Australian Government
Productivity Commission

Disability Care and Support

Productivity Commission Issues Paper

May 2010

Commissioners:

Patricia Scott (presiding), David Kalisch, John Walsh (Associate Commissioner)

Key dates

Initial public hearings	June/July 2010
Initial submissions due	End June 2010
Release of draft report	February 2011
Second round of submissions due	April 2011
Public hearings for draft report	April 2011
Final report	31 July 2011

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All public submissions will be available for reading and download from the inquiry website at http://www.pc.gov.au/projects/inquiry/disability-support.

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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.

Contents

How to read this issues paper

This issues paper is intended to help you prepare a response to the Commission's public inquiry into long-term disability care and support. We pose many questions (in italics) about the issues throughout this paper. We would welcome your answers to any of them, but we do not expect people to respond to all of them.

Sections 1 and 2 summarise what the Commission has been asked to do and how you might contribute. You can send us your responses in several forms, not just as formal submissions.

Sections 3 to 13 contain the core issues that the inquiry will need to consider. These sections include questions that at this stage the Commission sees as relevant to its task. You do not need to address all the issues raised and you may comment on any other issues that you consider relevant to the terms of reference.

We have also provided the detailed terms of reference (attachment A) and administrative information to help those who want to make a formal submission (attachments B and C). Please also look at our first two circulars (on our web page) on how to participate in the inquiry.

Acknowledgements

The Commission has had initial consultations with many people and organisations. These include people with disabilities, carers, service providers, peak bodies, insurers and governments. The Commission would like to acknowledge their insights into the key issues involved in designing new arrangements for long-term disability care and support. We are particularly grateful for discussions on many issues held with the Independent Panel. The panel was established by the Australian Government to advise the Commission during the inquiry, and comprises people with expertise and knowledge of disability issues.

1 What has the Commission been asked to do?

There is a widespread view 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. This has been a consistent finding of recent reports, such as the Way Forward report (Disability Investment Group or DIG 2009a) and the 'SHUT OUT' report (National People with Disabilities and Carer Council 2009).

Many people think that disability services are often in crisis mode, with very inadequate provision of services. They argue that whether people get good services can be a 'lottery', based on where they live and how they acquire their disability. People often have little power over, or choice about, the services they receive. Carers often find it hard to cope if they have to provide most of the support and are uncertain about future care arrangements. There are many fragmented programs, and weak evidence about what achieves good outcomes. The mounting concerns about these systemic and enduring inadequacies have led to this inquiry. In announcing the inquiry, the Government 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 Commission has been 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, respite, transport, 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.

The Australian Government has asked the Commission to consider how a national disability scheme could be designed, administered, financed and implemented. This includes consideration of a variety of options, including a no-fault social insurance model and approaches used in other countries. The Commission is to assess how these models would interact with Australia’s health, aged care, informal care, income support and injury insurance systems. (The full terms of reference can be found in attachment B.)

The structure and performance of the current system is not covered in this issues paper because comprehensive up-to-date descriptions by the Australian Institute for Health and Welfare (AIHW 2009, pp. 137ff) and the Steering Committee for the Review of Government Service Provision (2010, p. 14.1ff) can be readily accessed. With the exception of community contributions and some disabilities associated with injury or third party negligence, the current system is based on funding care and support for people with disabilities through ‘pay as you go’ taxes collected by Australian governments. That revenue is channelled through a variety of programs, in the disability area explicitly, but also through government employment and educational services.

Language

Many people feel uneasy about the language labelling disability. All people have a complex set of traits (their preferences, jobs, hobbies, personalities). A disability is just one aspect of their lives. For that reason, people usually do not want to be defined by their disability alone — they are people experiencing or dealing with a specific disability, not disabled people. In this issues paper, we have used terminology that appears to be customary in other reports. At times, we may nevertheless get things wrong when describing disabilities. Please tell us where that is the case.

2 How can you contribute to this inquiry?

Reviews of services for people with disability have shown many people are frustrated by current arrangements or get insufficient support, and feel alone, angry or depressed as a result.

The key question for the Commission is not how bad the current system is — nearly everyone thinks it needs to be overhauled. What we want to know is how to build a good system. You may have ideas about the features of a new long-term disability care and support scheme, based on your own experiences as a person with a disability, or as a service provider, carer, family member, friend, employer or workmate of a person with a disability. The rest of this issues paper sets out many questions that will need to be answered when designing a new scheme.

You can give us your ideas in many ways. You can:

- make a formal submission. In that case, you should look at attachment B about how to make a submission and attach the submission cover sheet so that we know it is a formal submission (attachment C). Submissions do not have to be long
- present at a public hearing
- provide answers to any or all of the questions in this paper, based on your personal experiences. This is different from a submission. It is not a formal process, so it is much easier to do. You do not have to read our detailed instructions on how to make a submission or include our formal cover sheet or tell us details about yourself. Just include the words PERSONAL RESPONSE at the start of your comments. You might write just a few lines on a good idea. Because these responses tend to be shorter, we will combine people's ideas into a single document. We will publish the document on our website, but will not publish your name to protect your privacy. We have used personal responses in

other inquiries, such as the inquiry into paid parental leave. For example, look at www.pc.gov.au/projects/inquiry/parentalsupport/personal-responses. If you are making a more detailed and lengthy response, you might want to think about making a formal submission.

Your views will help us prepare a draft report, which we will put out in February next year. After hearing more views from people, we will give a final report on a new disability scheme to the Australian Government in July 2011.

The key questions

Sections 3 to 13 set out many issues and questions in detail. However, the key questions are:

- who should be the key focus of a new scheme and how they may be practically and reliably identified
- which groups are most in need of additional support and help
- the kinds of services that particularly need to be increased or created
- ways of achieving early intervention
- how a new scheme could encourage the full participation by people with disability and their carers in the community and work
- how to give people with disabilities or their carers more power to make their own decisions (and how they could appeal against decisions by others that they think are wrong)
- how to improve service delivery — including coordination, costs, timeliness and innovation
- the factors that affect how much support people get and who decides this
- how to ensure that any good aspects of current approaches are preserved
- what to do in rural and remote areas where it is harder to get services
- reducing unfairness, so that people with similar levels of need get similar support
- getting rid of wasteful paper burdens, overlapping assessments (the ‘run around’) and reducing duplication in the system
- how to finance a new scheme so that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future

- the practical aspects of a scheme that will make it work, such as how existing arrangements would fit into a new scheme, how to manage risks and costs, and ideas for attracting people to work in disability services
- how long would be needed to start a new scheme, and what should happen in the interim.

These questions are only a guide to help you give us your ideas about some of the most important issues. The more specific your ideas are, the better. For example, telling us that more money should be provided does not tell us where that is needed, how much, the chief priorities for reform, where the money will come from, how it would be given out, and a host of other important questions that need to be taken into account in building a new system.

3 The prevalence and incidence of disability

Disability lies on a spectrum from the mild to the profound (box 1). In 2009, around 4.5 million Australians had a disability of some kind — or about one fifth of the population.[1] Around 550 000 people were primary carers of people with disabilities and a further 2.4 million were other carers. Many other people are involved with disability in their roles as family members, colleagues, friends and employers.

This inquiry will consider 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. While this inquiry mainly emphasises people with disability aged less than 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.

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[1] Based on Productivity Commission estimates using 2009 ABS population estimates and assuming that the 2003 age-specific rates of disability recorded in the ABS *Survey of Disability, Ageing and Carers* (cat. no. 4430.0) remained fixed over the ensuing six years.

Box 1 **Some definitions**

There is no single definition of disability. Modern definitions of disability, including those drawn from the United Nations Convention on the Rights of People 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.

According to the Australian Institute of Health and Welfare, and as also adopted by 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 2003, around one in five Australians had one or more disabilities.

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 task (core activity tasks are self-care, mobility and communication) or
- 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.

Second, the scheme is not intended to provide services to all people with disability, many of whom may need no or few supports. Rather, the scheme is intended for those in significant need of support. These would be mainly drawn from those with severe or profound disability, though an appropriate coverage may include some people with moderate disabilities and exclude some categorised by the ABS as severe or profound. There are various measures of the number of people with the most significant needs (box 2). For example, among those aged less than 65 years, there are around 180 000 people with at least regular daily care needs, about 245 000 people currently using specialist disability services and around 760 000 people with a profound or severe disability.

The estimates in box 2 are the total number of people with severe or profound disability at a point in time ('prevalence'). Each year, there are also *new* cases of disability ('incidence'). Of the 580 000 people with severe or profound disability identified by DIG (2009b), around 70 000 were new cases and 510 000 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 require long-term care.

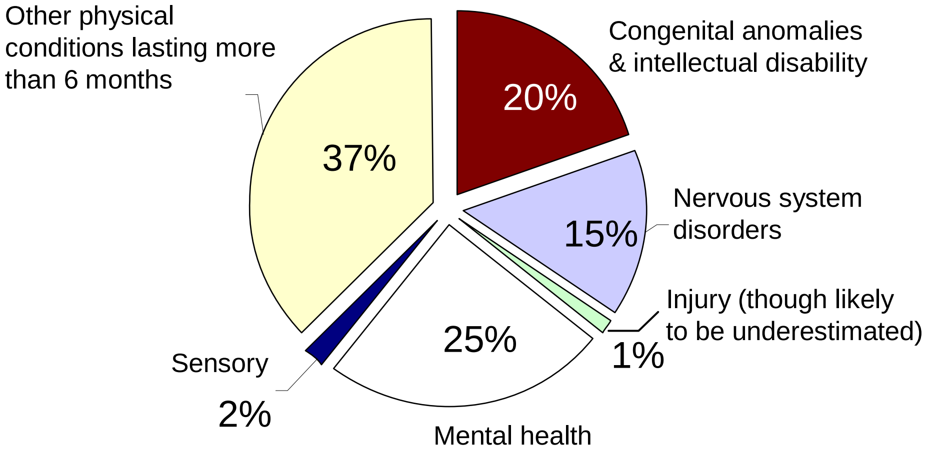
Box 2 **How many people have significant needs?**

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

- The Commission estimates that around 260 000 people aged less than 65 years had a profound disability in 2009 and 500 000 had a severe disability — or 760 000 in the combined group (applying the age-specific prevalence rates from the ABS Survey of Disability. Ageing and Carers (SDAC 2004) to the 2009 population).
- The ABS 2006 Census of Population identified a smaller group of people with severe or profound disability (around 400 000 aged less than 65 years in 2006), but this estimate is generally regarded as a less reliable measure than SDAC.
- DIG (2009b) estimated that there were around 580 000 people aged less than 65 years in 2009 with severe or profound disability using the AIHW Burden of Disease data. Of these, there were:
  - 40 000 people with constant support needs — people in establishments other than nursing homes or people who cannot be left alone for one hour
  - 104 000 people with frequent support needs. These need assistance with at least one core activity at least three times a day and/or cannot be left alone for more than a few hours
  - 32 000 people with regular support needs, who need assistance with at least one core activity one or two times a day
  - 86 000 people classified with a profound disability who had lower support needs
  - 316 000 people classified with a severe disability who had lower support needs.
- Usage of disability services provides other indicators of the numbers of people with the greatest need for support:
  - There were just over 245 000 people using specialist disability services under the Commonwealth State and Territory Disability Agreement (CSTDA) in 2007–08 (SCRGSP 2010, p. 14.15, p. 14.93). The CSTDA is directed at those whose disability was acquired before the age of 65 years.
  - There were around 180 000 people aged less than 65 years who used Home and Community Care (HACC) for services such as nursing care, allied health, and the provision of aids and equipment that were not available under the CSTDA. People would often use both CSTDA and HACC services, so total service users is not the sum of HACC and CSTDA services (AIHW 2009, p. 167).

The main source of disability for those needing constant or regular support were physical conditions, mental illness, congenital anomalies and intellectual disability (figure 1).

Figure 1 **The nature of disability for those needing constant or frequent support**



Data source: DIG 2009b.

4 Rationales for and objectives of a long-term disability care and support scheme

The overarching goal and government's role

Some form of care and support for people with disability has been a longstanding feature of the Australian social support system, though its motivations have varied over time. Currently, the overarching goal of Australian governments' disability policies is to enhance the quality of life and increase the economic and social participation of people with disabilities and their families, including enhancing and protecting their rights. That goal is reflected in a range of social, economic, regulatory and spending measures by governments. 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.

The possible creation of a new long-term disability care and support scheme reflects a desire by the Australian Government to achieve its overarching policy goal in better ways than current arrangements.

Why should government act?

There is a strong rationale for government 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
- the desirability of sharing the costs that fall on people with disability and their families among a wider group of people — through a form of social insurance — and the low likelihood that private insurance markets would function equitably or efficiently in this area.

What should a new system aspire to achieve?

People have identified many weaknesses in the current system. These flaws have motivated interest in a new approach and are its chief targets for change.

- *There are insufficient resources and gaps in certain kinds of services in some jurisdictions and location, with the result that:*
  - informal carers and people with disabilities bear too much of the costs associated with disability, with adverse consequences for their wellbeing. Primary carers and people with disability have lower rates of wellbeing than the public generally. Indeed, Cummins et al. (2007) found that carers had the lowest level of wellbeing of any group that they had studied. Whereas around 6 per cent of the Australian population are estimated to be depressed, well over half of carers are estimated to have depression
  - under-servicing in one area — such as insufficient access to aids and appliances — may result in costly additional servicing in another area or at a later time
  - excessively rationed services may build inertia into decision-making by people with disabilities and their carers. Someone who has finally gained access to one type of service after being on a waiting list may not want to try an alternative, potentially better, service if they cannot be given a guarantee of returning to the original service if the new service does not actually meet their needs
  - there are gaps in the availability of services at key transition points in life (for example, leaving school)
  - there is lack of attention to the benefits of early intervention
- *There can be inequity of treatment and the 'hit and miss' delivery of services.* Some people with similar levels of functionality get access to quite different

levels of support, depending on their location or the origin of the disability — what some call the 'lottery' of access to services. For example, someone who acquires a severe brain injury where no fault can be assigned gets full support for their injury in New South Wales through its no-fault Lifetime Care and Support scheme and much lower support in Queensland, which does not have a no-fault system. In practice this can mean that a few metres can make a huge difference to care outcomes (say which side of the road you were on in Boundary Street in Tweed Heads). Similarly, throughout Australia, someone acquiring cerebral palsy through medical malpractice would receive large benefits, while someone acquiring the same condition prior to birth would not

- *There is an insufficient capacity for people with disabilities or their families to exercise choice about the services they use and have control over the financial resources directed to them.*
  - For instance, some may wish to trade-off access to respite services or attendant care with other services that better meet their needs
- *The system does not always give people with disability and their families a reasonable level of certainty about the future.*
  - For instance, carers of children with a profound disability often worry about how their child will be supported when they get too tired, sick or die. When the prospect of care is for many decades, that anxiety can commence at an early stage after the onset of disability, and not just when the parent is elderly
- *There can be insufficient opportunities for employment or participation in the community*
- *There is often a lack of coordination, showing up through:*
  - the use of duplicated and sometimes inconsistent assessment methods for allocating services or funding
  - having access to one program restricted inappropriately because of receiving support from another
  - concerns about the interaction of the health system with the disability support system
  - incomplete links between services provided by different governments
  - inadequacies in information for planning and coordination, which frustrates evidence-based approaches to service delivery and outcomes (such as the best early interventions) and makes it difficult to plan for and manage future costs
  - lack of portability of services as people move

- *inappropriate models of support — such as care for young people with disabilities in aged care homes.*

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 (while avoiding new pitfalls).

The United Nations Convention on the Rights of Persons with Disabilities

Beyond the specific issues raised above, some point to the importance in any new scheme of adhering to the principles and obligations in the United Nations Convention on the Rights of Persons with Disabilities, which Australia has ratified (box 3). These principles may have additional implications for the objectives (and resulting design) of the scheme.

Are there tradeoffs between the aspirations for a new scheme?

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:

- seamless integration of services may be costly if there is a large amount of supporting infrastructure to do this or large 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 for what is public money and may not always serve all people well
- more choice for individuals and families may also mean greater uncertainty for service providers and coordinators, potentially leading to less coordination and greater costs.
- governments have many competing obligations beyond services for people with disability and their carers. They must provide other key services — health care, education and infrastructure. And they must ensure that tax rates are set at fair and efficient levels. Any new scheme would entail a significant increase in effective resourcing for disability care and support (partly stemming from realising efficiencies in the current system and partly from new funding). However, 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.

Box 3 The United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol

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)

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.

What other reasons are there for a new approach to a disability care and support scheme? What are the implications of these objectives for the design of the scheme?

What are the specific design implications of the UN Convention?

What weight should be given to each of the various objectives? How should the various objectives be traded-off against one another if they conflict?

5 Key design elements of a new scheme

The Commission is starting from the position that the broad rationale for some form of mandated contributions to provide disability support is soundly based, whether through taxation, compulsory contributions to insurance, or other means. The key question at this stage is how best to design a system to achieve that broad goal.

As in health and aged care, there are many choices about how to design a disability care and support system (figure 2). The core issues relate to who makes the decisions, who is in the scheme, what benefits they receive and the associated funding amounts, service delivery and financing methods.

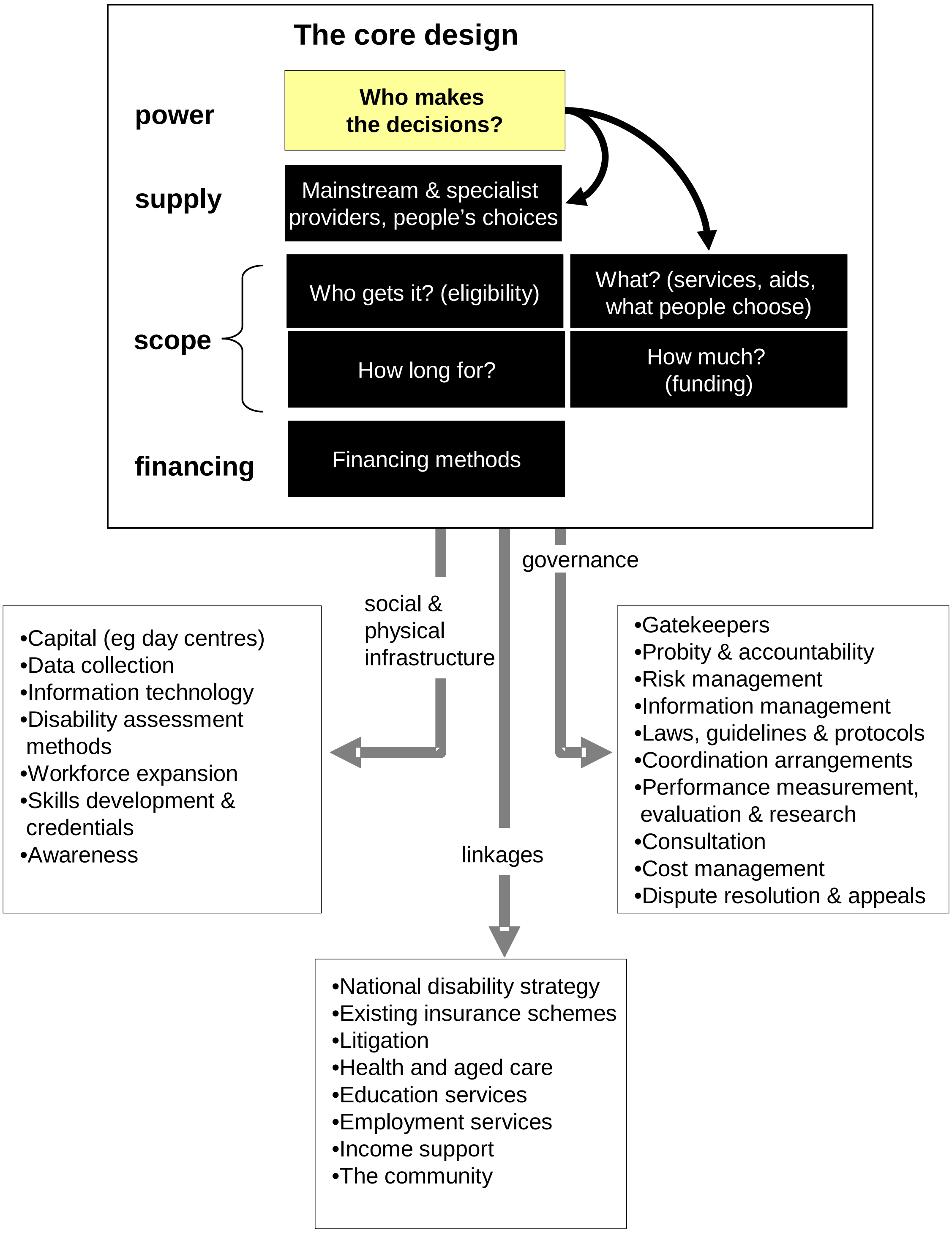
But realising a practically implementable and efficient scheme requires detailed attention to many other aspects of its design. Assessments of disability must be made (how?), the system must be organised and monitored (by whom?), linkages to related services and policies have to be identified and managed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

This issues paper does not address all of these design features in detail, but considers some key ones below.

Are there are other design aspects of a scheme that are important? How are they important and how should be incorporated into a scheme?

Figure 2 Key design elements of a disability care and support scheme



6 Who should be eligible?

The choice of eligibility criteria (and the assessment tools used as part of determining eligibility and needs — see later) should be based on the policy goals of the scheme. There are many different ways that eligibility for a disability care and support scheme could be specified. Different approaches would affect: the capacity of the scheme to provide benefits where they are most needed; the number of people who could access it; its complexity; fairness and cost; and the risks of perverse incentives.

The terms of reference for the inquiry indicate that the scheme is not intended to cover all degrees of disability, but ones where the needs are greatest. In part, this reflects concern about significant unmet needs. Such a focus may be consistent with the:

- relative capacity of people to participate in society without provision of specific disability services or aids. Some people with disabilities — often those with milder disabilities — can participate to the same extent as many other people classified as without any disability
- different approaches that are appropriate for people with varying levels of disability. A disability insurance scheme is not intended as the only approach to deal with the existence and impacts of disability. Acting on discriminatory social attitudes, changes to urban infrastructure, educational and employment policies, and the conventional health care system, are useful for many people with disabilities, but they may be all that is needed by many people with less restrictive disabilities
- 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 that this is often a more efficient and flexible way of addressing smaller risks than formal risk pooling through insurance. (However, as discussed below, there may be grounds for placing the scheme within a broader set of arrangements that provide more universal cover.)

Is need the appropriate basis for eligibility?

What groups have the highest needs or have been most disadvantaged by current arrangements?

Even if determining needs should underpin eligibility, assessing need may not be straightforward. The appraisal of how an individual's functional limitations — mobility, self-care, communication and so on — affect their need for support and care depends on the precise assessment tool and the way in which it is used. As an illustration:

- The ABS estimates of the numbers of people with disabilities of varying severity are based on self-assessment using the criteria in box 1.
- FaHCSIA's criteria for providing carer allowances for care of children with a disability depend on several overlapping classification approaches. Children are assessed against the 'Lists of Recognised Disabilities', which contain certain disabilities and medical conditions that are consistently severe enough to qualify the carer for the allowance (for example, Down syndrome). Where a child's medical condition or disability is not on the Lists, they are assessed using the Child Disability Assessment Tool (CDAT). The CDAT measures the child's functional ability according to standards appropriate to their age and is based on information provided by a treating health professional and the carer.[2] CDAT does not assess the care needs of the child, which is independently tested as one of the criteria for eligibility for the allowance.

Some think that severe or profound disability should be the basis for eligibility. However, this classification may not always be appropriate for deciding who should get the most assistance. For example, the ABS approach to measuring severe or profound disability may exclude people with mild intellectual disabilities who do not face the specified core limitations, but whose actual capacity to participate in society may be lower than those identified as having a daily core activity limitation. Early service provision and periodic mentoring may allow their full participation.

Similarly, in some cases, it may not be appropriate for a person classified by a given definition as having a severe disability to be eligible for the scheme. For instance, this might occur when the disability is expected to last for a relatively short period.

How does need overlap with core activity limitations or other criteria for identifying the severity of disability?

Is 'severe or profound' disability an appropriate criterion for the need for support?

To what extent should other facets of a person's life: their location, access to services, family circumstances and any disadvantages affect eligibility?

How should carers' needs be factored into eligibility?

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[2] Australian Government 2010, Guide to Social Security Law, section 3.6.8 Child Disability Assessment Tool (CDAT) (from http://www.fahcsia.gov.au/guides_acts/ssg/ssguide-3/ssguide-3.6/ssguide-3.6.8.html).

An overall criterion for eligibility might be those people for whom the expected benefits of additional resourcing and better service coordination would be greatest. Factors that could be relevant in deciding this are where:

- lack of support has significantly restricted participation in work or the community, or led to a low quality of life more generally for a person with a disability
- there are large returns from early intervention. For example, Myers and Johnson (2007) and Rickards et al. (2009) found gains from particular types of early interventions in autism and there are significant gains from quickly addressing acquired brain injuries (Turner-Stokes et al. 2005)
- local support and resources are low (some country areas) or where general disadvantage is combined with disability (some Indigenous communities)
- people and carers with long-term needs, compared with people whose disability is expected to be short-lived. (The current definition of disability covers people whose limitations last more than six months, and so would include people with disabling conditions expected to last for relatively short periods.) There may also be risks that characterising people with shorter-term core limitations as disabled might prolong recovery and rehabilitation
- carers have to bear most of the caring and support responsibilities with inadequate respite or where, even when significant respite is provided, the nature of the disability makes it hard for the carer to cope (for example, where personal safety of the carer may be at stake). Commonly cited examples include elderly parents providing care and support for a child with a profound disability, and parents who suddenly find their caring responsibilities rising significantly when schooling is complete
- people are suffering from a catastrophic injury (for example, acquired brain injury), but are not able to get assistance through litigation and are not covered by any existing medical, workplace, motor vehicle or other injury insurance scheme
- informal carers are unable to meet the complex needs of the person with a disability.

What other factors might be used as a basis for eligibility?

How do you ensure that eligibility processes are consistent, fair and transparent?

What about natural ageing?

The terms of reference exclude disability arising from ‘natural ageing’ from the national disability scheme (with this source of disability instead covered by the aged care system). There are several ways of defining eligibility to reflect this. Some options are:

- providing support for people of all ages, so long as the disability was acquired before age 65 years. This was the approach proposed by the Disability Investment Group (DIG 2009b) on a national disability scheme. This would have the effect that there would be two parallel funding and service management schemes — the aged care system and a disability insurance scheme — for people in old age with similar conditions (for example, dementia), although the services may sometimes be delivered by the same providers
- funding and managing the provision of services for all sources of disability at all ages, with the exception of certain conditions that are strongly related to ageing and that occur in people after middle age. For example, exclusions might apply to disability arising from dementia or Parkinson’s disease in someone aged 60 years or more. The aged care system has developed strong capabilities for the management of such disabilities because of their high prevalence among the aged. On the other hand, determining which conditions were ageing-related might be problematic and there may be other ways of tapping the expertise of the aged care sector for certain conditions with the funding still coming from a disability insurance scheme
- only covering people aged less than 65 years (or another age barrier) in the scheme. This would be a simple and objective criterion, but would include ageing-related conditions up to age 65 years and exclude non-ageing related sources of disability after age 65 years (for example, acquired brain injury associated with a vehicle accident).

Among other factors, the choice of funding source, service management and service providers will depend on the clarity of the criterion and the differing capabilities of the aged and disability care sectors.

The Commission is undertaking a parallel inquiry into aged care. Material related to that inquiry, including its terms of reference, can be found at http://www.pc.gov.au/projects/inquiry/aged-care.

How should the scheme address disability associated with natural ageing, and why?

What implications would the resulting eligibility criteria have for people outside the system?

Comprehensive versus narrower coverage

A national disability scheme could have wide coverage, with the potential for support and services for all people with at least a reasonable degree of need, but with support graduated to the level of need. (Basic services under Medicare follow this model.) Alternatively, a national disability scheme could be selective, providing substantial support for those who meet a stringent test for need and no support for others. Both have strengths and weaknesses.

Wide coverage

This would allow tailored support to all those who need some services. Sometimes a small amount of support at one time in a person's life can save large amounts of support later. On the other hand, it is possible that near universal access and graduated levels of assistance may lead to 'needs inflation', with a gradual increase in the demands for services by those rated as lower need, leading to blow-outs in costs or reduced resources for those with the greatest needs. For instance there have been large unanticipated cost increases in the New Zealand Accident Compensation scheme (Department of Labour 2009).

A narrow approach

The narrow approach targets resources at those people who are most in need. However,

- it misses many people whose needs may still be significant
- it may be unfair for people whose needs are similar, but who just fail to meet the eligibility test for entry into the scheme
- where people have the scope to overstate their needs without this being detected by the assessment tools, those with lower needs have strong incentives to appear to have higher needs in order to get much better access to care and support
- the costs of errors in assessment tools are higher if much greater benefits are likely to flow to those who meet the eligibility rules.

There may be several ways of addressing these dilemmas. 'Needs inflation' in a comprehensive scheme might be reduced by stringent assessment procedures and a strongly communicated ethos to the disability community of the importance of proportionate claims to ensure the system's sustainability.

In the case of a narrow scheme, a new national disability scheme might sit next to existing support arrangements, rather than subsuming them. In that case, people who miss out would still get support through existing funding, and they would benefit from wider reforms to the system (such as the assurance of knowing that a high need care and support system exists for when they need it, and reducing red tape and duplicated services). A narrow scheme might also act as a pilot scheme, from which governments would learn about the best arrangements for a subsequent comprehensive scheme.

Another possible variation on the coverage of the scheme is whether it would apply to all people or only to new cases of disability. The latter would be relatively low cost, but would miss out on the bulk of people with current significant unmet needs.

What are the implications of adopting more or less generous eligibility criteria on fairness, adequacy of services, costs and incentives, and how could these be addressed?

Should the scheme apply to new cases of disability or to all people with existing disabilities?

The focus of this report is on long-term needs, but it is not yet clear how long-term should be defined, or how often a person's needs should be assessed as they age.

To what extent should eligibility include people experiencing short-term disability (7 to 12 months) compared with people whose disability (and associated needs) is expected to last for many years?

How often should eligibility be re-assessed?

Should eligibility take account of people's income or assets?

Eligibility and any benefits received could depend on people's incomes or assets. Equally, any co-payments might be linked to people's ability to pay.

Some international schemes provide benefits to all people meeting disability and needs standards, regardless of their income and assets (such as Austria and the Scandinavian countries). Others, such as the United Kingdom and France, employ some form of means-testing, where individuals are excluded from the scheme, or the benefits they receive vary, based on their income and/or assets (AARP 2007, p. 6, ANED 2010). In the United Kingdom, the result of means testing and eligibility criteria meant that in 2005-06 about half of the spending on social care services were from private sources (Glendinning and Bell 2008 p. 4). Means and assets tests are common in many Australian income support and other assistance measures.

Each approach has its own potential strengths and weaknesses, such as:

- the value of public insurance would probably be lower for families with greater income and assets, though determining the point at which the value would be low could be very difficult
- means testing (or copayments for those with greater income) would free up funds for families whose own capacity for paying for their needs were low
- means testing of benefits could discourage future labour force participation (and investment in education) by people with disabilities and their families because the higher earnings from working could disqualify them from ongoing support. This would be contrary to one of the major objectives of a disability system. The size of the disincentive effect is unclear, and would depend on how means tests were designed.
- pragmatically, setting the appropriate levels of means tests could be difficult
- means testing would be perceived as unfair by people losing some or all benefits as a result of the test. They could see themselves as contributing to an insurance pool (such as through taxes), but with limited or no capacity to get value from their 'premiums'.

Should means or asset tests affect eligibility for the scheme, the amount or type of services funded by the scheme, and the size of any copayments? If tests were appropriate, what income or asset thresholds might apply?

What would be the impacts of means testing?

7 Who makes the decisions?

Disability services have largely been seen as part of the welfare system. As a result, in the past (and to some degree still), people with disabilities and their families were seen as passive recipients of government-funded services, with officials and service providers determining what, when and how much support was given, sometimes with little thought about the specific needs of individuals or their capacity to make their own decisions.

Increasingly, there has been a shift to provide people with disabilities and their carers with more control. That might involve giving them control over funding, greater choices among services, and an obligation by service providers to take greater account of people's individual needs.

Recently, so-called 'individualised funding' or 'consumer-directed' care arrangements have been developed to give people with disabilities (or where necessary, their carers) greater control over their lives. Under these arrangements, people receive an annual funding entitlement that they can spend on the services they want or can exercise greater control over the services they receive. The United Kingdom and Germany have some of the most developed arrangements in this area, and they are an important aspect of disability services in many states in the United States (Arntz and Thomsen 2008; Tritz 2005, Prideaux et al. 2009). Individualised funding is also used in some Australian jurisdictions, such as Victoria and Western Australia. People might buy mainstream services, hire their own carers on their own terms, and choose between attendant care and home modifications. In more liberal individualised funding models, people would have the freedom to buy many things not usually associated with addressing disability — for example, attending a gym class.

Evaluations of individualised funding or other consumer directed approaches have generally found positive outcomes for people with disability (Tritz 2005, Lord and Hutchison 2008; SCIE 2009).

However, while individualised approaches would give people with disabilities much better control over their lives, some have identified associated risks, such as:

- accountability for spending and the potential risks of what some may perceive as abuse of public monies (for example, discretionary spending, gambling or drinking the money away)
- the viability of service providers, which may need a certain critical mass of demand to survive. (On the other hand, some people argue that this uncertainty is similar to that faced by suppliers in all markets in which consumers make individual choices and may be the quid pro quo of meeting people's preferences. They say that while 'messier' than centrally controlled systems, individualised funding may better meet the changing and different preferences of people.)
- whether all people with disabilities or carers have the capability of making well-based choices. Payments of lumps sums for accident compensation – the ultimate form of individualised funding – are often seen as flawed payment arrangements that do not serve people well
- the difficulty in making informed decisions about various complex services of differing efficacy (for example, which interventions for autism might be best)
- tensions over the use of individualised funding may sometimes arise between informal carers and people with disabilities (for example, over the need for respite services for the carer)
- the risk of dependency. Individualised funding arrangements in which families effectively pay themselves for attendant care or use the money to purchase ordinary goods and services would mean that funding would become like

ordinary income. That might create dependency by carers on the support system and undermine the goal of achieving independence for the person with a disability. (Some see this as a feature of the New Zealand scheme.)

In addition, even where individualised funding (and personalised care) might be the dominant basis for decision-making in a new scheme, inevitably service providers and governments will continue to play a major role (determining who is eligible, funding rules, promoting innovation, quality assurance and so on). Accordingly, there are also issues around who makes these decisions and how.

How can people with disability and their carers have more decision-making-power in a national disability scheme? How would the success or failure of new approaches be tested?

What should be the decision-making powers of governments and service providers?

What have been the experiences overseas and in Australia with individualised funding, including their impacts on outcomes and costs? What lessons do these experiences provide for adopting this approach as an element in a national disability scheme?

Should individualised funding include the capacity to save some of the annual payment for future purchases of services or borrow from future payments to pay for current services?

How should the national disability scheme support people's decision-making under individualised funding, taking account of the spectrum of disability — both in terms of the nature and severity of disability? Should all people be able to access individualised funding, and if not, what guidelines would be appropriate?

What are the risks of individualised funding and how can they be managed? What guidelines would be appropriate? How would any accountability measures be designed so as not to be burdensome for those using and overseeing the funding?

Should people be able to treat funding as ordinary income and do what they like with it? Should primary carers or other family members be able to pay themselves for providing care?

How would individualised funding work in rural and remote areas where service availability is poorer?

Who would be responsible for monitoring individualised funding?

What would be the impacts of individualised funding on service providers and do these impacts matter?

Are there ways other than individualised funding that empower people with disabilities and their families?

8 The nature of services

People with disabilities need a range of services. The type of services, who provides them, the way they are delivered, and their responsiveness to consumers depend on how a system is designed. For instance, under individualised funding, people with disabilities or their families would have a greater capacity to choose the services that best met their needs. Service provision would then be consumer-focussed (as in most markets), and block funding of service providers by governments would largely disappear. Service suppliers would face greater uncertainty about their future viability. Mainstream providers of a diverse set of services (and goods) would probably play a greater role in the system compared with specialist services. Some people with disabilities would need support to help them make choices and information provision to people might be more important than in a system in which governments and service providers are the key decision makers.

The core formal services required for a well functioning disability care and support system are usually grouped into personal care services, respite and accommodation services, community access, community support, income support, employment, transport, aids and appliances, home modification, but also a range of intangible services, such as counselling and mentoring.

Are there any services not provided now that should be part of a national disability scheme?

What are the most important services, their costs, their likely demand and who would be the predominant users?

How should service providers be monitored and regulated with respect to quality, outcomes and cost effectiveness?

How would services be structured to increase the likelihood of participation in work and the community?

Should all services be free or should there be scope for co-payments? To which services and/or people might a co-payment be applied? How would the size of co-payments be determined?

What should be the relative roles of specialist compared with mainstream services?

What needs should not be met (for example, needs that would have existed in the absence of a disability)?

To what extent, if any, should people be able to cash-out the benefits from a basic service/appliance/aid (for example, a wheelchair that met assessed need) and use it as a part payment in purchasing a premium service (a more advanced wheelchair)?

How are service needs likely to change over time and how should that be accounted for in designing a long-term care system?

What are the challenges for delivering expanded services in remote and rural Australia, including for specific communities, such as Indigenous Australians, whose needs may vary?

How could innovation be encouraged?

Quite apart from the actual types of services provided, many of the key issues about services revolve around processes:

- how people's needs are assessed — both in terms of passing an eligibility test for entry to a new scheme, but also for what entitlements they will get
- how services are coordinated, both between disability services and with services provided outside the system.

How should people's needs be assessed?

Assessment tools are critical in determining eligibility (section 7), and the level of support people need. Unreliable and subjective tools would expose any national disability scheme to cost blowouts (risking sustainability), unfairness and widespread disputes.

Several frameworks for assessing and classifying the support needs of people with disabilities have emerged in recent years, and are still being developed and refined. However, existing approaches have some deficiencies, with support need instruments known to vary markedly in terms of perceived feasibility — the ease of administration, comprehensiveness, relevance to different disability groups and overall acceptance (Kirby 2003).

Assessment tools should ideally have several features. They should:

- identify needs of each individual, taking into account the variety and strength of those needs and the variety of functional limitations (including contextual factors and complexities associated with the use of aids and equipment, potential for skills development, natural ageing, episodic disabilities and co-morbidities)

  - Currently, some tools are designed only for specific types of disability, such as the Supports Intensity Scale (SIS) for intellectual disabilities. This can create problems for allocating resources across disability types and prioritising needs, though some evidence is emerging that an amended and shortened version of the SIS is valid for people with other than intellectual disabilities (Bossaert et al. 2009)

- be reliable and objective, so that different assessors reach the same conclusions and the risk of 'needs-inflation' is reduced
  - As an illustration, the Service Needs Assessment Profile, an Australian developed instrument to measure support needs and associated costs, was evaluated to have low reliability for people with psychiatric disabilities and in some domains, such as behaviour and night-time support (Guscia et al. 2005)
  - Inter-rater consistency appears to improve with the aid of a comprehensive manual and training of assessors, such as a degree qualification and several years experience applying the tool (Thompson et al. 2008)
- be able to assess needs for a variety of different types of support, so that people do not have to have multiple, overlapping assessments to get access to aids, home modification and attendant care
- be easy to administer and acceptable to people. Truncated or more detailed versions of the instrument could be applied depending on whether the purpose of assessment is to determine an individual's eligibility for services and the associated costs, or for broader program planning purposes.

New models for needs assessment have attempted to include these features, such as the I-CAN instrument and the D-Start and eFHROM tools. The i-CAN instrument has 98 per cent reliability with the use of good data. This new wave of instruments are generally known as 'supports-outcome' models, reflecting a more flexible allocation of resources based on an individual's needs and participation goals/desires (meaningful activities), rather than on what programs choose to provide.

How should the long-term care and support needs of individuals be assessed?

What are the appropriate features of assessment tools?

Should assessment gauge both eligibility and the extent of need in the one set of instruments, or should the assessments be distinct?

Should a nationally consistent tool be used (and what process would be used to achieve consistency quickly)?

What are the risks associated with different approaches and how can these be minimized?

Who should use assessment tools (GPs, specialist disability staff, specialists)? Who should employ or engage the assessors?

How would the accuracy of assessments and the performance of assessors be gauged?

On what basis should beneficiaries be reassessed? How should assessment processes take account of changes in life circumstances?

How would data from assessment be used? (for example, should it be available to a range of service providers?)

Service coordination and linkages with mainstream services

People with disabilities and their families access many mainstream services provided across the population — housing, employment, healthcare, transport and education. In many cases, there may be few adverse interactions between these various services. However, in some cases:

- unmet demand in health care may result in excess and costly demand for disability services — ‘cost-shifting’. For instance, a cash-strapped health service facing many competing demands may give lower priority to an early intervention that could subsequently save resources in separately-funded disability services
- people with complex needs may require ‘joined up’ services that address most of their needs in a coherent way. Appropriate access to housing, transport and education may be a necessary precursor to employment.

Many of the same issues arise between disability-related services. The terms of reference require the Commission to, among other things, assess the feasibility of providing 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.

The challenges of coordination may be compounded by the fact that many governments fund and deliver services. For instance, the Australian Government funds the national Continence Management Strategy and the Continence Aids

Assistance scheme, but Tasmania also runs a continence aids scheme. All states and territories provide subsidies for purchases of aids and appliances — though they structure these differently. The variations in the way services are structured administratively may not matter much for the person getting the service, but it may also run risks:

- of reducing the capacity for coordinated purchasing of aids and equipment (including exercising buying power and cost control) and for applying a common framework for assessment of their suitability
- people may be confused by the variety of schemes, and someone moving from one jurisdiction to another may need to re-negotiate access to services
- many separate silos for services may not give government the flexibility to shift resources around between competing demands
- there may be duplication and inefficiencies in running multiple schemes.

It is uncertain how big the problems are and how a new system might resolve them. It may be possible to adopt consistent eligibility and service options, with people able to move between programs with ease (both within and between jurisdictions).

The major Australian Government role in non-aged disability is the provision of employment services and payments of income support through programs like the Mobility Allowance, Carer Allowance and Disability Support Pension (DSP). A concern about the latter is that it is not allied with coordinated rehabilitation or other disability services, which are state responsibilities. People on the DSP rarely move to jobs or job search — and this may, in part, reflect the fact that the scheme sits in virtual isolation from the rest of the disability system.

What are the obstacles to a cohesive package of disability services, where do the problems most arise, and how can they be fixed? What processes might be needed to fix them?

What role would mainstream services play in any national disability scheme (such as coordination and facilitating access)?

How do you prevent cost shifting between services inside and outside of the scheme?

Where services remain outside a long-term care and support scheme, how can service delivery be best coordinated?

Should income support and disability service provision be coordinated as part of a package, and if so, who would do that and how? What conflicts or synergies could arise between a national disability scheme and income support?

How could the capacity for people to move between services — both intra and interstate — be made easier?

How should insurance arrangements for catastrophic injury link in with a disability scheme?

There are various existing systems for provision of disability services for people suffering catastrophic injury, mostly involving serious brain and spinal cord injuries. These include schemes for workplace injuries and, in some jurisdictions (like New South Wales and Victoria), no-fault insurance for motor vehicle accidents.

However, there are gaps in access to assistance for catastrophic injury depending on the cause, circumstances or location of the injury:

- Injured parties rely on litigation for obtaining benefits where the catastrophic injuries arise from medical accidents or accidents in the community (for example, an acquired brain injury from falling off a skateboard or a roof). This also applies to motor vehicle accidents in those jurisdictions that do not provide no-fault insurance schemes.
- There are capped benefits for catastrophic injuries associated with criminal assault and sporting injuries in some jurisdictions. Criminal assault is a rapidly growing area of disability and may even overtake disability associated with catastrophic injury from motor vehicle accidents. (This is apparently already the case in the United States.)

Accordingly, injured parties may receive relatively modest long-run care and support if they cannot secure damages from an at-fault party or their insurer. For instance, this would often arise for the driver in a single motor vehicle accident.

Even where a litigant succeeds in obtaining benefits to help them with a disability, the system may not always realise good health outcomes (Davies and Gould 2009, though this is contested by Spearing and Connelly 2010). The possible causes of adverse outcomes are that there may be significant delays in receiving benefits (affecting the prospect for early interventions); people may have weaker incentives to get well since this reduces their payouts; lump sum payments may not be spent on a coherent lifetime care package (and may be misspent early with double dipping from the public system later); and fees may significantly reduce the value of the payout.

On the other hand, some argue that litigation provides stronger incentives to curb negligence, is more flexible to changing needs, less subject to political influence, and that a no-fault scheme may dilute the benefits that a person would have got under litigation. Some consider that access to common law rights should exist alongside access to no-fault compensation (and indeed some co-existence occurs in Australia).

Accordingly, there are competing strengths and weaknesses of alternative systems for assisting injury victims (Allsop et al. 2009).

There are various options for addressing disability associated with catastrophic injury. Among others, these are:

1) leave the current accident insurance arrangements in place (including litigation-based systems), with coverage for any gaps in services through a national disability insurance scheme. This option would preserve the advantages for those who successfully mount litigation, while those who failed would still get partial assistance from broader health and disability services. However, it would not avoid some of the potential inefficiencies and inequities of current litigation-based arrangements

2) leave catastrophic injuries outside a national disability insurance system, but with states and territories moving to no-fault insurance for all catastrophic injuries. The no-fault schemes might be financed through various premiums (such as insurance for motor vehicles and medical indemnity). This approach would preserve and extend what are some see as well-functioning and administered no-fault state-based disability systems, and would use a relatively efficient and publicly accepted financing method (premiums). However, using this approach, services for people with injury-related disability could be different from those obtained by people with disabilities covered by a national system (for instance, congenital conditions, cancer, strokes, and degenerative diseases). It would also forgo any of the advantages of litigation-based approaches.

3) cover all catastrophic injuries within any new national disability system, absorbing all current specific state-based schemes. This may be more equitable and might generate some efficiencies in administration, assessment and service provision. On the other hand, it might put at risk existing well-functioning systems that are geared for handling catastrophic brain and spinal cord injuries.

State and territory governments would have to legislate for any changes to current insurance arrangements.

How should disability associated with catastrophic injuries be addressed?

What are the benefits and costs of alternative approaches, including any effects on service provision for those covered by existing systems?

How would any coherent Australia-wide approach be achieved given that catastrophic insurance is a state and territory matter? How would a national disability scheme be structured if jurisdictions followed different approaches to accident insurance?

Are there lessons from existing injury insurance systems in Australia and New Zealand for a national disability scheme — regardless of whether those systems are incorporated into a national scheme?

What rights should remain, if any, for common law actions if no-fault arrangements were introduced?

If governments introduced broader no-fault catastrophic injury schemes, what would be the appropriate premium income sources?

If catastrophic injury is bundled with the national disability scheme, how would this be achieved without disrupting existing coherent systems for providing care to people experiencing catastrophic injury?

9 How much is needed?

A key question for a new scheme is how much is needed to address the funding gap — or the extent of unmet need. Unmet need is the gap between actual service delivery and the needs associated with disability (whether experienced by people with disability or informal carers).

Official (AIHW) estimates of unmet need shown in box 4 are probably highly conservative since they relate only to expressed need. Moreover, they refer to the number of people, not the value of the extra services needed — which is the critical issue for determining funding.

The Disability Investment Group (DIG 2009b, pp. 91–105) estimated the value of services required by counting cases of disability by level of need and making assumptions about the appropriate level of formal or other publicly-funded support required. It then took account of existing funding. That approach suggested that in

2009, some $10.8 billion of funding was needed for disability care and support, aids and appliances, transport and home modifications (including administration costs). Given that around $5.6 billion was already provided by existing programs, the implied level of unmet needs would be around $5.2 billion in 2009. This might be one (initial) appropriate scale of additional resourcing for a new scheme.

But there may be other estimates of the value of unmet need — based on differing views about the underlying population sizes and, more particularly, the appropriate level of entitlements associated with different assessments. Future needs will be different again, and will depend on changes in support costs and the number of people with disability.

Box 4 **What is the extent of unmet need?**

While there are difficulties in defining unmet need for services, even conservative evidence suggests many people do not get adequate services, especially in respite and accommodation services. The AIHW estimated that in 2005 (the most recent data), unmet demand for people with disabilities aged less than 65 years for:

- accommodation and respite was 23 800 people
- community access was 3700 people. Community access services provide the support needed for a person to live in a non-institutional setting, including therapy, early childhood intervention, counselling and case management
- disability employment services was 1700 people (AIHW 2007 table 5.5).

These numbers will not capture many unmet needs by people with disability or their families — delays in access to appropriate aids and appliances, lack of flexibility in service provision and insufficient power for people seeking services.

What does an entitlement entail?

The terms of reference refer to the possible use of an ‘entitlement’-based scheme, in which eligible people would get the services determined by an assessment procedure. Some government programs are run on a full entitlement basis. For instance, people found eligible for unemployment and other social security payments are guaranteed to receive their benefits.

Other government programs — often also referred to as entitlement systems — aim to provide people with services based on need, but are subject to some rationing. For example, the terms of reference refers to universal health cover as providing services on an entitlement basis, though Medicare is clearly rationed to some extent (as is aged care, child care and public housing). Notably, unlike the income support system, all of the latter services depend on the coordination and supply of complex services and not just a payment. If there are supply bottlenecks due to unanticipated demand, labour shortages or inadequate investment, or runaway costs from new technology or heightened expectations, then services may struggle to meet the service targets suggested by a full entitlement-based scheme in some periods.

The United Kingdom system is often characterised as an entitlement-based scheme. In fact, while it may well provide people with more services and better decision-making power, their recent White Paper has revealed the significant variations in service provision for people in identical circumstances in different local government areas. Rationing and service restrictions may therefore remain as features of schemes characterised as entitlement based systems.

No nation offers a public long-term care program that provides an unlimited entitlement to services without a strategy for managing costs. Service provision for catastrophic motor vehicle accidents in New South Wales (under their no-fault scheme), must meet a ‘reasonableness’ test. Some countries limit benefits on a per person basis. Others stay within a fixed budget by adjusting eligibility thresholds, limiting services, or establishing waiting lists. For example, the Scandinavian long-term care systems nominally provide an entitlement to all appropriate services to anyone who needs them. In practice, however, the local governments that operate the program adjust the criteria for eligibility to fit available finances (Merlis and Van de Water 2005).

What is the magnitude of funding needed for a national disability scheme?

How should unmet demand be measured and what is its size in value and person terms? Where are unmet demands greatest?

What are the future levels of unmet demand associated with the current system, and with what implications for future funding?

What are the practical implications of an ‘entitlement-based system’ for the design of a scheme, its sustainability and for budget management by governments? How could costs be contained?

10 Financing options

Informal carers provide much of the current support for people with disability, contrary to the goal of pooling the costs of support and care more widely among the community. As a result, any new financing approach must principally involve new revenue from the community as a whole (taxes, insurance premiums and voluntary community contributions, such as more volunteering). The decision about which option (or mix of options) would be appropriate depends on several factors:

- the efficiency and equity of the funding method. Some taxes — such as taxes on capital — tend to have high inefficiency costs. Others may place too great a burden on those with low income
- low administrative costs and public accountability
- sustainability. People often experience disability for many decades. A financing method must ensure that these future liabilities will be met. Sustainability is also an issue in relation to informal care arrangements if carers are given inadequate support
- public acceptability of the financing method.

There are many possible financing options.

The form of financing

The first threshold issue is whether the costs of the scheme should be met through ‘pay as you go’ funding or take account of future liabilities.

‘Pay as you go’ funding

In a ‘pay as you go’ system, funds are provided to meet any given year’s costs. This would provide a flexible financing method, with annual accountability of spending by governments, but would be subject to a greater risk of rationing if costs were rising or if there were other demands on government.

A funding method that manages future liabilities

This involves putting aside funds for the financial liabilities associated with the future long-term care needs of people with disabilities. This could take several forms (or hybrids of these).

It could be akin to motor vehicle accident insurance arrangements used to fund lifetime care in New South Wales (through the Lifetime Care & Support Authority) and Victoria (through the Transport Accident Commission or TAC). In a fully-funded scheme, premiums are set and costs managed so that the average assets of the fund are kept in balance with the sum of the future expected liabilities associated with people who have entered the scheme. A variant of this type of financing was floated by DIG (2009b).

This type of funding arrangement might provide better incentives for managing risk and achieving cost reductions through prevention, case management, early intervention, and efficient purchasing decisions, than arrangements in which future liabilities are hidden. For example, the TAC is also responsible for measures to reduce the incidence and costs of motor vehicle accidents.

An alternative, future-oriented financing approach would be a ‘futures fund’, which would take account of the effects of an ageing population on future cases of disability. Under this approach, premiums would not only take into account the future liabilities of new cases of disability as they arose, but also partial funding of cases of disability expected to occur in later years as a result of ageing. Age-specific disability rates rise after people reach 44 years old, so an ageing population could also be expected to raise disability rates for those people aged less than 65 years. A ‘future funds’ approach spreads the costs of ageing across current and future generations.

While future-oriented approaches have significant advantages, they may pose some challenges:

- in a typical insurance product, premiums are adjusted as insurers get better information about their future exposure. That may not be so easily achieved if the source of funding is a levy or some other hypothecated tax
- unexpected (positive or negative) changes in costs and returns on capital could lead to over or underfunding of future expected liabilities, leading to drawdowns of reserves or dividends to governments.

The sources of funding

Another major issue is the source of funding. It could be:

- income tax — the most common source of revenue for government, and which, through its progressive tax rates, takes account of the varying capacity of people to pay
- a margin added to the Medicare Levy to fund a new scheme so that it becomes the ‘Medicare and Disability Levy’. To the extent that the levy fully funded the scheme, this approach would provide a transparent measure of the amount of funding. It would not require significant changes to tax arrangements since it would not be a new tax. By being dedicated to disability services it would provide a reliable long-run source of revenue less open to cutbacks than finance through general revenue. However, it would be hard to change the levy once the government chose a particular rate. Consequently, a bigger margin for uncertainty would probably need to be built into the rate

- premiums based on individual income, potentially paid through an arrangement like the superannuation levy (a common form in social insurance arrangements in Europe). This is similar to a margin on the Medicare levy, albeit collected in a different way. It could include waivers or concessions for low-income workers
- at least partial funding from the families of people with disabilities, as discussed in DIG (2009a,b). This might include encouragement for parents to set up trusts that could meet their children's needs when the parents age, tax-favoured savings schemes, co-payments or, like Medicare, a safety net in which people meet costs up to some maximum threshold, with full coverage after that spending threshold (or 'front-end deductibles', a common feature of health insurance products)
- the scope for top-up private insurance for services not fully covered by the scheme
- voluntary contributions by the community, which may be in-kind or financial support.

There may be other options involving new taxes or 'premiums'.

Funding consolidation?

In all cases, an open question is the extent of funding consolidation. Currently, all levels of government provide some funding for disability services (local government, state and territory, and Australian governments). And, at each jurisdiction level, many portfolios have their own funding streams partly directed at disability services (education and housing departments, for example). There are two aspects of potential consolidation:

- some or all current revenue sources for disability services could be replaced by a single financing method under a national disability scheme. If this applied to all existing disability services (such as income support, education and housing), then a new disability-specific levy/premium would have to be high
- existing funding sources would be largely maintained, but with the funds combined with the supplementary income from a national disability scheme hypothecated tax/premium to form a consolidated 'fund of funds'. This would then be allocated to services using one coherent system.

What would be the best way of financing a national disability scheme and why? What are the strengths and weaknesses of alternative financing arrangements, including 'pay-as-you-go' and funds that take account of future liabilities?

To what extent would a national disability scheme draw from funds currently collected through general revenue? Would it replace some existing funding sources or consolidate them?

What are the equity and efficiency implications of different models? Who would be the 'tax' collector?

How would cost overruns be managed by different approaches (for instance, using a cash reserve or using the treasury to lend money in times of need)?

What would happen if the fund value exceeded the value of future liabilities (provide dividends to government, serve as a buffer)?

How would exposure to varying investment returns affect the sustainability and prudential management of a future fund?

How could a financing method take into account future demographic pressures? Would it be desirable to do so?

Should there be private funding contributions to a national disability scheme? How much? Through what means?

How could a national disability scheme be used to leverage greater community contributions to the care and support of people with disabilities and their families?

Who would be the funds manager? What should be the investment strategy?

How could a financing method be structured to create the maximum incentives for getting the best outcomes for people with disabilities and their families, increasing efficiency and in achieving early interventions?

Should the funds manager/collector be the body that oversees the national disability scheme more generally?

What lessons are there from overseas approaches for appropriate financing methods?

11 Workforce issues

The bulk of support for disability is informally provided by predominantly (female) family members. Formal disability services are delivered by a range of practitioners from the health and community sector. There is already a shortage of workers in this area. An ageing workforce and increasing competition for the same services by other sectors, such as aged care, will add to these shortfalls. Efforts are underway to attract new workers, including by improving wages, working conditions, training and career paths. However, increasing a workforce's capacity is typically a slow process.

In any event, the skills of the workforce will need to change over time to accommodate new and better ways of delivering services and supporting people with disabilities.

How can workers be attracted to the industry? What role should government play in this process?

What type of skills and workers are required?

What role should government play in upgrading the skills and training opportunities available to workers?

How can a scheme be implemented so that extra funding results in more and/or better services rather than paying more for the same service?

What transition arrangements if any, are required?

How long would it take to build up the required workforce?

Are there particular skill bottlenecks that need immediate attention?

What role could volunteers and workers in mainstream services play?

Allied health professionals have specialist qualifications, whereas those providing direct care, such as personal care, are subject to lesser requirements — mainly aimed at ensuring minimum levels of service provision.

What is the appropriate level of training required before commencing work in the industry? Should any existing certification requirements be altered to reduce obstacles to people working in the disability sector?

What role is there for national accreditation?

Given prospects for ongoing workforce shortages, realising unexploited productivity and efficiency gains will also be important. But there are diverse views on the extent and attainability of these unexploited gains.

What scope is there for productivity and efficiency gains in the sector?

12 Governance and infrastructure

An effective national disability scheme requires appropriate governance mechanisms and associated social and physical infrastructure (figure 2).

- It would be necessary to collect and analyse data about service utilisation, costs, outcomes for people and fund performance to underpin evidence-based practices, effective cost management and optimal premium setting. A research capacity to use this information would also be needed.
- Significant coordination problems between different levels of governments and across different service providers are likely to remain and would need to be addressed.
- Decisions and oversight would be required regarding funds management, especially where large funds are accumulated over time.
- Accreditation, regulation and oversight of service providers may be required.
- A workforce would need to be built up (as discussed above), new physical infrastructure built (such as day centres), assessment tools agreed to, probity and accountability systems developed, laws written and dispute processes designed and implemented.
- Different levels of government would have to agree about their functions in the new system and the way funding might move between them.
- People would need to know about how to use the new system and their entitlements.

Who should do what in a national disability scheme (probity and accountability, data collection, financing, planning, gatekeeper, claims management), and how would these functions be organised?

- *should government departments or an independent statutory body administer the scheme?*
- *to what extent could one agency act as the fund holder and overall decision maker (the role performed by the Transport Accident Commission in Victoria for people affected by catastrophic motor vehicle injury)?*
- *what is the scope for outsourcing various functions of a national disability scheme (for example, claims and risk management by private insurers)?*

Would the new management structure replace, either wholly or partially, the existing systems? How would the various actors in a national disability scheme engage with each other to ensure a coherent system (governments, service *providers, departments)? If existing schemes remain, how will the new scheme interact and communicate with these schemes?*

What kind of information gathering system about outcomes, costs and individual records should be developed, how would it be run, and how long would it take to develop? How would privacy concerns be managed?

What sort of public reporting would be necessary to ensure the accountability and transparency of a new scheme?

How can we reduce the need for form-filling and unnecessary re-assessment?

How might coordination achieve cost savings for governments through buying power, shared investment in systems or in other ways?

How would costs and service quality standards be oversighted and 'red tape' burdens avoided?

What measures should be in place to address adverse unintended outcomes (such as inappropriate claims in personalised funding accounts)?

How would stakeholders be given a 'say' in a national disability scheme? (for example, through an advisory board and formal consultations). Who should be represented?

What arrangements should be in place for:

- *making complaints (for example, a disability ombudsman; complaints devolved to service providers or a centralised complaints arrangement process)*
- *reaching determinations in any disputes (for example, internal departmental arrangements, independent boards, courts or tribunals, or a process involving a number of layers)?*

What would be the appropriate dispute resolution processes?

How would people find out about what they were entitled to (online, one-stop shops, service providers)?

When and how would a national disability scheme be evaluated?

What is the role of research and innovation in a national disability scheme? How could it be promoted, and who would do it?

What are the lessons from existing state and territory arrangements for effective governance of a national disability scheme?

Implementation issues

As discussed above, a national disability scheme involves many complex features and the need to develop capabilities (workforce, administrative systems, assessment tools and so on) to run an effective scheme. A prematurely implemented scheme may expose people with disabilities, carers, governments, and service providers to substantial risks.

That suggests implementation would need to be carefully planned.

What is the realistic time plan and sequence of initiatives for implementing a national disability scheme?

Are there some aspects that can be implemented early (for example, some service expansion, support to a targeted group, key infrastructure)?

What are the priorities for immediate development?

How will stakeholders be engaged during implementation, including their inputs into a scheme and in raising awareness of how to use a new scheme?

Would there be grandfathering of any existing benefits?

The Australian Government and the states and territory governments have quite different roles, and the systems in each jurisdiction vary significantly from each other. That raises major challenges for moving to a more coherent system.

How would governments plan together for the orderly implementation of a national disability scheme?

What are the options if some jurisdictions do not cooperate on key issues?

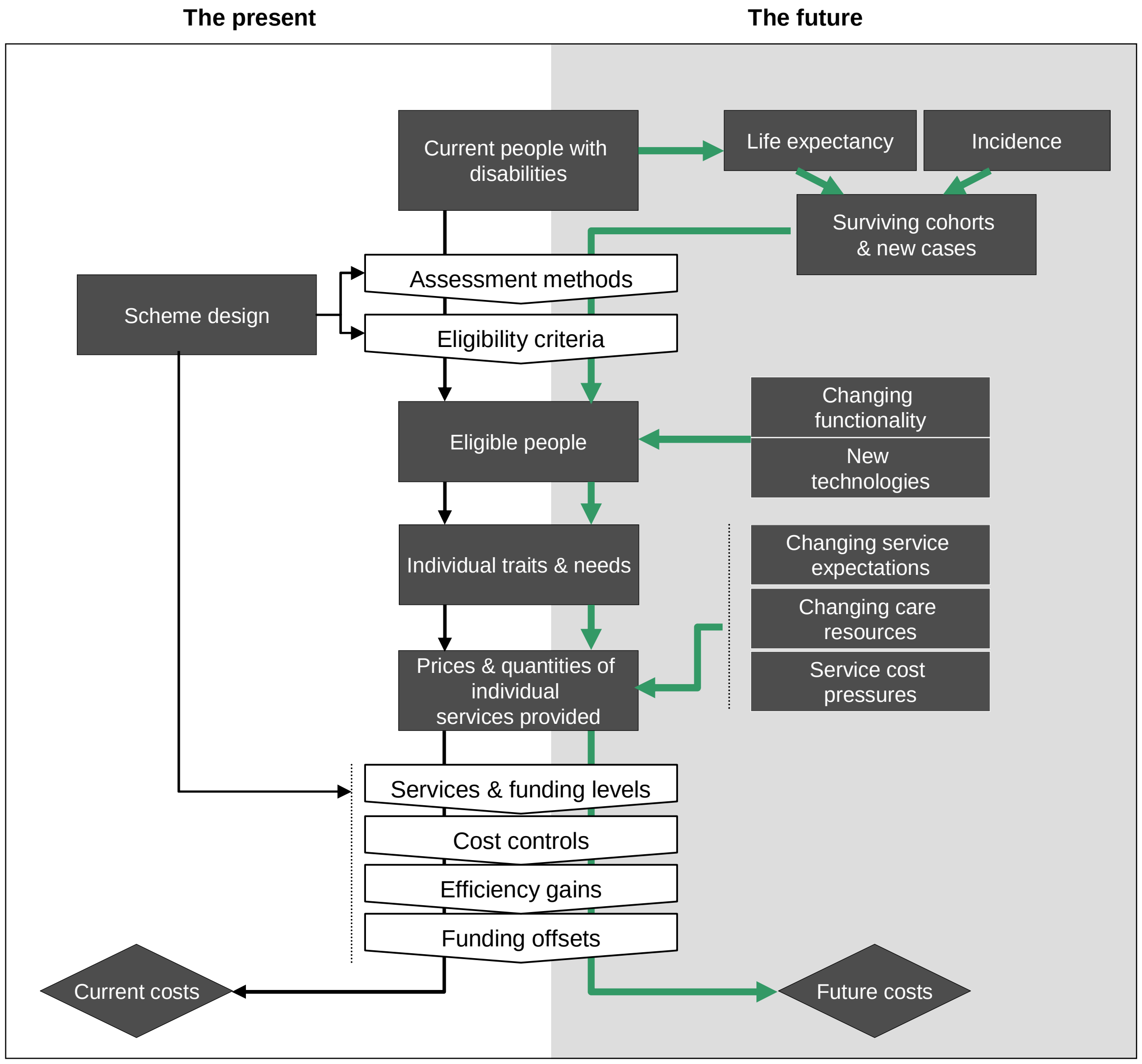
13 Appraising costs, risks and benefits

Judgments about the extent to which various schemes would meet the objectives set out in section 4 is an important way of assessing the best options. The Commission has also been asked to assess the benefits and costs (which includes risks) of new options for disability care and support. This will involve several challenges.

Costs and risks

The long-run costs of a new scheme depend on the number of people eligible, the prices of the services and their quantities — both now and in the future (figure 3).

Figure 3 **Costs of a scheme depend on its exact design**



There are many complexities in estimating costs for any given set of eligibility criteria, which give rise to some financial and other risks:

- *new eligibility criteria and assessment methods* identify different target populations for which information about needs are incomplete
- *existing data on costs by disability subgroup are crude* and typically require assumptions. Different datasets provide significantly varying estimates of the size of some groups. For example, DIG (2009b, p. 75) found that, depending on

the data source, between 6 and 11 per cent of those aged 0 to 14 years with severe or profound disability needed constant care — a relatively wide margin of uncertainty for a high cost segment of the population

- *unmet need is hard to estimate*, not least because the concept of 'unmet' demand is difficult to define. A measure of unmet demand requires a judgment about what constitutes an appropriate or reasonable level of service provision as the benchmark for assessing the shortfall of existing service provision
- *supply bottlenecks and technological factors* will affect future prices and costs. Cost data are incomplete now and are subject to even greater uncertainty over time. There are already significant pressures on caring workforces (child care, aged care, health care and disability). These will rise with the ageing of the Australian population, and are expected to be accentuated by the steadily reduced role of children as carers for ageing relatives. Even if the biggest pressures arise in aged care, the increased demand for services will tend to raise the relative wage rates of all caring labour. And, as has been the case more generally in the health care sector, new technologies tend to add to costs because they are sold at higher prices than legacy technologies, and their better quality tends to increase demand for them
- *future prevalence rates are affected by many factors*. There are changing patterns of new cases (incidence) of disability, while future prevalence also depends on life expectancy, technology and the social environment. Ultimately, the total costs of a new scheme and forward projections of costs are likely to involve a significant margin of error
- *behavioural and incentive effects can affect usage and costs.* A new scheme affects the incentives of people with disability, carers, service providers and (potentially) the multiple levels of governments active in disability care and support. Behavioural impacts — such as greater demand, reductions or increases in cost-shifting between governments (or arms of government), and increases in service prices — may contribute to costs. On the other hand, a shift from informal care to publicly-funded disability services would provide government with stronger incentives to strengthen public health policies that could reduce the incidence and prevalence of disability
- *different funding methods have different cost implications.* The efficiency impacts of increasing funding should be incorporated into costs. These efficiency costs (the 'marginal excess burden of tax') can arise because taxes affect people's incentives to work or invest in capital. Different models for collecting taxes — a levy, income tax, a 'future' fund, and other alternatives — have varying efficiency impacts. (These efficiency costs may be offset by the

increased participation of people with disability, or their family, in the workforce and community.)

How much do various services cost (for example, attendant care, accommodation, day centres), and what pressures are on these costs?

What cost methodologies (and data sources) are appropriate? What are the strengths and weaknesses of alternative costing approaches?

How should unmet needs be measured?

What are reasonable assumptions about future incidence and prevalence?

What would be reasonable assumptions about future cost pressures arising from labour shortages and other factors?

What is the scope for productivity increases to reduce costs or increase service quality?

What would be the efficiency costs of the financing method associated with a new scheme and how does that affect the choice of method?

How should uncertainty be modelled and what implications, if any, does uncertainty have for the design of the scheme and for risk management?

How could the reliability of cost modelling be assessed?

There may be savings in some areas:

- any new scheme will involve some offsets as existing services for eligible people are subsumed into the scheme.
- there may be scope for lowering costs by eliminating duplicated and inefficient services, through innovation, and by using early interventions to reduce lifetime costs. For example, appropriate early interventions for acquired brain injuries have the strong potential to reduce further claims on health, disability, education and even corrective services (noting the increasing evidence that acquired brain injuries are significant among prison populations and may be a precipitating factor for crime — Chan et al. 2004)
- providing better support for informal carers may create a more sustainable informal care system, with long-run savings for formal care. As non-paid care provides far more support than formal paid care, a 10 per cent reduction in the provision of informal service provision translates to a far higher percentage increase in the need for funded services to achieve the same overall level of support (DIG 2009b, p. 2).

To what extent could a new scheme produce cost savings (or other offsets) and what design of the scheme would be likely to maximise these without limiting service delivery?

Benefits

As discussed above, the impetus for a new scheme stems from the flaws in current arrangements.

In some cases, it may be possible to estimate the value from eliminating or reducing these flaws for various scheme options. For instance, it may be possible to estimate the net savings from early intervention and of the gains associated with increased net employment. It may also be possible to estimate the benefits of providing greater assurance to people.

It is more difficult to value the benefits in some areas — such as the value of more equitable treatment of people, greater quality of life, and more choice. The difficulty in putting a dollar value on these benefits does not reduce their importance — there are many well-based public policies for which similar problems arise. However, there may be some ways of assessing the number of people who benefit from possible features of a new scheme, even if it is hard to put a dollar valuation on those benefits. For example, it is likely that reasonably reliable estimates of the number of people who could get cover for catastrophic accidents not relating to a motor vehicle accidents could be made.

Benefits may also vary for different groups of people or with the size and scope of a national disability scheme.

Overall, there may be some weighing up of the various benefits and costs of different options that are more rigorous and objective than others.

What are the benefits from a new disability care and support scheme? Which are most important? Who would benefit most from a new scheme? Where would additional resources be best spent? What level of funding maximises the gains from a new scheme?

How could the benefits of various scheme options be qualitatively or quantitatively assessed?

What criteria should be used to assess the merits of different models of disability care and support? Are there existing studies that provide lessons on how to undertake rigorous assessment of options in this area?

The introduction of any policy can result in unexpected and unintended consequences. Some of the reasons for unintended impacts include the interaction of different policies, but others arise because, throughout the community, people have differing preferences and social and economic circumstances.

Can you foresee any possible unintended consequences from the introduction of a disability care and support scheme?

What could be done to avoid or reduce the impact of any unintended consequences?

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Attachment A Terms of reference

Productivity Commission Inquiry into Disability Care and Support

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 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]

Attachment B: How do you make a submission?

As discussed in section 2 of this paper, you can give us your views in several ways, including by making a formal submission, making a presentation at one of our public hearings, or by giving us a response that reflects your personal experiences. (In the latter case, we will collate the ideas into a document and put this on our webpage, but without names to protect your privacy.) Your ideas are one of the main ways of helping us design a practical scheme that provides real support to people. If you want to make a personal response, rather than a formal submission, send us your views *without* a submission coversheet. Just mark your response PERSONAL RESPONSE. If you want to make a formal submission, then please read this attachment and complete the form shown in attachment C.

What is a formal submission?

A submission sets out your views. A submission can be short. You could set out your key points in one or two pages. Or it can be long with your assessment of many issues. You decide what goes in a submission and how long it is. Where possible, you should provide supporting data and documentation.

While every submission is welcome, multiple, identical submissions do not carry any more weight than the merits of an argument in a single submission.

You can make more than one submission

You may want to put in more than one submission as you respond to what others have said or have new ideas.

Some examples

It may be helpful for you to look at some of the submissions made by people to other inquiries run by the Commission. Some examples of a long and short submission from the Commission's inquiry into paid parental leave are Elizabeth Hill and Barbara Pocock, (submission number 220) and Leanne Nicholson (submission number 67). These can be found at:

www.pc.gov.au/projects/inquiry/parentalsupport/submissions#initial

Sending in your submission

If possible, you should send in submissions by email, and as a text document (.txt, .rtf), a Microsoft Word document (.doc) or similar format, rather than Adobe Portable Document Format (.pdf), to ensure screen readers can access it. Please remove any drafting notes, track changes and other hidden text, as well as any internal links and large logos and graphics. This will enable people to easily view and download submissions from our website. Please fill in attachment C as a cover sheet for your submission.

You may also send submissions by mail, fax, audio cassette and in video formats. We explain how you can contact us on the inside cover of this issues paper.

You can find out other peoples' views

As this is a public inquiry, the Commission will make public submissions and transcripts available for others to read on its website (www.pc.gov.au) and at the Commission's offices in Canberra and Melbourne. Please contact the Commission for information about arrangements for obtaining access to hard copies of submissions.

Can I provide confidential information?

The Commission likes people's submissions to be public for all to see. We will usually place submissions on our website shortly after receiving them.

However, we know that in some cases people do not want to be identified or do not want everyone to see their submission.

- You might want others to see your submission, but do not want your name to be published because the material in your submission is highly personal. In that case, please mark the submission as 'REQUEST NAME BE WITHHELD'.
- You may not want your submission published at all if you are worried about highly sensitive personal or commercial material. Please mark the submission as 'CONFIDENTIAL'.
- You might want to make some of the information in your submission confidential and some information public. In particular, the Commission would still like you to include your views on what a disability support and care scheme should look like — this part of your submission should be public. Please provide the confidential part as a separate document — just let us know which document is confidential.

Copyright in submissions sent to the Commission belongs to the author(s), not with us.

If you have any queries please contact us.

Attachment C

Disability Care and
Support Inquiry

SUBMISSION COVER SHEET

(we do not publish this page)

Please complete and return this cover sheet with your submission to:

Disability Care and Support Inquiry Productivity Commission, GPO Box 1428, Canberra City ACT 2601	**OR**	By facsimile (fax) to: Roberta Bausch (02) 6240 3377 By email: disability-support@pc.gov.au

Person

Organisation and position (if relevant)

Address *Suburb/town*

State *Postcode*

Email address *Phone ( )*

Fax ( ) *Mobile*

Please indicate if your submission:

☐ contains NO confidential material

☐ can be made public, but should have the name withheld. Mark 'WITHHOLD NAME'

☐ contains SOME confidential material (provided under separate cover and clearly marked)

☐ contains confidential material and the WHOLE submission is provided 'IN CONFIDENCE'

For submissions made by individuals, all personal details other than your name and the State or Territory in which you reside will be removed from your submission before it is published on the Commission's website. Submissions will be placed on the Commission's website, shortly after receipt, unless marked confidential or accompanied by a request to delay release for a short period of time. Submissions will remain on our website as public documents indefinitely.

Please note:

Confidential material should be provided under a separate cover and clearly marked 'IN CONFIDENCE'. Copyright in submissions resides with the author(s), not with the Productivity Commission.