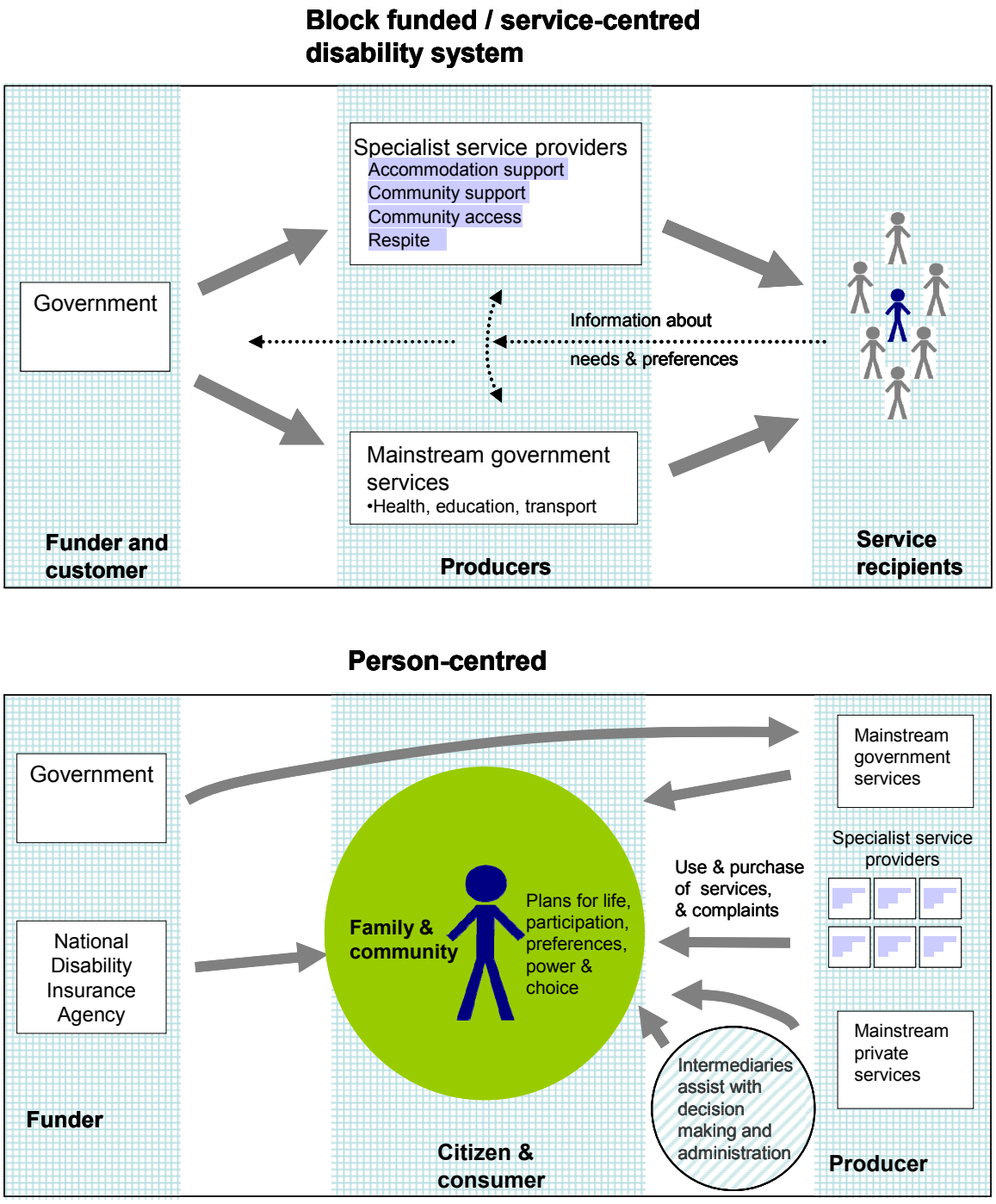
In 1991, Australian governments entered into the Commonwealth and State Disability Agreement. This agreement — which demarcated responsibility for the provision of disability services by different levels of government. Its intent (if not its actual achievement) was to address the overlap, duplication, gaps and lack of coordination that had previously been a feature of the sector.

Three subsequent agreements have been entered into:

- 1998 CSDA – aimed at more flexible service delivery models, improved accountability and performance reporting and increased use of technology
- 2003 CSTDA – aimed at strengthening support for families and carers and improving cross government linkages and access to generic services
- 2009 National Disability Agreement – aimed at improving early intervention, lifelong planning and person centred approaches. This agreement identified ten priority areas required to underpin the policy direction and achieve these reforms. (AIHW 2011).

In 2008, the Australian Government ratified the United Nations Convention on the Rights of Persons with Disabilities. The convention entails certain obligations on parties ratifying it, such as adopting legislation and administrative measures to promote the human rights of persons with disabilities, eliminating discrimination in workplaces and society; providing information to people with disabilities, undertaking disability-relevant R&D and appropriate consultation with people with disabilities in developing and implementing legislation and policies and in decision-making processes that concern them.

Figure 8.1 **The changing dynamic of the proposed NDIS**



This chapter briefly describes the disability service sector (section 8.1) and examines how the provision of support services and equipment can become more responsive, efficient and more adept at meeting the needs of people with a disability.

Given the magnitude of the proposed changes, it will be important for the NDIA to provide adequate support to both people with disability, and to specialist providers, as they adjust to the new system. A central aspect of this is understanding how historical problems in the disability sector may persist under the proposed system, and how best to address them. Prominent amongst these is the complexity of the disability system and the difficulties experienced navigating the disability system — for both consumers and service providers. Section 8.2 discusses how this can be reduced under the proposed NDIS.

Ensuring that support services are of adequate quality is another ongoing challenge for the sector. Under the proposed scheme, consumers would play a much greater role in this than they currently do. In addition, a system of regulatory oversight would be required to deliver high quality services. This should take account of the need to protect vulnerable consumers, and the costs and efficacy of regulation and monitoring. These issues are considered in section 8.3.

Finally, there are specific areas where traditional approaches, such as block funding or government provision of services, may deliver better outcomes for consumers than market-based solutions. This is examined in section 8.4, with a particular focus on the difficulty of providing services in rural areas.

8.1 Disability support services

People with disabilities and their families rely on a range of good and services in order to fulfil their care needs and to maintain the quality of their lives. Comprehensive data on the government-funded specialist disability services is gathered as part of the Commonwealth State and Territory Agreement, and published annually in the Disability Support Services report (AIHW 2011). This data collection categorises disability support services into five main groups: accommodation support, community support, community access, respite and employment services (box 8.2 describes these groups in more detail).

While this comprises the majority of the sector, it does not account for services privately purchased by people with a disability. In addition, it does not provide information on aids and appliances or home and car modification. These physical goods play a vital role in the wellbeing of people with a disability, but are a relatively small part of the sector. For example, attendant care alone (itself a sub-category of accommodation support) can comprise up to 80 per cent of the individual funding package offered in the NSW LTCSS. Similarly, around $1.4 billion was spent on disability services in NSW in 2007-08, dwarfing the

$54 million budgeted for aids and appliances, prosthetic limbs and the home respiratory program in that state for 2010-11 (sub. 536, p. 24).

Box 8.2 Types of disability services

Accommodation support: Services that provide accommodation to people with a disability, and services that provide the support needed to enable a person with a disability to remain in his or her existing accommodation or to move to more suitable or appropriate accommodation. This includes attendant care and in-home accommodation support, as well as group homes and other residential facilities.

Community support: Services that provide the support needed for a person with a disability to live in a non-institutional setting. This includes therapy, early childhood intervention, behaviour specialists, counselling and case management.

Community access: Services designed to provide opportunities for people with a disability to gain and use their abilities to enjoy their full potential for social independence. This includes learning and life skills development, recreation and holiday programs and other community access programs.

Respite: Services providing a short-term and time-limited break for families and other voluntary caregivers of people with a disability, to assist in supporting and maintaining the primary care-giving relationship, while providing a positive experience for the person with a disability. This includes own-home respite, centre-based respite and host family/peer support respite.

Employment: There are three types of employment services which provide employment assistance to people with a disability. *Open employment* provides assistance in obtaining and/or retaining paid employment in the open labour market. *Supported employment* provides employment opportunities and assistance to people with a disability to work in specialised and supported work environments. *Targeted support* provides people with a disability structured training and support to work towards social and community participation, or opportunities to develop skills, or retrain, for paid employment.

Advocacy, information and alternative forms of communication. Services that represent the interest of individuals or groups, campaign for systemic change, and provide accessible information to people with a disability, their carers and families, as well as related professionals.

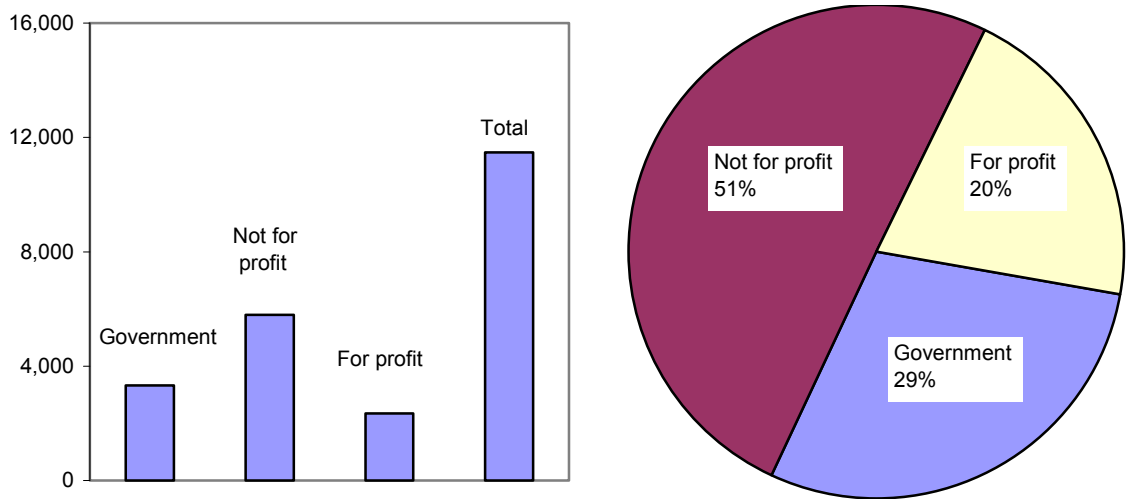
Other support. Includes research and evaluation, training and development and peak bodies.

Source: AIHW (2011).

In 2008-09, almost $5.4 billion was spent on CSTDA services, which were delivered by 2200 agencies through around 11 500 service outlets. Of these, around 51 per cent are not-for-profit, 20 per cent are for-profit and 29 per cent are government run (figure 8.2). Accommodation support — mainly in-home support

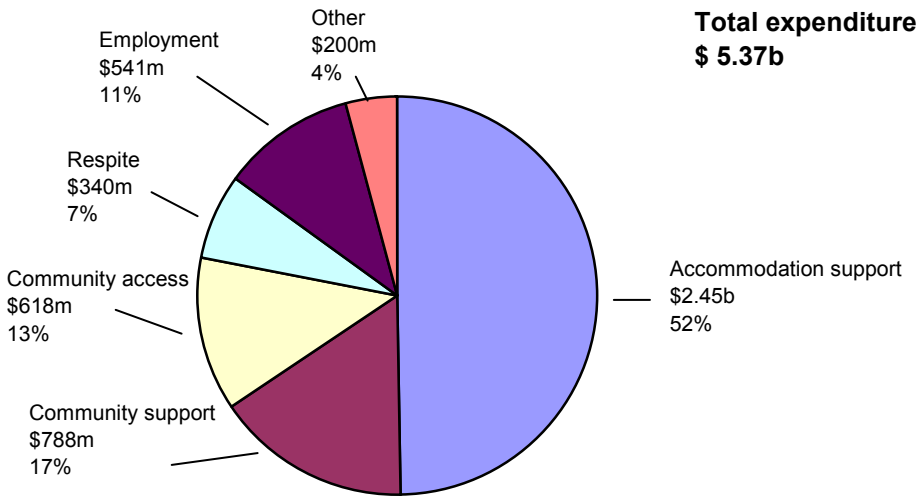
(50 per cent of users of this category) and group home facilities (34 per cent) — is a central feature of CSTDA-funded services, with around 46 per cent of all government expenditure spent in this area (figure 8.3). There are more accommodation support outlets than any other type (figure 8.5), and providers tend be smaller, servicing fewer clients (8.5 on average) but spend considerably more per client ($63 000) (figure 8.4). Conversely community support and employment services providers tend be larger, servicing greater numbers of lower cost clients.

Figure 8.2 **Number of funded service outlets, 2008-09**



Data source: AIHW (2011, table 2.2).

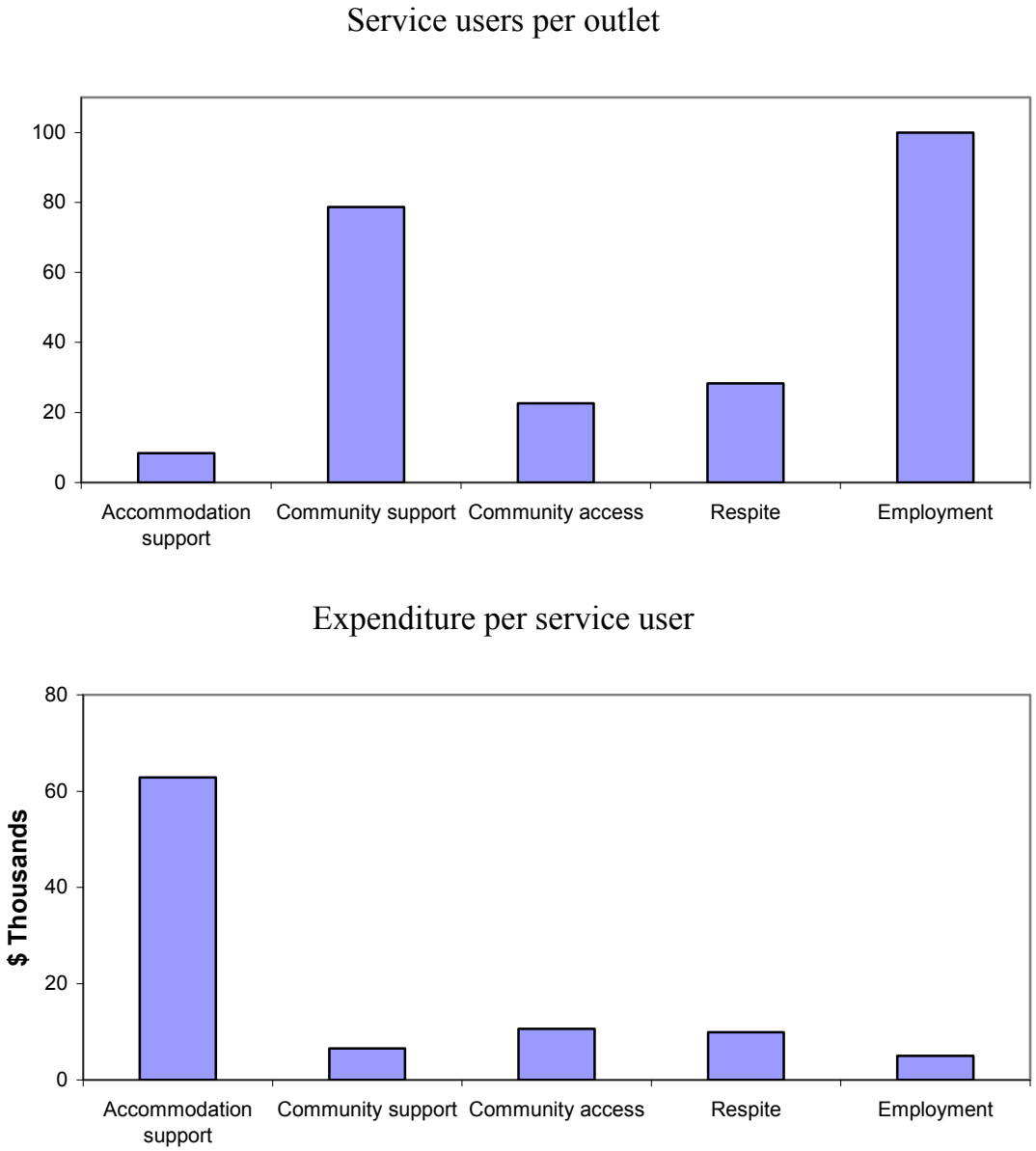
Figure 8.3 **Expenditure share, 2008-09**



a The category 'Other' includes advocacy and information services, administration and other services. Figures exclude expenditure on administration and capital grants. These are included in the total expenditure figure.

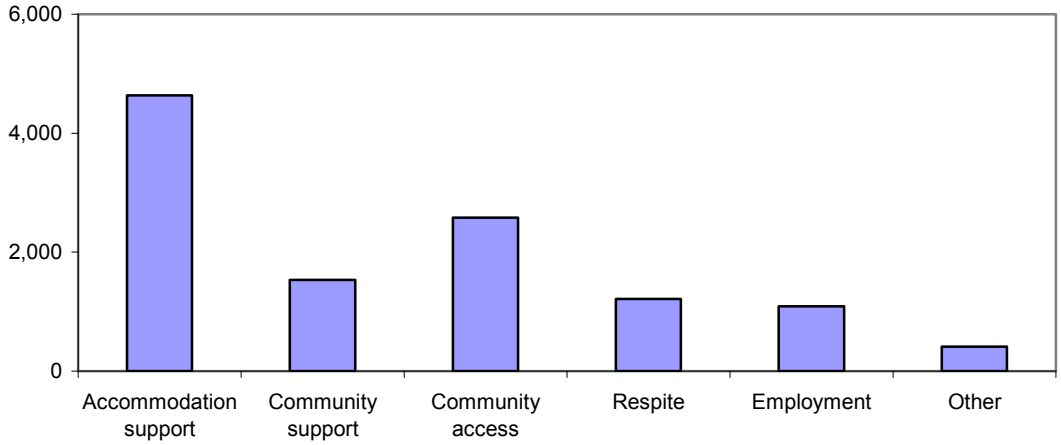
Data source: AIHW (2011, table 2.8).

Figure 8.4 **Average number of users per service outlet, 2008-09**



Data source: AIHW (2011, tables 2.4 and 2.8).

Figure 8.5 **Number of service outlets by type, 2008-09**



a The category 'Other' includes advocacy and information services, administration and other services.

Data source: AIHW (2011, table 2.2).

8.2 Navigating the disability system

People often see the costs of a service in terms of the dollar prices they pay. However, there are many other costs people experience in using the disability system: trying to find out what is available, assessing the quality of alternative providers, filling in forms, completing assessments, and waiting. These 'transaction' costs (box 8.3) represent yet another burden on people with disability. In particular, rationing with the disability system compels people to:

- enter long queues in order to receive support
- waste time and energy applying for support that is ultimately denied (or only partially granted) for reasons other than relative need.

While the hardship that people face when trying to access disability goods and services is largely driven by the high degree of rationing in the system, it is not the only source of such 'transaction' costs. A common theme amongst participants in this inquiry is the extraordinary difficulties they have encountered merely in finding disability services (hence the 'maze'), and the ongoing time, energy and expertise required to fulfil the administrative requirements even after entitlement to services has been established. While transaction costs cannot be eliminated, minimising such costs can lead to significant efficiency gains (better allocation of resources and less leakage through administrative costs) and can be of considerable benefit to consumers.

Box 8.3 What are transaction costs?

In all markets, consumers and producers face search, information and other 'transaction' costs when dealing with each other. These include the costs faced by producers and consumers in finding each other, communicating what they need and can offer, and understanding and meeting the laws, regulations and contractual obligations that govern their exchanges. Transaction costs can relate to monetary costs of the transaction (the cost of petrol to drive to a shop or the cost of a lawyer to draw up a contract between two parties) or to time and energy put into finding the right producer or customer. In the broader economy, such costs are pervasive, often unavoidable, and not usually grounds for government involvement. (In private markets where transaction costs are high, firms can invest heavily into advertising, can integrate vertically to avoid the difficulties they face in procuring inputs into production, and intermediary firms often emerge to match products with consumers, such as real estate agents, eBay etc.)

In the case of the disability sector, these transactions costs largely reflect the central role of government in the disability system. Most of these costs are not measured and fall on some of the most vulnerable people in Australia.

In practical terms, where transaction costs are excessive (and administrative burden is disproportionate to the risks to taxpayer funds) people with disabilities receive less assistance than they otherwise would have and experience greater difficulty in accessing it.

Finding out what is out there (and how 'good' it is)

People with disability and their families need to be able to assess whether services exist in their local area, and their quality and suitability. This is a costly process — in terms of time, energy and money — and the costs are highest when a person first enters the disability system, when they also typically are struggling to adjust to a newly acquired or diagnosed disability. This experience is often repeated at key transitional points in people's lives, such as when they leave the education system or retire. At worst, this type of transaction cost limits peoples' choices in much the same way as shortages — most conspicuously through the unmet need that arises through 'hidden' programs that people would access if they knew of their existence. For example, Carers Australia said:

> A familiar phrase when carers are talking amongst themselves is "why didn't someone tell me about that? Or "why wasn't I told?" Many carers are unaware of the services and support available. There is a strong need for carers to be well informed about any support or services to be funded under the scheme and the operation of the scheme itself. (sub. 406, p. 17)

Similarly, the difficulty of observing quality (prior to delivery) may make people reluctant to try new approaches, given that the application process is time consuming, uncertain in itself and could potentially affect eligibility for existing arrangements (Kate Evans and Frank Beard, sub. 278, p. 3).

Finding out how to get it

Whilst people's experiences vary, it is apparent that many struggle with the ongoing administrative burden of applying for and maintaining disability care and support services (box 8.4). People with disabilities and their families must often simultaneously become managers and advocates, dealing concurrently with multiple disability service providers, government agencies and health professionals. Typically eligibility (and assessment) must be individually established with each body, and often people must periodically reapply even if their situation has not changed, resulting in them retelling their story over and over again.

Box 8.4 The administrative burden is high for many people with disabilities and their families and carers

There has been expressed need in consultations to reduce the need to repeatedly prove eligibility for different forms of support… …The overarching family-centred assessment process suggested in this submission may assist in this challenge, providing a single assessment to access multiple services. (Carers Australia, sub. 406, p. 17)

Paperwork is the bane of both service providers and families. We have been told we need to update our application for funding even though there is no prospect of a success. This process takes quite some time, requires that we paint ourselves as incapable, requires service provider time with no provision for recompense. The application will need to be vetted and entered into a database, thus using bureaucratic time with no direct service provision. (Bill and Alison Semple, sub. 43, p. 1)

When Ava was three and I began to have concerns about her development I had to ask to be referred to early intervention. My referral was placed with the wrong area, I was sent to information sessions irrelevant to Ava and I and it was only after I queried when someone would call me that the error was found and rectified. I wasted 12 weeks gathering irrelevant material only then to have to wait another 3 weeks for someone to see me. All up, it took nearly 10 months for Ava to receive any intervention and 18 months before I got to see a social worker. NOT GOOD ENOUGH! (Joylene Donovan, sub. 40, p. 7)

We deal with over 30 agencies related to Sammy's disability …The transaction costs for us and the agencies are very significant. Many families are deterred from accessing services for this reason. The efficiency losses are large, real and constant. (Australian Catholic University, sub. 356, p. 4)

As an agency supporting consumers, we grapple with complications of complex service delivery system — even with our 25 years experience in the industry it is still difficult for us to understand the intricacies and changes that occur. How can we expect clients to understand? (Housing Resources and Support Service Inc, sub. 207, p. 9)

Those who are educated, articulate, confident, creative and have managerial skills and strong support networks are better placed to cope with the demands of the disability system. Conversely, those who are most isolated, vulnerable and in need, experience the greatest difficulty in finding assistance and, as a result, are less likely to have their needs met. At an extreme, participants have reported that some

families ‘drop out of service provision because they find it too hard to continue self-referring for services’ (Royal Children’s Hospital, sub. 405, p. 6).

Even those best placed to deal with the administrative burden still face all the other anxieties and emotional distress of their own or a relative’s disability. For example, one participant spoke of the trauma of having to periodically detail all of things their child will never be able to do (Susan Freeme, trans. P. 533).

Why are the system navigation costs so high?

The complexity of the disability sector is driven by a combination of structural and historical factors. In large part, it arises from the logistical problem of matching a highly diverse array of services (see box 8.2) with a large group of people with highly diverse needs. That is, the varied and complex combinations of services that people with a disability need do not lend themselves easily to a simple supply model. This has been compounded by the conditions under which the disability sector has emerged, including binding resource constraints and the constant changes to the sector. Lindsay (1996) argues that much of the sector has grown through specific advocacy actions resulting in ‘ad hoc programs’ that ‘respond to specific needs and demands without any consistent policy framework or philosophy’.

Navigating the disability system is also made more difficult due its fragmented nature. As pointed out by Lindsay (1996), this fragmentation is partly a design feature of CSDTA and partly a consequence of the natural division in portfolio responsibility within government.

Fragmentation is not inherently bad, especially for service provision. Indeed, it can drive specialisation, variety and experimentation, as in markets for many mainstream goods and services. However, fragmentation of departments that fund and determine access to disability services increases the general complexity of the system and can blur the boundaries of responsibility and accountability, resulting in both duplication and holes in service provision. It also increases the number of ‘entry points’ and ‘check points’ that people must discover and traverse in order to access services.

Advocacy groups, support groups and other networks have been an important response to this. Among other things, they provide information and advice to people with disabilities, and highlight gaps or other problems to service providers and government agencies.

How can transaction costs be lowered?

The central design features of the NDIS proposed in this report should significantly reduce transaction costs in three key areas:

- increased funding will reduce the search costs caused by rationing
- the consumer choice model (both self-directed funding and choice of package) will make it easier for people to trade off one type of support against another in order to secure the bundle of goods and services most appropriate for them
- the assessment process will provide a single entry point for many of the support services and equipment that people with a disability need and a clear path for determining eligibility and entitlement (see chapter 5).

However, it is important to note that the NDIS cannot be a 'one-stop-shop' that facilitates the full range of government services that people with a disability are eligible for (for example, income support through Centrelink, the provision of public housing, education etc). While there are no perfect remedies for this, there are several ways of ways of reducing other transaction costs by making information flow more effectively throughout the market for disability support services and equipment.

Providing information portals to consumers

One way to do this is through the systematic compilation of information about service providers, into a single searchable database. While most state and territory government offer some form of this, their quality and usefulness is varied. There is merit in substantially enhancing these facilities in the short term, and for the NDIA to provide a nation wide facility following implementation of the NDIS. Ideally, a service provider database should:

- be easy to find and use, particularly in terms of searches for type and location of service. It should also include both advocacy and relevant mainstream services in it search results
- be comprehensive, up to date and link to an accurate description of the services offered
- indicate excess capacity or anticipated waiting lists for particular suppliers
- reveal prices
- be compliant with best practice in accessibility

- link to standardised measures of performance and quality (developing such measures is not straightforward and is likely to be an ongoing task. This is discussed in section 8.3).

While this would improve the transmission of information about service providers, most people entering the disability system will need personal advice and information at some point in their life. This may be about what services exist, how to put an assessment plan into practice given the local resources, what other programs they may be eligible for (through other government agencies) and what administrative steps are needed to accomplish this. For this reason, a well-resourced and appropriately designed coordination support service will play a key role in lowering the burden on people seeking disability services (box 8.5). To some extent, this already occurs through case managers, though the access and effectiveness of this is uneven. Depending on the jurisdiction, type of disability and how it was acquired, people may be allocated: no case manager despite the need for one (sub 255, attachment 1, p. 24); several case managers when only one is desired (sub. 251, p. 4), or one case manager but with inadequate access (sub. 11, p. 7).

The proposed NDIS offers the opportunity to implement a better resourced and better focused version of case management. Currently, case managers often dedicate significant amounts of time and energy to determining the eligibility of their clients to different programs and securing funding. As this would be completed in the assessment phase of the proposed NDIS, their role would appropriately be redirected to: providing their clients with the information needed to make informed decisions; assist in planning; see those decisions eventuate in the delivery of a disability goods and services; muster any community supports; and to monitor their effect on the client over time. In that sense, the model of a 'local area coordinator', as used in Western Australia, may be the best form of case management. Key aspects of case management under the proposed scheme include:

- *accountability for the welfare of the client*. While many people may be involved in bringing a support plan into fruition (for example a panel may be involved in arriving at and approving a support package), there should be one clearly defined person with ultimate responsibility to ensure that clients are receiving the supports they are eligible for, that support services are of an adequate quality, and to monitor their wellbeing over time
- *clearly demarcated work responsibilities*. In particular, case managers should be able to lay a clear pathway for clients to acquire the support they need. This includes through the NDIS itself, as well as advising clients on supports available through other government agencies (for example State and Territory education departments), who to contact and how to go about securing them. However, generally any administrative requirements would still be undertaken

by the clients themselves, or they would contract these to brokerage services out of their individual budget (DSOs), or seek to buy packages of support from service providers

- *tailored support according to the needs of the client.* The level of involvement by a local case manager should take account of the preferences of the person with disability, his or her capabilities, the complexity of services needed, and the risks (both to the person, any carers and to public monies). It will often need to evolve over time, reflecting changes in people's life circumstances and capabilities. Assistance will often need to be most intensive when people first enter the disability system, and at key transition points in their lives.
- *Some degree of specialisation*, in particular, knowledge about disability services and community resources within a particular geographical area. (The local area coordinator program in Western Australia is a useful example of this.) Beyond this, there are benefits in specialisation, in terms of the life cycle (such as early childhood, transitions out of school and the family home, and retirement); the nature of the disability (intellectual disability, physical disability and mental health); particular community groups with distinctive needs (such as Indigenous people with disability or people from a non-English speaking background). Such specialisation will only be feasible where the potential population of clients is large enough
- *A capacity to interface between clients, allied health professionals and service providers to ensure effective communication*. Local case managers are well placed to assist in the first instance when disputes and misunderstandings arise between clients and service providers
- *The application of knowledge of local government and non-government providers, community resources and family resources to provide flexible and creative ways of meeting clients needs*
- To provide some accountability checks where self-directed funding is involved and where people employ family members and other people not attached to a service provider.

DRAFT RECOMMENDATION 8.1

The NDIA should support consumer decision-making by providing:

- ***a centralised internet database of service providers that indicates the ranges of products and services, price, availability and links to measures of performance and quality***

- ***well resourced and effective provision of advice and information to clients, as well as monitoring of their wellbeing. These services should be graduated in terms of the needs of the client and concentrated at key points, such as when entering the disability system or important transition periods.***

Box 8.5 Calls for a centralised port of information

Each family needs a case manager who can guide people through the maze of options available. We are in shock when we are first confronted with disability. We are not thinking clearly. We need clear appropriate guidance to all possible services we may require. (Sandy Findlay, sub. 193, p. 1)

It is the usual experience of children with disability and families that negotiating the service system is fairly random. If they are fortunate, families may access effective case management or come into contact with someone who has a thorough knowledge of the service system. It is commonplace however that families just stumble upon services … how do you a provide a road map to the jungle? (Children with Disability Australia, sub. 532, p. 9)

We believe that there would be little value providing financial support to people to access care without also providing support coordination. (Care Connect, sub. 407, p. 5)

The RCH supports a scheme design that includes. … A community based case manager to help locate, access and coordinate services. Families generally have no experience in navigating the service system and are in urgent need of support and linkage to appropriate services. (Royal Children's Hospital, sub. 405, p. 2)

The scheme should also recognise that the introduction of choice and control requires an investment in information, resources and advocacy to ensure people with a disability, their families and carers are provided with the tools they need to make informed choices. The scheme should recognise that some individuals will require greater support to plan and exercise choice than others … The scheme should provide a range of choices to individuals – from complete self management to a brokerage system in which individuals would be responsible for planning but not direct purchasing. (National Carers Alliance, sub. 413, p. 7)

… supported decision making should be an integral part of the process of identifying support needs and responses to those support needs … The level of decision making support required will be different for each person with a disability. Providing funding for supports on an individualised basis will enable and support greater choice for people with a disability but in some cases, the person will require support to make informed choices. All people with a disability need portability of funding to enable them to exercise choice about and to change support providers and individual disability support workers. (Scope, sub. 432, p. 19)

Easing the burden of providing information

While assessment will reduce the need for multiple applications to determine eligibility, service providers still need to be provided with details about their clients in order to meet their needs effectively. Similarly, people will still be required to communicate their needs, what they have received and the outcome it has had on them, as well as reveal any changes in their circumstances to multiple different parties. In addition, there will still be instances when paperwork will be required to

match people with appropriate goods or services, for example when replacing a major appliance or seeking supported accommodation.

One way to reduce the costs associated with these activities is through allowing for the electronic submission of all forms and applications. This is already a feature of some schemes[1] and is a low cost of way of reducing the impost associated with paperwork, as well as potentially increasing the speed that it is processed.

However, decreasing the current level of administrative duplication requires a greater capacity to share information between different parties, rather than having to provide it to each individually. Many participants advocated a shared electronic record that government and service providers could access in lieu of continual filling out forms containing similar information (around 40 submissions advocated some version of this, for example, sub. 267, p. 4; sub. 181, p. 1; and sub. 9, p. 2). This would substantially reduce the paperwork involved in securing services offered under the NDIS (such as attendant care, respite, transportation etc). Over time, there is also the potential scope to develop linkages with other government agencies (such as Centrelink) whereby required information relating to someone's disability could also be accessed (with the individual's permission).

In addition to the substantial benefits associated with reducing the administrative burden placed on people with a disability and their families, a shared electronic record and central database would also have a number of other broad long-term benefits, including:

- greater continuity of care. For example, when there are staff changes (such as a new attendant carer) or movement from one service provider to another, an electronic record (with appropriate privacy safeguards is an effective way of communicating essential information about support needs
- portability of entitlements. Barriers to geographical mobility for people with a disability would be greatly reduced if there was an electronic record of each client's assessed need and financial entitlement applicable throughout Australia
- improved communication and collaboration between allied health professionals and service providers, and better coordination of care
- ease of billing. With appropriate IT infrastructure linking service providers to the NDIA, the electronic record could also house information about purchases made by people with a disability and expedite payment to service providers (for example something like HICAPS). It would also be useful record to ensure that

[1] For example, Australian RehabWorks argued that this has been successful in the NSW LTCS scheme, stating that 'unnecessary paperwork and duplication have been reduced by all necessary forms being delivered and submitted electronically …' (sub. 451, p. 4).

the services provided by specialist disability agencies and the prices they charged, were appropriate

- greater understanding of the costs of meeting the needs of people with disability. The ability to interrogate a central database (but still in a way that strictly protects privacy) could provide rich comparative analysis about the costs of different types of disability and the payoff to certain types of interventions (such as early childhood, or home modification rather than attendant care) in terms of future liabilities. It would also greatly improve the ability to anticipate and plan for changes in the overall cost of maintaining a NDIS (chapter 10)
- the ability to evaluate the effectiveness of therapies, treatments and aids and appliances based on systematic statistical data.

Expenditure by people managing their own entitlement under self-directed funding would not be recorded in detail on the record at the point of sale (because that would defeat the purpose of self-directed funding and be practically unfeasible). However, the NDIA would periodically record major purchases made under self-directed funding, using information based on the periodic reports provided by people using such funding.

The benefits of a shared electronic record, and the system required to deliver them, bear a close resemblance to the Personally Controlled Electronic Health Record (PCEHR) in the Australian Government's E-health strategy. The Australian Government committed $466 million to developing PCEHRs in 2010-11. As many of the challenges involved in this task are relevant (to varying extents) to establishing a electronic disability record (see box 8.7), the experience garnered will be invaluable to the NDIS.

This raises the question as to what level of linkage or interaction there should be between the two records. Clearly, the electronic disability record should be designed such that it can easily incorporate information from the PCEHR relevant to care and support (and where consent has also been given by the person with a disability). The electronic disability record could potentially also make use of a common software platform. However, differences in scale, costs, relative benefits and the difficulty involved suggest that there is merit in independently developing and housing the electronic disability record used in the NDIS.

First, the database would be much smaller and more manageable, as its population would include only those eligible for the NDIS (as opposed to all Australians) and the disability industry is much smaller than the health sector. Also, the types of information recorded in the electronic disability record would tend to simpler than the type of technical data required for clinical diagnosis and treatment. This would

include things like: simple personal details; assessed need; services required, received and the prices paid; client outcomes and other additional notes.

Second, the majority of those included in a NDIS would be frequent users of disability services (and therefore frequent beneficiaries of the convenience of having a electronic disability record), suggesting a very of high ratio of overall benefits relative to costs.

Box 8.6 Challenges involved in implementing PCEHRs

Many of the challenges involved in implementing PCEHRs will also affect (to varying extents) attempts to establish a electronic disability record. These include:

- *the difficulty involved in finding solutions to some problems*. Foremost amongst these are privacy and security issues, how to standardise the data that is input into the system and how to uniquely identify providers and people within the system
- *the difficulty involved in coming to an agreement*. There has been substantial growth in the use of IT and E-health technologies across Australia. However the technologies employed have not been coordinated between state health departments or within states (between GPs, specialists and hospitals), resulting in discrete, incompatible information systems.[2] Transitioning from this situation to a unified system requires an agreement as to what the platform should look like — either picking a winner from existing platforms or designing a new one. As the transition from existing systems will be difficult, costly and potentially risky to patients, reaching such an agreement is not straightforward
- *high set-up costs*. In addition to the direct costs, such as hardware, software and training, there are also costs in finding solutions to problems and reaching an agreement about how to transition to a coordinated system. These costs involve consultation, research and pilots.

Third, the organisational restructuring that would accompany the implementation of a NDIS provides a useful opportunity to develop a compatible IT system that is required for electronic disability records. Part of this would be due to the expansion of service provision that would accompany a NDIS, with new entrants receiving consistent advice of software requirements to facilitate access to the record. This is complemented by the relatively low use of E-health type technology in the disability sector, reducing the extent of disruptions caused by changes to IT systems.

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2 One expert in this field estimates that 'there are probably 200 companies that are all trying to sell different electronic health record systems and none of them can communicate effectively with each other. And it's actually so bad that there are companies for whom their product from 2010 is not compatible and can't talk to the product that they sold in 2008' (ABC 2010).

Fourth, the electronic record will assist core functions of the NDIA, such as: facilitating the financial sustainability of the scheme; building evidence of about the effectiveness and cost effectiveness of different services and interventions (chapter 10); helping case managers to monitor the welfare of their clients; and ensuring that appropriate and high quality services are being delivered (section 8.3).

As with, PCEHR, the electronic disability record will require careful and clearly articulated privacy protocols, which should be developed in consultation with the Australian Privacy Commissioner. One important facet of this would be differing levels of access. For example, service providers would only have access to a specified range of information, with active consent from the client. In some cases, a person might not want a provider to have access to the record at all, and in that case, the person would have to provide the required information to service providers in the traditional way. Similarly, protocols will also need to be established for entering data onto the record (privacy issues are discussed further in chapter 10).

DRAFT RECOMMENDATION 8.2

The Australian Government should fund and develop a national system for a shared electronic record of the relevant details of NDIA clients, including assessed need, service entitlements, use and cost of specialist disability services, outcomes and other key data items with privacy safeguards.

Supply side transaction costs

In an ordinary market, consumers and producers directly communicate what they want, what they can offer and how satisfied they are with each other. However, in the disability market this exchange is filtered through government. Government tells consumers what they can have and producers what they should offer, and is then tasked with monitoring the output, consumption and satisfaction of both parties. This requires prescription and subsequent monitoring of prices, quantity and quality, through the intensive use of contracts, regulation, standards, self-reporting and audits. As a result, producers face administration costs associated with:

- reaching an agreement about price and quantity and then securing funding (such as forming contracts and applying for grants)
- demonstrating compliance with regulations, standards, quality assurance frameworks and financial reporting.

Several participants have expressed concern at the cost of overheads, administration fees and management fees associated with the current system (Suzanne Sutton, sub. 19, p. 2; Redland District Special School Parents and Citizens Association,

sub. 463, p. 2). However it not clear whether this is indicative of regulatory burden, poor administrative practices, inefficiencies arising from contractual arrangements like block funding (see section 8.4), or simply an inherent feature arising from the complexity of service delivery in the sector.

A survey of NSW non-government community service organisations (including disability service providers) suggested several concerns with funding arrangements including: short funding cycles, multiple and incompatible reporting requirements for government funding programs and funding body reporting requirements constantly changing (SPRC 2010).

Similarly, Anglicare pointed to inefficiencies arising from inconsistencies in tendering processes, contractual and reporting requirements and acquittals process:

> Each tender is specific and different from every other tender — with different criteria and demands. … every government department, including ADHC has different funding agreement or contract with different accountability requirements. This creates issues in terms of multiple reporting. … the acquittals process is complex and inconsistent among programs. (sub. 270, p. 20)

As the proposed NDIS would reduce the role of government in deciding what would be purchased and how much, the nature of these costs would change, though it is not clear by how much. In some instances, they would probably fall. For example, providers could often avoid the onerous reporting conditions and acquittal procedures associated with grant applications and contracts with multiple funding bodies. Instead, providers would bill the client themselves, or the NDIS, on a per service use basis (as is the common practice under Medicare arrangements). Moreover the Australian Government is currently considering the adoption of standard business reporting for the not-for-profit sector to reduce regulatory burden. This should make reporting of any required financial information to the NDIA easier and less costly.

However, some participants have suggested that consumer choice models (such as self-directed funding) may impose additional costs on providers, and generate additional cash flow management issues (NDS, 2009). That would depend on how the NDIS implemented self-directed funding and on adaptations by existing service providers as the supply model moved away from its current centrally coordinated form. Notably, the costs involved in managing customer accounts are both unexceptional and entirely manageable in other sectors of the economy. As many service providers are unfamiliar with this business model, the costs incurred transitioning to the new model are likely to be significant, though the gradual implementation of the proposed scheme should prevent these costs from being overly disruptive.

Compliance with current regulations and requirements about the quality of services can also represent a large cost to service providers, particularly to smaller ones. On the other hand, such quality assurance measures serve an important role in mitigating the risk of harm to consumers. The following section explores this issue in more detail.

8.3 Safeguarding quality

There are strong grounds for government to play a role in promoting safe and high quality disability support services, due to the vulnerability that many people with a disability experience. This vulnerability increases the risk of harm (under current arrangements and under the proposed NDIS), and arises in a number of ways:

- important decisions are often made in times of intense stress and it can be difficult to get good information
- there can be a power imbalance between providers and people with a disability, due to their reliance on uninterrupted provision of care and support
- people with an intellectual disability may have a diminished capacity to make informed rational decisions that serve their best interest and may have a limited ability or confidence to express any inadequacy in the services they are receiving
- support is often delivered in private settings, such as people's homes or group homes, where inadequacies are less likely to be detected by others
- bad experiences with service providers or within society more generally may have an adverse impact on the confidence of people with a disability to demand high quality services or complain when their expectations are not met.

This increases the risks that people with a disability could be subject to unscrupulous or criminal behaviour (such as disrespectful or dishonest treatment, or physical, sexual or psychological abuse) or poor service practices (which, among other things, can result in neglect and deprivation, such as inadequate meals, bathing, cleaning, unfulfilling activities and ignoring the wishes of the client themselves). There are two basic strategies to address this:

- the government could set rules that service providers must obey, such as through legislation, standards or funding agreements. Government would then be tasked with monitoring compliance with these rules, and addressing breaches through alerting providers and offering advice to how to achieve compliance, or if that fails, through punitive measures such as the removal of that specialist provider from the approved list (tantamount to withdrawing their funding)

- the NDIA and DSOs could help people to make informed choices and purchases by providing information, advice and support. This effectively empowers people with a disability themselves to both discipline *and reward* service providers through their consumption decisions. In turn, this facilitates greater responsiveness to consumers amongst service providers and competition to deliver better quality.

A good quality assurance framework should provide a combination of these. However, shortages and lack of consumer choice means that much of the disability sector currently relies almost totally on the first strategy. The following section provides a brief overview of the current approaches to regulation in the disability sector.

Current approaches to quality assurance

Ensuring that suppliers consistently deliver an acceptable standard of quality is relatively straightforward for physical goods, such as aids and appliances. These goods will often be subject to broad industry standards (such as for electrical goods). In addition, products deemed to be 'therapeutic goods'[3] are subject to the quality, safety and performance requirements of the *Therapeutic Goods Act*. Before a therapeutic good can be sold in Australia, it must be assessed against these standards by the Therapeutic Goods Administration and entered into the Australian Register of Therapeutic Goods. This appears to be a reasonably effective regulatory regime, although some participants have called for more vigorous enforcement of TGA requirements (sub. 477, p. 13; sub. 348, p. 3; sub. 265, p. 2).

It is considerably more difficult to observe and enforce quality standards in the provision of disability services, due to their intangible and highly varied and personalised nature.

Service providers are subject to various (Commonwealth, state and territory) regulatory and statutory provisions in areas such as home and community care, occupational health and safety and building codes. However, state and territory governments mainly regulate service delivery through their respective disability laws (with the exception of disability employment services, which are subject to the Commonwealth *Disability Services Act 1986*). The scope of legislation varies widely, with some Acts as short as seven pages (South Australia) and others over

[3] Goods that are intended to prevent, diagnose, cure or alleviate a disease, ailment, defect or injury and that influence, inhibit or modify a physiological process. (http://www.tga.gov.au/docs/html/tga/tgaginfo.htm).

200 (Victoria). Most include requirements for dealing with complaints. Some have more detailed prescriptions relating to the provision of services, such as:

- requirements for criminal history screening (Queensland)
- enactment of certain monitoring bodies (such as community visitors and the office of the senior practitioner in Victoria)
- specific laws relating to service provision (such as the provisions for residential disability services in Victoria).

Most importantly, legislation confers power on the relevant disability authority (a government department in all cases except for Western Australia, where it is a Commission), to implement a quality assurance framework for the disability services industry. Some Acts stipulate this explicitly (Victoria and Queensland). In other jurisdictions, it is implicitly enabled through the power granted to state and territory bodies to fund and regulate service provision, subject to the principles and objectives of the relevant Act.

There is a basic level of consistency in the approach to quality assurance, which is driven by the common origin of the underlying service standards. The first Commonwealth State Disability Agreement outlined eight minimum National Disability Service Standards (box 8.8) aimed at guiding service delivery practices and ensuring a basic level of quality was maintained amongst service providers. (developed in 1992 and implemented in 1993). The National Quality Framework Working Group is currently updating the National Disability Service Standards (NDSS) in order to better reflect contemporary organisational practices, modernise the language and concepts, emphasise outcomes for service users and address gaps identified by the states and territories.

The NDSS forms the basic guide to the standards that are actually implemented at a state and territory level. While some states (such as the Australian Capital Territory and Western Australia) have implemented standards closely resembling the NDSS, others have interpreted, elaborated on and supplemented the NDSS in various ways over time. In either case, the standards essentially articulate the objectives of service delivery, while the associated supporting standards (sometimes referred to as performance indictors) tend to reference systems or processes that aspire to certain consumer outcomes or accord with principles of good management and social justice. For example, self-assessment forms commonly direct service providers to demonstrate evidence that their business practices and policies meet objectives such as: tailoring services to individual needs and aspirations; maximising their clients' participation in decision-making processes; and encouraging staff, clients and stakeholders to provide feedback, including complaints.

Box 8.7 National Disability Service Standards

The National Disability Service Standards listed below are each accompanied by detailed supported standards. For example, supporting standards for service access include that agencies have developed written entry and exit policies, that these are accessible by potential and current consumers and are implemented in practice (supporting standards 1.1, 1.2 and 1.3 respectively).

Standard 1 Service access

- Each consumer seeking a service has access to a service on the basis of relative need and available resources.

Standard 2 Individual needs

- Each person with a disability receives a service which is designed to meet, in the least restrictive way, his or her individual needs and personal goals.

Standard 3 Decision making and choice

- Each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives.

Standard 4 Privacy, dignity and confidentiality

- Each consumer's right to privacy, dignity and confidentiality in all aspects of his or her life is recognised and respected.

Standard 5 Participation and integration

- Each person with a disability is supported and encouraged to participate and be involved in the life of the community.

Standard 6 Valued status

- Each person with a disability has the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community.

Standard 7 Complaints and disputes

- Each consumer is free to raise and have resolved, any complaints or disputes he or she may have regarding the agency or the service.

Standard 8 Service management

- Each agency adopts sound management practices which maximise outcomes for consumers.

Compliance regimes typically involve a combination of self-assessment by the providers and external audit. In large part, self-assessment is geared towards compliance with service standards (as articulated by the state or territory

government department). However, some jurisdictions also incorporate other elements, such as compliance with broader legislative obligations (such as in NSW) and plans for continuous improvement (such as in Queensland). There are large variations in the comprehensiveness of self-assessment processes, ranging from around 20 pages (Western Australia) to around 260 pages (Victoria). Self-assessment is required on an annual basis in a number of states (Victoria, Queensland, Western Australia) and every three years in New South Wales[4] and South Australia. This is accompanied by external auditing, which occurs every year in Queensland, every two years in Victoria and every three in New South Wales, Western Australia and South Australia. With the exception of New South Wales, auditing is conducted independently from the disability authority.

Lessons for an NDIS

Current approaches to quality assurance partly reflect the system in which it is embedded, whereby there are few alternatives to government taking a lead role in promoting service quality. This is due to:

- a traditional agency-based model of service provision, in which government and service providers are typically the contracting parties and principal choice makers. Thus, for a large portion of the disability services sector, competition in service quality is primarily expressed through meeting government requirements (self-assessment, auditing, competitive tendering) rather than through directly attracting clients
- the limited capacity for people with disability to discipline poor performing suppliers by taking their business elsewhere. This is partly a function of underfunding, but is also due to poor publicly disclosed information about the quality of alternative service providers
- paternalistic assumptions about the capacity for people with disability or their proxies to limit risks themselves and to gauge quality. Many people would have that capacity if given the right information, and while people with severe intellectual disability or profound mental health problems may be unable to make fully informed judgments, that will often not be true for people acting on their behalf.

The NDIS will give people with disability the capacity to make most choices themselves (through the various tiers of consumer choice described in chapter 6), and with an additional level of funding and support that will make choice a realistic option. This provides a powerful driver of quality *in addition to* regulatory

4 Service providers are also required to provide a short annual compliance return in NSW.

measures. Consumers have a strong personal interest in the quality of goods and services they receive, can observe actual quality first hand (rather than through an audit, for example) and are able to change providers if they are dissatisfied. This directly links service provider's viability with their capacity to satisfy consumers' needs, rather than their ability to fulfil the administrative requirements issued by their funding body. In conjunction with measures to promote robust competition and targeted consumer protection mechanisms, this represents a powerful incentive to deliver high value and high quality goods and services.

However, realising the gains from such competition will neither be automatic, nor immediate. While many participants in this inquiry are clearly well-equipped to make good informed decisions about the support services they wish to use, to demand high quality services and to complain or switch providers when their expectations are not met (if given the opportunity to do so), this will not be the case for all. As discussed above, the vulnerability of many people with a disability increases the risks of harm or poor outcomes, even when consumer choice is greatly enhanced under the NDIS.

As such, both service providers and consumers will require assistance in ensuring that a more market-based system can deliver good outcomes. Many people with a disability have had little choice available to them in the past and will require support in adjusting to the new scheme. As such, a public education campaign should accompany the introduction of the scheme, including how to seek help, people's rights as consumers and how to make complaints. Direct assistance will also be provided to people with a disability through better advice and support from case managers. This will help consumers make good informed choices, as well as better understanding their rights and how to exercise them, as well as the standard of support they should expect from service providers. NDIS clients will also be allowed to use their entitlement to purchase additional support from DSOs if they wish (see chapter 7) to assist with administrative requirements and as service brokers. The national online database of service providers will be a valuable source of information to clients of the NDIS, and to the case managers and the DSOs assisting them.

Exercising choice will also sometimes mean switching providers when clients are not satisfied with them. This can be difficult for people with a disability and can represent a major disruption to their life if the transition is not handled smoothly. Case managers and DSOs will be an important source of support at such times.

It will take time for a competitive and responsive market for disability support services to emerge. On the supply side, the NDIA should provide assistance to service providers as they transition from a block-funded system to market based

arrangements. For example, this may include assistance establishing payment systems that interface easily with NDIA, advice on governance structures or expectations about standards and how to best meet them, and industry best practice in service delivery. The NDIA should also contribute to innovation in service quality in the disability sector through an innovation fund that service providers could access on a competitive basis (this is discussed further in section 8.4).

In addition to empowering consumers through support and information, it will also be vital to make sure there are adequate protections in place to minimise the risks of things going wrong. This will be an ongoing task, but will be particularly important in their early stages of the scheme as the market grows and changes in structure. As such, quality assurance within the NDIS should include a rigorous provider approval processes, certification against standards, specific regulation in high-risk areas such as restrictive practices, and an ongoing and *effective* monitoring regime.

Approving specialist providers

As a pre-requisite to applying for funding, service providers are currently required to seek approval from the government agency overseeing disability services in their state or territory. This is aimed at ensuring that services providers eligible for funding are legitimate enterprises and have the basic corporate and functional capacity to deliver disability services. In concert with state and territory government agencies, and drawing from their experience with this process, the NDIA should develop its own approval process.

This should include ensuring that service providers:

- have appropriate corporate governance structures
- have appropriately experienced management and qualified staff
- have the essential financial capability
- are fully aware of service standards and how to meet them. Where appropriate policies and plans should meet specific standards (for example in relation to privacy and confidentiality, and complaints and disputes)
- are fully aware of any other legislative requirement specific to the type of services they are delivering (such as OH&S and building codes)
- understand their duty of care and have developed appropriate risk management strategies.

This should be streamlined for existing service providers approved within the jurisdiction they operate. Where the existing approval process includes all of the

above elements, such providers should be automatically approved**.** The approval process should also be shorter for specific types of applicants — for example, people who are looking after family members, or are freelance attendant carers. It will be important for the NDIA to conduct basic background checks of such applicants. However, many of the requirements that a large organisation will be subject to, would not be relevant to individuals (for example having an induction policy for the executive officers of the governing body of the organisation), and would pose compliance costs that would frustrate much needed flexibility (chapter 6).

In the early stages of the scheme, significant resources may be required to ensure that approval processes are efficient and effective in order to reduce the risks of bottlenecks or premature approval of service providers.

The role of standards

Well designed standards can provide practical guidance about good management, accountability and customer service, which may be especially useful to smaller operators. Also with an effective monitoring and enforcement regime, standards improve service providers' incentives to provide high quality supports. If standards are known and clear to consumers they can provide a reasonable service expectation for consumers and empower them to complain when this is not met. In short, standards should continue to play a role in promoting the quality of service provision under and NDIS.

Objective observation of whether a service standard is being met or not is a key difficulty in developing effective disability support standards. This is further complicated by the variety and personalised nature of the sector. The trade-off between generality and clarity is most pronounced for standards that are aspirational in nature (for example participation in the life of the community). Conversely, standards that reflect basic provisions that all providers should be able to deliver as a threshold to entry into the sector are more conducive to broad application and objective observation (such as the safety and fundamental wellbeing of clients, rights to privacy, dignity and confidentiality, sound management practices, effective complaint and dispute resolution policies, appropriately screening, and training and monitoring staff).

As funding moves towards a national basis, a single set of national standards and an associated accreditation process should be developed to provide greater national consistency in service quality and to facilitate equivalent treatment of service providers across jurisdictions. These standards should be complete rather than augmented on a state-by-state basis — essentially replacing state and territory

equivalents for the purposes of the NDIS. A period of mutual recognition of state and national accreditation would be required to minimise the transitional impact on service providers.

These standards could be developed by National Quality Framework Working Group. Alternatively, the NDIA could request Standards Australia to design the national standards. In either case, development of standards should consult with service providers, advocacy groups and consumers, as well as drawing upon the jurisdictional experience from evaluating the effectiveness of existing regimes. As noted by the Disability Service Standards Working Party (which developed the original national standards) standards should be understandable, agreed upon, state-of-the-art, achievable, practical, relevant, outcome orientated, measurable, and cost-effective (1992). Above all, they should be as simple and short as possible so that:

- industry actually uses them and to reduce compliance burdens, noting that compliance burdens for industry entail fewer services to people with disability. For that reason, it will be important for the broad industry impact of any standards to be factored into their construction and ongoing evaluation. While standards should evolve with changing industry practices and philosophical shifts, this should not mean the accumulation (rather than consolidation) of standards. That would result in an ever increasing burden on service providers in demonstrating their compliance.
- consumers can realistically interpret what compliance with a standard would actually mean for service quality
- the NDIA can cost effectively assess compliance. Overly complex standards potentially undermine the capacity for effective oversight, and therefore the main objectives of the quality assurance system in first place.

There is merit in further exploring the potential to 'sub divide' disability standards to better recognise the diversity of disability service products. For example, advocacy services in Queensland are subject to a specific set of service standards designed to reflect to the nature and objectives of advocacy work.

Restrictive practices

For people with severe intellectual disabilities who exhibit challenging behaviours (such as harming themselves or others), at times it will be in their best interest (and the interest of their carer and others around them) for restrictive practices to be used. These practices include: containment (preventing free exit from a service provider premises) seclusion (solitary physical confinement), chemical restraint (involving the prescription of a pharmaceutical for reasons other than a medical

condition) mechanical restraint (any device that restricts movement) and physical restraint. While these practices may be unavoidable in certain circumstances, the recognition that, by definition, they impinge upon basic human freedoms, implies a strong need for clear guidelines and regular scrutiny and reporting.

As such, the NDIS should be accompanied by clear legal obligations on service providers regarding restrictive practices. Specific ongoing monitoring measures will also be necessary to ensure compliance (discussed below). In doing so, the knowledge and experience of state and territory government agencies should be drawn upon, with particular attention to the approach taken in Victoria. Similarly, drawing on the Victorian model, regulation of restrictive practices should include:

- a special office within the NDIA, which should be charged with oversight of the use of restrictive practices
- a requirement that service providers apply to NDIA for approval to use restrictive practices
- that restrictive practices cannot be used unless a specific criteria is met
- that the type of restrictive practices to be used are specified and are themselves part of a broader behaviour management plan (except in an emergency). This plan should be submitted to NDIA for review
- that the use of the restrictive practice be explained to person with a disability and their guardian. Both should have a right to seek a review of the decision to include restrictive practices in a behavioural plan.

In devising regulatory guidelines for the use of restrictive practices, care also needs to be taken to avoid putting services providers in conflict with their duty of care to their own staff and occupational health and safety legislation.

Effective oversight, monitoring and use of information about service quality

Under the proposed scheme, both of the primary drivers of quality in the disability sector (regulatory oversight and market forces) are dependent on the quality of information available to consumers, services providers and the NDIA.

As welfare of people with disabilities is the primary motivation for industry oversight, consumer outcomes represent the most direct form of observing service quality, and should be a key feature of an NDIS quality assurance framework. Indeed, the trend towards greater emphasis on outcomes for people is increasingly a prominent feature of state and territory frameworks.

Beyond this, oversight of service delivery should reflect the primary (and inter-related) regulatory objectives of protecting people from significant harm, helping people make good decisions and harnessing competitive market forces to promote quality service products. As such, monitoring effort should reflect the needs of the users of the information gathered and should pay particular attention:

- on areas where the risk of harm is highest
- where the value of the information to service providers and the NDIA is highest in terms of
  - identifying and remedying acute problems
  - identifying and remedying systemic problems
  - evaluating the effectiveness of certain types of services or rehabilitation techniques
- where monitoring provides a reliable signal to consumers and improves their ability to make informed decisions, as well as gives providers a strong incentive to compete in terms of service quality.

The extent to which these areas can be targeted effectively depends on the appropriateness of the monitoring system in place. The following sections examine this.

The role of self-assessment and auditing

Self-assessment requirements and periodic audits are currently a key monitoring strategy. While in some contexts this is a very attractive approach (such as self-assessment of taxable income), it also has several drawbacks that suggest it should not be the only strategy employed.

First, obtaining accurate and credible information about quality from service providers themselves is reliant on the capacity for effective verification. However, verifying self-assessments would often require direct observation of service delivery and frank interviews with service users. This means that the auditing process would tend to be expensive in order to be effective, particularly if standards are complex.

Second, the time used by providers and senior staff to complete self-assessment forms, gather the necessary supporting evidence and participate in any audit could be a source of significant cost burden.

Third, in practice, self-assessment and auditing tends to focus on the existence (or non-existence) of documented policies and procedures, which are a poor proxy for quality of service. Compliant providers may actually deliver lower quality services

(for example, nicely completed forms, but unempathetic staff), and non-compliant ones may be more responsive and effective at meeting people's actual needs.

Fourth, burdensome self-assessment and auditing regimes may have anti-competitive effects, since they typically involve fixed costs that loom large for smaller providers offering niche service products. This undermines consumer choice and reduces the competitive pressure on providers to deliver high value and quality service products.

For these reasons, once initial certification has been achieved, self assessment requirements should be concise and aimed at informing providers of their obligations (in terms of standards and other laws and regulation) and the explicit policy or procedures they must have in place to meet them.

Auditing should remain a feature of the NDIS, and this form of monitoring would be particularly important in the early stages of the scheme as the market matures. However, as a competitive market emerges, frequent and intensive auditing will become a less cost-effective way to support service quality. Thus, over time, the NDIA should move towards a graduated auditing regime with a random component that takes account of:

- the historical levels of compliance
- new information indicating a serious problem (such as a complaint or report of a serious incident)
- the risk profile of the consumer group or service type
- the size and scope of the operation.

Other monitoring instruments

In addition to self-assessment and auditing, there are numerous others sources of evidence that can be used to observe whether standards are being met, as well as providing other useful information about service quality to the NDIA, consumers and service providers themselves. These monitoring instruments currently have varied levels of implementation and effectiveness among jurisdictions and include:

- *Complaints mechanisms.* Simply by buying services, consumers of disability services (and their families) can often monitor the quality of providers. However, where standards fall below an acceptable level, making a complaint can be difficult, particularly under current arrangements where consumers are disempowered by scarcity, lack of choice and lack of support. Establishing an effective complaints mechanism would be an important feature of the quality assurance under the NDIS. This should be easily accessible and multi-tiered,

with a formal process for reporting back to people on the outcome of complaints. Under the disability service standards, providers would continue to be required to demonstrate effective complaints policies and procedures. In addition, clients of NDIS could also make their complaints through their case managers, or directly to the NDIA itself (chapter 7).

- *Consumer surveys*. These are used periodically in a number of states to gauge satisfaction with service delivery (Victoria, Queensland, Western Australia and South Australia). These surveys are designed to deliver 'big picture' levels of satisfaction to different service types, rather than provide direct feedback on the quality of the service delivery of specific providers. Nevertheless, with appropriate sampling, careful targeting of questions, and surveying methods that protect the privacy of respondents, surveys such as these represent a cost effective way of obtaining information about the quality of service provision from those receiving it.[5])
- *Community Visitors Schemes.* These operate in New South Wales (under the NSW Ombudsman) and Victoria (a volunteer based scheme under the Office of the Public Advocate).[6] The community visitors have specific legal powers to make unannounced visits to accommodation facilities, talk privately with residents or employees, inspect operational documents and report on the adequacy of services provided. In addition community visitors support the quality provision of service in a number of other ways:
  - they can draw issues to the attention of service providers
  - when serious issues are detected, they can instigate further investigation by the NSW Ombudsman, the Office of the People's Advocate or police
  - in Victoria, the publication of the annual report provides information to consumers about ongoing issues with certain providers and to government about broader industry challenges and trends in service delivery.
- Community visitors are a well targeted way of monitoring groups with particular vulnerability who receive care and support in situations where poor practices our outcomes are more likely to go undetected. The capacity for random inspection strengthens industry wide incentives to comply with service standards as well as other laws and regulation. As such, these schemes should be extended on a national basis under the NDIS. In doing so, the NDIA could fund state agencies with community visitor schemes or public advocates to take on this work (and

5 For example Western Australia has already indicated the potential for these surveys to be used within their Quality Management Framework, Disability Services Commission 2008.

6 The Commission for Children and Young People and Child Guardian in Queensland also runs a community visitor scheme for facilities with children (including specialist disability services).

assist establishing new ones where necessary). Alternatively, it could establish a national scheme with community visitor rights incorporated into funding agreements between service providers and the NDIA.

- *Bodies that monitor the use of restrictive interventions.* For example, in Victoria, behavioural support plans that include the use of restrictive interventions must be submitted to the Office of the Senior Practitioner, who assesses their compliance with the relevant provisions under the *Disability Act 2006*. Moreover, the Office has the power to visit any premise where disability services are being provided. A similar, nation wide monitoring body, operating from within the NDIA, should be developed under the NDIS. There should also be mandatory reporting to this body concerning the use of restrictive practices and serious incidents.
- *Local case managers*. As described above, these play a key role in periodically assessing the welfare of their clients (section 8.2). This role will be particularly important for those who choose to pay family members or partners to provide the majority of their attendant care (if this capacity is adopted following the trial proposed in chapter 6), where there would otherwise be little external oversight of their ongoing health and wellbeing.
- *Reporting through the medical system*. Contacts with general practitioners, hospitals and allied health professionals are also a valuable source of information about the health and well-being of people with disabilities.

The Commission seeks further feedback on the effectiveness of these monitoring instruments and any others that could potentially be used to assist oversight of the disability sector.

What should the NDIA do when problems are detected?

The NDIA would have a range of potential responses to complaints or other evidence that there may be a problem with a service provider (that cannot be resolved by the client and service provider themselves, or through mediation with case managers). Initially it would investigate the issue through discussion with clients, their case manager and the service provider, as well as through visiting their facility. If this process revealed non-compliance with service standards, the service provider would be given a time frame to improve their operations, and if necessary, advice on how to do so. Such service providers would be subjected to greater oversight (including more frequent auditing against service standards) for a period afterwards.

Incidents of non-compliance would also affect their 'star rating' (see later), and other information about them made available to consumers.

For serious or repeated breaches of service standards, the NDIA could impose sanctions (such as fines) on service providers, or remove them as a registered provider, which would mean that people would no longer be able to use public funds to purchase disability supports from them.

Evidence of criminal wrongdoing, or breaches of other legislation, should be recorded by the NDIA and passed on to the relevant authority.

Developing indicators that are both used and useful

Quality indicators can be qualitative or quantitative (or both – for example, the number of complaints against a service provider is a quantitative indicator, while the complaints themselves are qualitative). Qualitative indicators can give richer, nuanced and qualified information about quality, but are harder to aggregate, standardise and use comparatively. On the other hand, quantitative indicators are easier to aggregate, standardise, simpler to use for comparative and analytical purposes, but have a greater risk of being misleading, misinterpreted and inappropriately emphasising features on the basis of their measurability rather then their actual value. As such, no single measure can definitively describe service quality. Rather, a balanced impression of service quality has to take account of the limitations, purposes and context of the various indicators and sources of evidence.

Broadly speaking, indicators serve two basic functions. First, they can be used to detect serious problems ('red flag' indicators), such as a failure to comply with the laws relating to service provision in the disability sector, broader laws and regulations, as well as serious breaches of services standards. Red flag indicators could potentially come from a variety of different sources including health professionals (such as inappropriate presentations to hospitals), service provider reports from community visitors or senior practitioners (for example indicating use of restrictive practices at odds with stated support plans), or through complaints mechanisms. This information is of primary importance to the NDIA. As noted above, evidence of serious non-compliance could involve fines or de-registration.

Red flag indicators are also useful to consumers and producers. For example, consumers may want to know if a large number of complaints have been made against a service provider, or the outcome of the last service audit. For service providers, red flag indicators ensure that those who are compliant with standards and regulation are not disadvantaged relative to those that 'cut corners'. (That is,

good providers are advantaged when those who 'cut corners' are identified and penalised.)

Second, quality indicators can be used to convey some kind of ordinal information about the quality of service provision (differentiators). This enhances decision-making and allows consumers to trade quality against price (and therefore quantity). When changing providers is costly or disruptive, credible indicators of quality will empower consumers to leave lower quality providers.

Information could be sourced from consumer surveys (for example general satisfaction with a provider, indicator about punctuality, reliability, continuity of staff and respite), through publicly available reports on service providers (such as community visitor annual reports, outcomes of intensive audits by NDIA) or from the providers themselves (such as easily verifiable input measures like staff qualifications or staff-to-client ratios, and the percentage of clients who had achieved agreed outcomes within a certain period of time with the service provider).

Quality indicators are also useful to service providers and the NDIA. For service providers, these measures recognise and allow them to capitalise on investments made into improving service quality. For the NDIA, the measures can be summarised in industry trends that give insight into its own performance. The NDIA would also have a particular interest in indicators that can demonstrate the relative efficacy of one type of service or treatment relative to another. Long-term costs are one obvious (and straight forward) indicator of interest, but so are others, such as health, mobility, employment and life satisfaction, which could be gathered through regular sources (for example through the type of data that is routinely gathered through interaction with the health system or through general consumer surveys) or through indicators specifically designed to measure the success or failure of a particular trial.

The usefulness of these data ultimately depends on the ease of access by users. The most appropriate central access point for consumers would be the national internet database of service providers described in section 8.2. This database could contain information about simple quantitative indicators, could link to more detailed qualitative indicators and, over time a summarising indicator (for example a 'star rating' as used in the Job Network) could be developed by some combination of these, as well as from the personal level data contained in the electronic disability record. Case managers, and potentially DSOs, would be available to assist consumers in interpreting these measures.

In many cases, the NDIA would receive red flag indicators directly from those who gather them (people with disability themselves or their guardian, case managers and

health professionals). However, there is also scope for the NDIA to use the rich personal information contained with the electronic disability record to forensically mine the data to detect problems. This could be proactive or even automated according to rules or triggers. Alternatively, interrogation of the electronic disability record could be used to investigate whether a specific complaint is indicative of more widespread problems with a particular service provider and if intensive auditing is warranted.

The NDIA should develop the indicators in consultation with consumers, service providers and relevant experts. The NDIA should also monitor the indicators for their usefulness, and any unintended impacts they may have. Table 8.1 describes several indicators that may be useful as a starting point.

DRAFT RECOMMENDATION 8.3

The NDIA should develop and implement a quality framework for disability providers, which would include:

- ***the development of complete, nationally consistent standards that would apply to all funded specialist service providers and disability support organisations. The NDIA should monitor compliance with these standards and other regulations through a range of instruments, including graduated and rolling audits of service providers, community visitors, senior practitioners, independent consumer surveys, complaints, surveillance by case managers and interrogation of the electronic disability record***
- ***arrangements that encourage the diffusion of best practice throughout the disability sector***
- ***providing consumers with information about the quality and performance of service providers on the national internet database of service providers***
- ***establishing an innovation fund that providers would use for developing and/or trialling novel approaches to disability services.***

Table 8.1 Potential indicators and sources of evidence about service provider quality

Indicator	*Source*	*Type*	*Purpose*	*User notes*
• annual reports • specific service provider report • service provider audit	community visitors, Office for the senior practitioner and the NDIA	qualitative	quality differentiator	made available on centralised data base for use by consumers
			red flag	used by NDIA to identify instances of breaches of regulations or standard
mandatory reporting requirement about: • use of restraints • adherence to behaviour plans • serious incidents	Office for the senior practitioner	qualitative and quantitative	red flag	used by NDIA to identify instances of breaches of regulations or standard
range of medical outcomes: • inappropriate presentation to hospital • infection rates (urinary, bedsores, respiratory etc) • other evidence of harm	health professionals	qualitative and quantitative	red flag and quality differentiator	entered into clients electronic disability record and used by NDIA
satisfaction, with services, health and life as well as other indicators such as: • how often is your service provider late, unable to assist at a certain time etc. • indicators of continuity of service providers staff and access to respite	consumer survey	quantitative	quality differentiator	made available on centralised service provider data base for use by consumers; potentially used by NDIA to evaluate efficacy of different types of services
serious incidences	police, health specialist, teachers, case managers	qualitative	red flag	used by NDIA to identify instances of breaches of regulations or standard
complaints	consumers, case managers	qualitative	red flag	used by NDIA to identify instances of breaches of regulations or standard
staff-to-client ratios staff qualifications	service providers	quantitative	quality differentiator	made available on centralised database for use by consumers; potentially used by NDIA to evaluate efficacy of different types of training, or ways of delivering services

8.4 The implications of consumer choice for block funding, government-run services and rural areas

The dominant direction of change would be much greater choice by people with disability, underpinned by the market-based delivery of disability services. However, are there residual areas where the traditional service models could still be relevant? For example, some have argued that block funding itself redresses certain market failures and should continue to be a part of the NDIS. There is also the question of whether government run services should continue to play a role in the scheme. Finally, there is the issue about the current and anticipated difficulties of delivering services to rural areas. These questions are discussed in the following sections.

Block funding

The move towards a consumer choice model (self directed funding and choice of package) in the proposed NDIS represents a shift in the way service providers are funded. While jurisdictions have already implemented consumer choice to varying extents, service delivery continues to be underpinned, in large part, by some form of block funding. Block funding essentially refers to any agreement whereby a funding agency (rather than a service user) purchases a 'block' of services from an organisation or firm to be delivered to clients who meet a certain criteria, or are referred to the provider as part of an 'individualised plan'.

In practice, this can cover a range of different types of arrangements, from grants and short-term contracts to longer term undertakings. In general, block funding has become more contestable and transparent, with more explicit contractual obligations and greater reporting requirements. For example, providers may be required to competitively tender for the delivery of a particular service. If successful, governments contract them to deliver a certain volume of services (number of clients or client hours) over a given period, with their interim funding being dependant on satisfying a quality assurance framework and meeting reporting requirements to the funding body.[7]

Notwithstanding the measures to promote quality and efficiency of services, as well as the efforts of some service providers to develop more 'personalised approaches' (National Disability Services, sub. 454, p. 16), the block funding model has considerable disadvantages compared to self directed funding or other ways of giving people choice. In particular, it is very difficult to reconcile with the core

[7] In theory, re-tendering could occur at the end of the contract period, though in practice it is often extended as a matter of course (so long as funding is still available).

principle of maximising peoples' control over their own lives. This is because block funding is the outcome of a negotiation that excludes consumers. As stated by Advocacy Tasmania Inc:

> It is a mechanism whereby funding agencies make an assessment of aggregate consumer needs, make a determination of the service models they (the funding agencies) believe are most appropriate to meet those needs, and choose the service providers they believe are best placed to deliver the identified services. That is, three kinds of decisions (about need, about service model, and about service provider) have been taken on behalf of the consumer, not by the consumer. (sub. 483, p. 13)

Thus, despite the efforts and goodwill of both service providers and funding agencies, by its nature block funding shifts decision-making away from service users and in doing so, limits their choices and opportunities. This undermines the value that people derive from choice in itself and is antithetical to widely held social norms, such as the freedom, equality, rights and dignity of people with a disability (chapter 6). From an economic point view, it:

- impedes consumers from obtaining the bundle of services most appropriate to them
- dilutes consumer signals as to the relative value they place on different services, reducing the capacity for efficient allocation of scarce resources
- diminishes competition between providers by failing to appropriately reward providers those who deliver good value, high quality, responsive services (or punishing those who don't).

As block funding implies that provider viability is critically determined by their relationship with the funding agency (rather than with their customer), it also risks a number of other adverse effects:

- Highly prescriptive contractual arrangement reduces service provider autonomy and can effectively make them a 'branch of government'. This reduces their flexibility, responsiveness to clients and capacity for innovation and experimentation.
- Historical funding relationships can dominate decision-making, making reallocation of public resources difficult (PC 2010a).
- Block funding reduces the financial penalty of under-delivery of services (Scope, sub. 432, p. 22).
- The competitive tendering process that underlies block funding can bias resource allocation towards low cost (rather than high value) service provision (Local Government Association of South Australia, sub. 519, p. 6).

Box 8.8 **Participants' views on block funding**

Block funding has shielded operators and has not punished underprovision. (Scope, sub. 432, pp. 22–23)

Block funding for shared supported accommodation — funding tied to the service provider rather than the individual reinforces a 'group approach' to service provision rather than a system that services the needs of the individual. (Office for the Public Advocate Victoria sub. 255, attachment 1, p. 19)

Block funding with one organization holding funding and power as landlord and service provider with no individualized package is not in keeping with disability legislation, inhibits choice and is not acceptable to us. (Mary Nolan, sub. 545, p. 11)

Through laziness and partly through confusion, some governments and providers in Australia have tended to collude in short-circuiting this intended process (individualised services), with funders making block grants to providers for a certain number of 'places' or 'clients', and tagging these funds for use by individual 'clients', subject to a consultation exercise with the relevant clients. This process can not be regarded as a genuine process of self-direction or self-determination in disability support. (National Federation of Parents, Families and Carers, sub. 28, p. 4)

The provision of block-funding to service providers, rather than personalised budgets to consumers, has reduced the choices available to consumers, denying them fundamentally important forms of control over their own lives. We assert that this is a form of de facto substitute decision-making, applied in contexts where independent decision-making and forms of supported decision-making are both possible and desirable. (Advocacy Tasmania Inc, sub. 483, p. 9)

This simple market based mechanism would allow users to 'shop around' to find a service provider that best meets their needs and aspirations, and would be likely to have a much greater influence on service quality than any 'feedback' form or 'quality' audit. The increasing granting of block support funding by DoCs to service providers rather than directly to the person with a disability is antithetical to this and fosters the need for such complex and ineffectual reporting systems. Furthermore, it underestimates and stereotypes all people with disabilities as unable to control their own lives or affairs. (Ben Lawson, sub. 103, p. 5)

However, participants have pointed to a number of areas where block funding or government provision of services, may deliver better outcomes for consumers than market-based, or is required to overcome specific sources of market failure.

Does block funding allow timely responses to crises?

Inevitably, some people with disability experience unforeseen crises, such as medical complications or changes to life circumstance, such as a death of a partner, loss of accommodation or the sudden breakdown of an essential aid or appliance (National Disability and Carer Alliance, sub. 413, p. 7; Northcott Disability Services, sub. 376, p. 14; Melissa Ryan, sub. 251, p. 3). While additional support usually could be obtained with the assistance of case managers and through reassessment (if necessary), self directed funding may often be inadequate in

meeting acute and immediate need. Even if interim provisions could be put in place that allowed people to draw upon an anticipated *future* entitlement, existing providers may be limited by capacity constraints, or may not be equipped to offer the specific type of crisis support required. The maintenance of block funding to specialty disability providers offering crisis care (or for crisis care as service type in its own right) is one way of addressing this.

Does block funding provide certainty to service providers?

Some participants have expressed concern that the wholesale replacement of block funding with direct consumer choice and payment of suppliers would generate high levels of revenue uncertainty and would result in unmanageable volatility in demand. They argue that this could undermine the viability of suppliers and the loss of services valued by consumers:

> … a shift to the funding of the individual would make financial planning and future strategic planning vastly more difficult due to the lack of certainty of incoming funding. Many service providers within disability are not for profit organisations that operate on very tight budgets and this type of financial uncertainty may well be the difference between solvency and insolvency for some and that is certainly not what we would want to see in this sector. (Parents of the Hearing Impaired of South Australia, sub. 222, p. 3)

> Portable, individualised funding could lead to sudden loss of people attending traditional services or specific organisations; some services may no longer be viable, thereby the amount of choices available to people with disabilities may actually be diminished. (Northcott Disability Services, sub. 376, p. 15)

> Without core funding, the proposition of running a service which meets fluctuating and hard-to-predict levels of need, will deter many providers, limit choice for families and impact on quality of provision. (Wesley Mission, sub. 541, p. 14)

> A move away from block funding to individualised funding has administrative and cash-flow implication for organisations. The right of an individual to move easily from one provider to another reduces income predictability. The management of uneven cash flow requires service providers to have sophisticated financial skills and take on increased risk, particularly if the payment for services occurs some weeks, even months, after they are delivered. (NDS 2009)

However, others have suggested that certainty is neither a reasonable nor a beneficial expectation:

> In some cases, these arrangements have arisen in response to claims by service providers that they need 'certainty' in planning business operations from one year to the next. We say that provider organisations should accept that they operate in a market for their services, and that no business in a market environment can expect their customers to give them a blank cheque. People with disabilities do not owe service

providers, or their staff, a living. (National Federation of Parents, Families and Carers, sub. 28, p. 4)

In general, the Commission does not support the proposition that reducing service provider uncertainty is a legitimate justification for block funding. Uncertainty about future levels of demand and revenue is common in other sectors of the economy and has been accepted as a necessary cost of doing business. Indeed, this 'uncertainty' functions as powerful motivation to understand and fulfil customer needs and drives competition between providers — to the benefit of consumers.

Moreover, in reducing uncertainty, block funding also reduces the necessity for service providers to respond efficiently to variations in demand. In contrast, a consumer choice model advantages providers with systems in place to deal with variation in demand, and gives a strong incentive for others to develop them. Thus, rather than 'fixing' the problems of uncertainty, block funding represent an obstacle for the disability services industry to properly account for the inevitable uncertainty and to adapt accordingly.

It is possible that in the transition to a consumer choice model, some consumers will lose access to a service that they are happy with, as other customers who were previously dissatisfied are given the ability to leave it (making the particular service unviable overall). However, this will be offset by the additional funding to disability services after the introduction of the NDIS, which will take place in market conditions where demand already significantly exceeds supply. This means that, in general, services will tend to be expanding rather than contracting and consumers will likely have more service options rather than less. Also, overall revenue uncertainty in the disability services industry will be much lower than other sectors, as it is based on hypothecated income. In this context, it is likely that exits will be concentrated among providers whose services are valued the least.

In any event, much of the costs incurred through increased uncertainty will be transitory, as service providers adjust to the new business environment and adopt practises that have been long accepted in other sectors. As noted above, the NDIA will provide assistance and advice to service providers throughout this transition, and will monitor the ongoing impacts on consumers.

Is block funding required to account for infrastructure, training and administration costs?

Another potential risk of withdrawing block funding in favour of a consumer choice model is that it might undermine providers' ability to service their fixed costs (such as rent, capital maintenance administration and other overheads) or make capital

investments (including human capital such as training) to expand or improve the quality of their services.

> Another major financial risk that individualised funding poses is how fixed costs will be serviced – that is, how to maintain infrastructure and administrative functions within a demand-driven model? (Northcott Disability Services, sub. 376, p. 14)
>
> Block funding has also enabled the coverage of costs not able to be recovered through individualised packages. (National Disability and Carer Alliance, sub. 413, p. 7)
>
> A very real concern of service providers is how fixed costs will be serviced — all organisations require resources just to open their doors, prior to the delivery of any services to people with disability. The question of how organisations will maintain infrastructure and administrative functions within a demand-driven model is critical. (NDS 2009, p. 17)

These problems are not unique to disability service providers and have been widely demonstrated to be surmountable in other industries. The core issue is not the method of payment, but the price paid. Failure to properly reflect fixed costs under the proposed price setting model would be problematic for both producers and consumers — but no more so than is the case under current arrangements.

For many disability services, fixed cost are low relative to labour costs (which can be more easily observed), so the required adjustment to price (and the consequences of the NDIA getting this wrong) would be small. However, in some areas, particularly residential services, accurately estimating industry fixed costs and incorporating these estimates into prices, will be critical to maintain service standards (or to prevent excessive profits and poor value to consumers). The Commission's parallel inquiry into aged care has an in-depth discussion about financing residential care, which may also be relevant to this issue in the disability sector (PC 2011).

The necessity of such price regulation may diminish over time with the development of a mature competitive market. In this case fixed costs would be driven by consumer preferences and reflect a variety of service models. For example, in the broader economy, industry wide trends towards business models with lower fixed costs frequently benefit consumers. Similarly, models of care with inherently lower fixed costs may deliver substantially greater value to people with a disability (for example, by directly employing someone to provide attendant care rather than going through service providers maintaining physical premises and corporate functions).

Conversely, consumers will often be willing to pay more for products requiring substantial capital investment. The higher prices reflect the required contribution to that investment. Of course, in some situations, there may be a role for governments

in setting prices (for example in rural settings or where market competition is inadequate). However, ideally, prices should only be constrained by the pressures of competition and the usual safeguards against the abuse of market power and anticompetitive practices.

Market-based approaches also have the advantage that suppliers can use innovative pricing to efficiently recover fixed costs from different customers. This includes measures such as discounts for regular use of services, or for periods where demand is often lower.

It is sometimes claimed that block funding mitigates the problems posed for raising finance for not-for-profit entities. Such entities have lower equity buffers, no tax deductibility of debt, and non-commercial governance structures and broad objectives. However, there is little evidence that these are large obstacles to funding or that block funding is an appropriate remedy.

Is block funding a useful tool to support innovation?

Increased competition in the disability sector will enhance the rewards and necessity for service providers to find innovative ways to meet the needs of their customers. However, some innovations also have broader value in enhancing the stock of knowledge available for all service providers. As individual providers will not usually consider these wider benefits, there may be less research and experimentation than is socially desirable — particularly if it is costly or risky. In the case of the disability sector, innovation may take the form of a new assistive technology, a new approach to therapy or rehabilitation, or a new way of engaging with the community in order to deliver services to people who are the most reluctant or unable to otherwise access them (such as Indigenous Australians, people in remote areas, people with sensory disabilities, or people who are not from English speaking backgrounds).

There are grounds for competitive grants to support research and experimentation in areas that are likely to provide broad social benefits. This could be funding a trial, or 'seed capital' to start a new highly innovative service (in a similar fashion to the Job Services Australia Innovation Fund). In some cases, there may also be benefit in research funding on an ongoing basis, for example through supporting research divisions of disability service providers. (The broader research functions of the NDIA are discussed in chapter 10.)

Is block funding necessary to guarantee services in areas where the market would fail to deliver them efficiently?

In some cases, the potential market for disability service may be too small to support the competitive provision of specialist disability support services under a consumer choice model (in particular under choice of package arrangement where approved service providers must be used). This may occur in rural areas or for people with very complex needs or very challenging behaviours — potentially resulting in under-servicing and unmet need, or in local monopolies overcharging consumers.

The first of these issues can be largely addressed by allowing providers to take the higher costs (arising from diseconomies of scale) into account when determining prices and individual entitlements. However, the later problem would remain, resulting in the ongoing issue of disentangling monopoly rents from diseconomies of scale. Block funding through competitive tender is one way of addressing this.

It is not clear how prevalent such market failures will be in practice. As discussed in chapter 6, the use of self-directed funding appears to operate reasonably well in rural settings, suggesting that the actual need for block-funded rural providers may be low in practice, outside of specialist health support services, therapy and centre based respite. Some alternative approaches for delivering services in rural settings are also considered below.

The market is likely to fail consumer groups that are not willing or able to engage with traditional service providers. In particular, the combination of remoteness and cultural aversion to traditional models of service provision dramatically increases the risks of exclusion and harm for indigenous Australians. Service providers directly working to redress this should receive continued block funding, in addition to the provision of funding for trialling innovative approaches mentioned above. We discuss an Indigenous strategy in chapter 9.

Putting it all together

Despite the challenges implicit in the transformation of a block-funded industry into one based on consumer choice, most service providers involved in this inquiry have recognised both the necessity, and the desirability for change. For example, Yooralla writes:

> There will be uncertainly and instability for disability service providers as individualized funding replaces block funding which has more financial certainty. However, service providers are having to move toward individualized funding models of support whether the scheme is implemented or not. (sub. 433, p. 40)

The Commission considers that the shortcomings of the block funding model warrant its use only in very specific circumstances. That is, self-directed funding or other avenues for consumer choice (such as choice of supplier) should become the norm for the industry. Some of the rationales for retaining block funding have little merit. In particular, arguments about uncertainty or the need to cover fixed costs are not generally accepted reasons for government intervention in comparable industries and should not be accepted here. However, block funding should continue to play a role:

- to ensure that crisis care needs are met
- to support research, experimentation and innovation in the industry
- as a tool to redress market failure.

Where block funding is judged to be the preferable funding method, the NDIA should develop standardised tendering, contracting, reporting and acquittal requirements in order to reduce compliance cost. Findings from the recent Productivity Commission report into the not-for-profit sector (PC 2010) are relevant to the implementation of block-funded services, including:

- a collaborative approach between the NDIA and service providers that: includes both parties in the design of programs; embeds and funds agreed evaluation processes; regularly reviews and revises service delivery approaches in light of finding from evaluations and changing demands or environmental conditions
- the length of service agreements and contracts should reflect the length or the period required to achieve agreed outcomes, rather than having arbitrary or standard contract periods.

Government, not-for-profit and for-profit service providers

People with disabilities in Australia receive services from for-profit and not-for-profit (NFP) providers, as well as directly from government themselves. The trend in most jurisdictions has been for increasing reliance on NFP provision, which reduces the actual and perceived conflicts of interest posed by the dual role of government as suppliers and regulators. It has also been suggested that NFP providers have a number of other benefits compared to government run agencies, such as:

- NFPs are well placed to respond to community needs and are closer to the target group of a particular service.
- Some NFPs are able to access resources that are unavailable to the government, such as volunteers and private sponsorship.

- NFPs sometimes have a longer history of involvement in specific service areas than government agencies — leading to considerable expertise and links to the target group.
- NFPs are seen as being more flexible and adaptable to client needs, as well as having the ability to package government-funded services with other services (PC 2010a).

Nevertheless, it is likely that government supply will probably continue to play an important role in some areas. In particular, government providers may sometimes be able to exploit economies of scope, such as the ability to integrate with health services. They might also act as a 'last resort' supplier. For example, this might include providing support in very remote areas (and especially those Indigenous communities where no other provider exists), and for clients with very complex needs or challenging behaviours.

Similarly, moving disability supply away from centralised control to a more market setting is likely to make the disability sector more attractive to for-profit-providers (The Victorian Government noted that increased provision of individual support packages has been associated with the entrance of for-profit agencies in that state (sub. 537, p. 14).)

Ideally, from an efficiency perspective, competitive neutrality would be maintained between these three different types of providers. Competitive neutrality aims to ensure that a provider does not enjoy competitive advantages over a competitor simply by virtue of their ownership. There are several risks to neutrality in the disability sector:

Concessionary taxation arrangements benefit NFP providers — in particular the fringe benefit tax (FBT) concession. The concession allows a NFP provider to pay its workers in-kind rather than in cash, lowering taxes on workers' incomes. This means that a NFP provider can pay a worker at a lower pre-tax wage rate, but at an equivalent post-tax wage rate, compared with government-owned and for-profit providers. The pre-tax wage rate is one of the major determinants of costs in the disability sector. All things being equal, this means that a less efficient NFP provider may displace a more efficient for-profit or government provider.

The Productivity Commission (2010a) argued that the distortionary effects of the FBT are particularly problematic in the hospital sector and, to a lesser extent, in the aged care sector. It is also potentially an issue in the disability sector. Both the Commission and the Henry Tax Review have argued that more transparent and less distortionary forms of support for NPF providers are preferable to input concessions such as FBT. Because the FBT concessions apply across the entire NFP sector, it

would not be realistic or desirable to quarantine reforms to the disability part of this sector alone:

- Changing FBT rules for the disability sector alone could introduce further distortions (for example disadvantaging the ability of the disability sector to compete for labour with the aged care sector).
- Beyond changes to FBT, the means available to restore competitive neutrality are limited. In theory, when receiving tenders for block funding, the NDIA could attempt to estimate the *true* cost of service delivery by NFP organisation (on a provider by provider basis) by estimating the income tax revenue foregone to the Commonwealth. However, the complexity and additional cost involved in doing this are likely to be considerable. While, accounting for these costs are not currently required under Commonwealth Procurement Guidelines, the Productivity Commission (2010a) has recommended that 'the Departments of the Treasury and Finance and Deregulation should jointly conduct a review into the feasibility, the costs and the benefits of requiring value for money assessments for government procurement to consider significant input tax concessions'. The outcome of such a review would usefully inform the approach taken by the NDIA.

Two other sources of competitive non-neutrality are sometimes raised, but neither are likely to be a significant concern.

- NFP providers can often use volunteers to provide services, putting themselves at an advantage to other enterprises that have little scope to use volunteers. However, the policy application of competitive neutrality is always subject to the proviso that the benefits outweigh the associated costs. There are clear benefits from attracting volunteers to the disability sector, and it would not be in the public interest to penalise those providers who are good at doing this.
- Government providers could, in theory, have competitive advantages over other providers as their activities can be cross-subsidised by government and because they may allocate joint costs (like a personnel or IT function) to the non-competing parts of their activities. However, all Australian governments have agreed to implement competitive neutrality policies as part of the National Competition Policy reform package. Moreover, in practice, determining whether there are genuine breaches of neutrality in this area is complicated, as indicated in the investigation reports made by the Competitive Neutrality Complaints Office (an office attached to the Productivity Commission).

These issues aside, as a funding and purchasing agency, NDIA should give no preferences to suppliers based on their ownership (whether that be government, for

profit or NFP), giving consumers the ultimate power about where to buy the services and supports they want.

Rural issues

Numerous participants have expressed concern about the quality of, and access to, services in rural areas. The remoteness of these areas, and the small size of their markets, present considerable challenges for service provider viability, effective competition, consumer choice, infrastructure adequacy and availability of specialists.

The flexibility of self-directed funding would be likely to ameliorate some of these issues (chapter 6). In particular, by allowing the use of mainstream services and other community assets, as well as letting family and community members take on paid caring roles, self-directed funding is likely to increase competition and choice, as well easing shortages. Local case managers will play a key role in taking full advantage of these local resources.

In some areas, the increase in funding associated with the NDIS would be particularly effective in a rural setting. For example, the land, (and in some country towns buildings also) required for accommodation and other services would often cheaper and more freely available. Similarly, higher unemployment and lower labour force participation rates in rural areas mean that, for services where training requirements are minimal, labour supply constraints would be less binding.

However, these solutions are unlikely to be adequate in all situations, resulting in shortages in some types of services, and excessive market power for others. As indicated above, competitively tendering for block funding, (open to NFP, private and government service providers on an equal basis) is a potential response to this.

A key area of concern is the lack of access to specialists (such as occupational therapists, speech therapists, physiotherapist or even GPs), which will continue to be an acute issue under the NDIS. Appropriately pricing the cost of private specialists (including travel time) when determining individualised budgets should improve access to some degree, particularly to regional centres (as opposed to very remote areas). Another way to alleviate the bottleneck is through coordinated and periodic visitation of remote towns with teams of specialists, such as the 'assist teams' in South Australia (Australian Federation of Disability Organisations, sub. 495, p. 41).[8] This would improve access for people who require multiple specialists and could potentially allow travel costs to be split between specialists

[8] Similarly, Australian Hearing specialists also visit remote communities to test hearing.

travelling together, and the patients commuting to see them. Similarly, Anglicare suggested the development of 'the equivalent of a flying doctor service for specialist intervention and support services' that would follow a published circuit through remote areas (sub. 270, p. 23).

The greater use of information technology is also likely to be viable in rural areas where access to specialists and health professional is limited. For example, some have pointed to the potential for telehealth technology to monitor health conditions remotely and telerehabilitation to deliver specialist advice remotely (Medical Technology Association of Australia, sub. 479, p. 15). In some situations, the simple ability to 'skype' with a GP or allied health professional may be an adequate method for advice or referral (Sydney Hills Autism Support Network, sub. 212, p. 5; Parents of the Hearing Impaired of South Australia, sub. 222, p. 5). Deaf Australia also highlighted the potential for remote interpreting services (sub. 374, p. 12). The feasibility of these technologies is primarily limited by the speed and level of internet access in rural areas. As this constraint should lessen over time, the NDIS should actively promote the use of these technologies by conducting research into their efficacy and, where demonstrable benefits arise, funding them (for example, by providing a laptop and satellite broadband connection).

While improving disability services in rural Australia would be a key objective for the NDIS, ultimately, like most other services, it will not always be possible to match the range and quality of services provided in major cities. For people with very complex needs, relocation may be necessary to take advantage of highly specialised services. In such cases, the scheme would also assist with relocation. Nevertheless, the proposed NDIS should represent a considerable improvement for disability care and support in rural areas.