

# Disability Care and Support

Productivity Commission Inquiry Report

No. 54, 31 July 2011

**Executive Summary** 

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# Executive summary

The current disability support system is underfunded, unfair, fragmented, and inefficient. It gives people with a disability little choice, no certainty of access to appropriate supports and little scope to participate in the community. People with disabilities, their carers, service providers, workers in the industry and governments all want change.

Most people know little about Australia's current disability system and do not know how poorly they would be served were they to need it — this is a system marked by invisible deprivation and lost opportunities. Yet major disability can happen to anyone and at anytime — a simple fall can lead to quadriplegia, and an illness to severe brain damage. Most families and individuals cannot adequately prepare for the large costs of lifetime care and support. The costs of lifetime care and support can be so high that the risks and costs need to be pooled.

It was against that background that the Australian Government asked the Productivity Commission to look at the costs, cost effectiveness, benefits and feasibility of replacing the current arrangements with a properly funded and managed long-term disability scheme. This short summary outlines the Commission's ideas for a new way of meeting the care and support needs of people with a disability. The table below provides a snapshot of the current system and what the Commission thinks it should look like. There is also a more detailed overview, which includes the 86 recommendations of the report. The Commission has produced an additional 1200 pages of supporting material setting out how a new scheme could be implemented at a detailed level and providing in-depth evidence for the recommended approaches. The inquiry drew from 23 days of testimony in formal hearings held around Australia and extensive evidence from nearly 1100 submissions from people with disabilities, carers, service providers, governments and business. You can find this material on the Commission's webpage: http://www.pc.gov.au/projects/inquiry/disability-support. The last page of the executive summary indicates what has changed since the draft report.

The bottom line of this report is that a new national scheme for disability — like Medicare — is feasible, that it would produce very large benefits for Australians and that a realistic and clear implementation pathway is available.

The Commission also recommends the establishment of a National Injury Insurance Scheme — run at the state and territory level — that would provide lifetime support for people acquiring a catastrophic injury from an accident. It would draw on existing arrangements in some states.

# 1.1 Overcoming the problems of the present system

Commont much la man	How the managed emergence we detailed address the comment we blows		
Current problem:	How the proposed arrangements would address the current problems		
Poor national insurance	Full coverage of all Australians for the costs of long-term disability care and		
(people without a disability have no clear coverage if	support, so people without a disability could feel confident that they or their		
they acquire a disability)	families would be supported in the event of a significant disability. Insurance has value for people even if they make no claims		
Inequitable	A national scheme with national standards and entitlements that would cover		
	people with significant disabilities arising from non-accidents		
(eg what you receive in assistance depends on	State-based arrangements for no-fault insurance coverage of all catastrophic		
where you live)	accidents — with minimum national standards		
Underfunded with long	Funding would be doubled and tied to the Australian Government's revenue-		
waiting lists	raising capacity (characterised by more efficient and sustainable taxes)		
Failures to intervene early	The schemes, like all insurers, would aim to minimise long-term costs, so they		
(eg people stuck in hospital	would have a strong incentive to undertake early intervention where it is cost		
because of insufficient funds	effective. The scheme would spend dollars to save more dollars and people		
for minor home	would not have to wait for basic supports like wheelchairs and personal care		
modifications)			
Fragmented	Universal schemes; locally responsive within nationally coherent framework;		
	funds and assessments portable across borders and support providers		
Lack of clear responsibilities	Assessments under the NDIS would identify and facilitate referrals to the right		
	supports outside the NDIS		
People with disabilities and	People would be able to choose their provider or providers. They could		
their families are	choose to have a disability support organisation manage their packages or to		
disempowered and have	act in other ways on their behalf		
little choice	They would be able to manage their own funds if they wish (within rules)		
Little future planning	The NDIS would encourage and support people into work and/or being more		
	involved in the community. People's short and long-term plans would be		
	reflected in their individual support packages		
Family and carers are	The support provided by families would be considered in assessments, and		
devalued	where appropriate, carers also assessed and given additional supports		
Insufficient engagement with the community	The NDIS would leverage a bigger role for community groups and not-for-		
	profit organisations to connect people with disabilities with the community		
Economically unsustainable	Appropriate funding would stabilise the withdrawal of informal care under the present crisis-based system (which is leading to the costly withdrawal of		
	informal supports by non-coping carers)		
Inefficient with weak	The new scheme would be run to insurance principles by a commercial board		
governance	with strong and constant monitoring by Treasury. Advice from a council of		
governance	stakeholders (people with disabilities, carers and providers). People with		
	disabilities and their families would have more control over the services they		
	receive. They would have a strong incentive to maximise outcomes, and a		
	direct stake in cutting waste and unnecessary services. Many safeguards to		
	ensure costs did not get out of control. Benchmarking against schemes		
	overseas and between the NIIS and NDIS		
People have no confidence	The scheme would focus on long-term care and support needs. People would		
about the future: what	have clear entitlements to their assessed needs. There would be		
services will and will not be available	arrangements to guide people through the system, with strong complaints and appeals mechanisms		
avallable	Strong reserves to buffer the insurance fund. The scheme funds would not be		
	tied to the annual budget cycle, but would have mandated funding		
	hypothecated to a separate fund		
Poor information, poor data	Information provision through web and other means by a single national		
collection for disability	agency, disability support organisations to act on behalf of people, availability		
services to ensure efficient	of objective information about supplier performance; coherent collection of		
management	data by the scheme to manage costs and to assess outcomes		
Poor evidence base	Research function and evidence-based practice		

# 1.2 Key features of the NDIS and NIIS

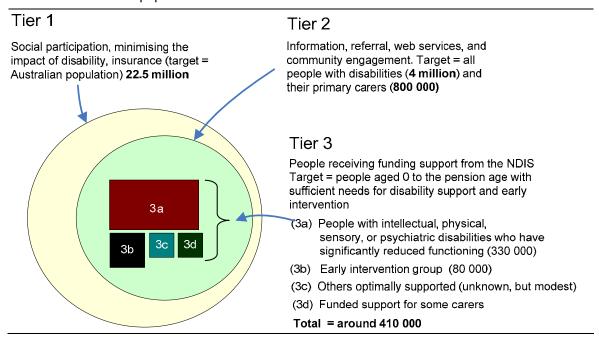
The largest scheme would be the National Disability Insurance Scheme. It would be like Medicare, in that all Australians with a significant and ongoing disability would get long-term care and support (but *not* income, which would be left to private insurance and to the Australian Government's income support system). A second smaller scheme (the National Injury Insurance Scheme) would cover the lifetime care and support needs of people who acquire a catastrophic injury from an accident. The smaller scheme would be based on the motor accident compensation schemes that operate in some states and territories.

	National Disability Insurance Scheme (NDIS)	National Injury Insurance Scheme (NIIS)
What kind of scheme is proposed?	A national scheme to provide insurance cover for all Australians in the event of significant disability. Its main function would be to fund long-term high quality care and support. Other important roles include providing referrals, quality assurance & diffusion of best practice	A federated model of separate, state-based no-fault schemes providing lifetime care and support to all people newly affected by catastrophic injury. It would comprise a system of premium-funded, nationally consistent minimum care and support arrangements for people suffering catastrophic injuries
Who would be covered?	All Australians would be insured. Funded support packages would be targeted at all people with significant and permanent disability, whose assistance needs could not be met without taxpayer funding. Anyone with, or affected by, a disability could approach the scheme for information & referrals	All causes of catastrophic injuries, including those related to motor vehicle accidents, medical accidents, criminal injury and general accidents occurring within the community or at home. Coverage would be irrespective of how the injury was acquired, and would only cover new catastrophic cases
What it would provide?	The NDIS would provide reasonable and necessary supports across the full range of long-term disability supports currently provided by specialist providers.  Services such as health, public housing, public transport and mainstream education and employment services, would remain outside the NDIS, with the NDIS providing referrals to them	The NIIS would provide lifetime care and support services broadly equivalent to those provided under the Victorian TAC and NSW Lifetime Care and Support scheme. This includes reasonable and necessary attendant care services; medical/hospital treatment and rehabilitation services; home and vehicle modifications; aids and appliances; educational support, and vocational and social rehabilitation; & domestic assistance
What would be the cost?	The scheme would cost approximately \$6.5 billion above current spending (around \$295 per Australian). Total expenditure would be around \$13.5 billion per annum	Net annual costs of a comprehensive no-fault scheme covering all catastrophic injuries could be around \$830 million (around \$35 per Australian)
How it would be funded?	The Australian Government should direct payments from consolidated revenue into a 'National Disability Insurance Premium Fund', using an agreed formula entrenched in legislation.	The additional funding required for the NIIS would come from existing insurance premium income sources
How many people would receive funding?	new cases	The NIIS would cover new incidence of catastrophic injury (around 900-1000 people each year), but over the long run, 30 000 people would be in the scheme
When would the scheme commence?	A full-scale rollout in a few regions of Australia in mid-2014. It would extend to all Australia in 2015-16 covering those most in need, and then progressively expand to all significant disabilities by 2018-19	As a starting point, jurisdictions should implement no-fault catastrophic injury schemes for motor vehicle accidents by the end of 2013. The NIIS would cover all catastrophic injury by the end of 2015

#### 1.3 Who is in the NDIS?

The NDIS comprises three tiers. The bulk of the funding is directed at 'tier 3'—those receiving funded supports.

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



For tier 3, the critical entry requirements focus at those most in need. A person receiving funded support from the NDIS would have a disability that is, or is likely to be, *permanent*. The definition of 'permanence' would include people with long-term functional limitations who may only need episodic support. In addition, people would have to meet at least one of the following conditions. They would:

- have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support (3a). As a result, the scheme would cover the support needs of people with major physical disabilities and cognitive impairments (mainly intellectual disability and significant and enduring psychiatric disability)
- be in an early intervention group (3b). This would encompass people for whom there is good evidence that the intervention would be safe, cost-effective and significantly improve outcomes.

The Commission estimates that these criteria would cover around 410 000 people. There would also be scope to include people who have large identifiable benefits from support that would otherwise not be realised (3c) and for some support for carers (3d).

## 1.4 What supports would the NDIS provide?

Aids & appliances and home & vehicle modifications, including prosthetics and communications aids.

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

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

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

**Respite** to provide a short-term and time-limited break for people with disabilities, families and other voluntary carers of people with a disability. Respite is designed to support and maintain the primary care giving relationship, while providing a positive experience for the person with a disability and includes:

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

**Specialist accommodation support**, such as group homes and alternative family placement (but not places that provide primarily clinical supports).

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

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

**Supported employment services and specialist transition to work programs** that prepare people for jobs.

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

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

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

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

# 1.5 When will it happen? Implementation of the NDIS

#### Date Milestone COAG would: Second half of 2011, or agree to an MOU that sets out in-principle agreement that the NDIS should early 2012 commence in stages from July 2014 create a high level taskforce with agreement of participating jurisdictions, to be headed by a person with insurance or disability experience who has driven change successfully in a large organisation (appointed with the agreement of participating jurisdictions) The taskforce would: develop a draft intergovernmental agreement for final signing in 12 months establish an expert project management implementation team with experience in commercial insurance and disability to work full time on planning the details of the scheme including targeted consultation and early work on key operational arrangements, including assessment tools, risk management and transition arrangements report regularly to Heads of Treasuries meetings and COAG on milestones reached in the planning for the commencement of NDIS in July 2014 July 2012 During 2012-13, the following need to be well underway: drafting of legislation June 2013 preparing MOUs with government departments developing data collection protocols researching appropriate IT arrangements recruiting and training of staff testing of assessment tools preparing manuals determining pricing arrangements working with providers to identify likely areas of workforce shortage and strategies to address them, with a particular focus on regional launch sites drawing up of tenders developing communications strategies detailed planning for the regional launch sites, including with new and potential service providers, DSOs, not-for-profit organisations and community groups By Feb 2013: final consideration and agreement by COAG to the intergovernmental agreement, including an agreement on funding arrangements March to June 2013: Commonwealth to introduce legislation to create NDIS and NDIA, with an initial appropriation

state legislation and further Commonwealth legislation to follow

Announcement of the NDIA board

(Continued next page)

Date	Milestone
July 2012 to June 2013 (continued)	<ul> <li>The NDIA board to commence formally</li> <li>the board to appoint a CEO</li> <li>the board to appoint interim staff from the taskforce executive, the project management implementation team, and/or from elsewhere, as determined by the board</li> <li>staff recruitment to begin</li> <li>The NDIA should be established by June 2013.</li> </ul>
July 2013 to June 2014	<ul> <li>During 2013-14:</li> <li>NDIA staffing levels would be rising (including regional offices)</li> <li>IT infrastructure would be purchased</li> <li>workforce strategy would be implemented</li> <li>capacity building would commence, including providing information and assistance to service providers in preparation for moving away from blockfunding</li> <li>Intensive work for rollout of the scheme in selected launch regions, including:         <ul> <li>appoint and train NDIA regional managers (July – Dec)</li> <li>establish local and regional offices for NDIA for the initial launch regions (July – Dec)</li> <li>regional managers would engage with existing and potential service providers (Aug – Dec)</li> <li>and check on their preparations for expansion in 2014, including recruitment, and testing of IT systems (early 2014)</li> <li>intensive training of allied health professionals as NDIS assessors for the initial launch regions (early 2014)</li> <li>recruitment and training of local area coordinators</li> <li>public information campaigns and outreach in the initial regional launch sites by local area coordinators to local disability organisations, people with disabilities, existing and potential service providers, local community service groups and local media (early 2014)</li> <li>information sessions in these regions for people with disabilities, their families and carers, service providers and the general community (early 2014)</li> <li>what the NDIS will do for people</li> <li>the assessment process</li> <li>people's rights and responsibilities</li> <li>disability support organisations may also undertake group information sessions</li> <li>call for interest and pre-registration of those participating in the initial launch</li> </ul> </li> </ul>

Date	Milestone
July 2014	In July 2014, the NDIS would commence providing full services in a few regions of around 10 000 clients per region
	<ul> <li>thereby providing high quality services to many thousands of people, while allowing fine-tuning of the scheme in the light of lessons learned</li> </ul>
	Throughout 2014-15, all local and regional offices would be established across Australia, with local staff engaged and trained
	<ul> <li>a national information campaign would be undertaken, including information sessions by local area coordinators to local disability organisations; people with disabilities, their families and carers; existing and potential service providers; local community service groups; local media; and the general community</li> </ul>
	<ul> <li>in all regions, work would commence with local groups on a compact to increase social participation and employment opportunities for people with disabilities</li> </ul>
	The NDIA would work with providers to monitor the developing workforce and to address emerging shortages.
July 2015	In July 2015, the NDIS would extend nationally to cover all of Australia
	<ul> <li>progressively it would be expanded to cover all relevant people with a disability, commencing with all new cases of significant disability and some of the groups most disadvantaged by the current arrangements.</li> </ul>
2016-17	Second year of national rollout
2017-18	Third year of national rollout
	NDIA evaluation of effectiveness of self-directed funding
2018-19	Final year of national rollout: all current and new clients to be receiving NDIS services
2020	Independent review of NDIA and NDIS

Gradual implementation has several major advantages because it would allow

- time to get legislation in place and a high quality management team
- time to get the detail right
- time to build up resources (noting present labour shortages and the need to rollout national infrastructure)
- an orderly transition from current arrangements
- gradually rising fiscal pressures, consistent with the financing capabilities of the Australian Government (the full costs arise in 2018–19).

#### 1.6 What will the NDIS cost?

The bottom line is that the incremental costs of the NDIS would be around \$6.5 billion, compared with current funding of around \$7.1 billion — representing a 90 per cent increase in funding. The magnitude of the spending reflects how bad the current system is. Over the longer run, there would be some important downward pressures on the direct scheme costs. These arise from:

- the gradual coverage of disability arising from catastrophic injury, as the NIIS (the sister scheme) fulfils that role
- the benefits from cost-effective early intervention, which will produce better outcomes for people and reduce costs for future taxpayers
- the likelihood that a coherent and well-governed system based on insurance principles would improve productivity in the sector.

#### Progressive costs of the NDIS, 2011-12 to 2018-19

Year	Stage of implementation	Likely annual costs
remainder of 2011-12	getting agreement	\$10 million
2012-13	<ul><li>planning the details of the scheme</li><li>setting up legislation</li></ul>	\$50 million
2013-14	<ul> <li>bedding down administrative arrangements</li> </ul>	\$550 million
2014-15	scheme begins with regional rollouts	\$900 million (net)
2015-16	first full year of national rollout	\$2.4 billion (net)
2016-17	second full year of national rollout	\$3.9 billion (net)
2017-18 third full year of national rollout		\$5.4 billion (net)
2018-19	final year — rollout now complete	\$6.5 billion (net)

# 1.7 What will be the benefits of the NDIS and the associated reform package

Fundamentally, the NDIS (and other complementary reforms) addresses the large list of deficiencies present in the current system.

These benefits arise from many sources: wellbeing gains to people with disabilities and informal carers; efficiency gains in the disability sector; savings to other government services; increased labour force participation, and the resulting fiscal gains.

The net *economic* cost of the NDIS is not the budgetary cost of around \$6.5 billion (which is a transfer of resources from one group to another). Rather, the economic costs reflect the distortionary impacts of raising the revenue, which can arise as people work less or through reduced investment. That represents a cost of around \$1.6 billion. Given this, the NDIS would only have to produce an annual gain of \$3,800 per participant to meet a cost-benefit test. Given the scope of the benefits, that test would be passed easily.

The most important of the economic benefits are the welfare impacts for people with a disability and their carers. While not counted in official statistics about the performance of the economy, these are genuine and large economic gains. One, partial way of assessing these gains is the value of the implicit income transferred by the NDIS to people with disabilities. Commission estimates suggest benefits of around \$7.8 billion annually (and this already takes account of the lost consumption for those people funding the scheme). This is likely to significantly understate the benefits.

It is harder to measure some of the other economic *benefits* of the NDIS, but it is possible to assess some of its economic *effects*. These will take some time to emerge. Were Australia to achieve employment ratios for people with disabilities equivalent to the average OECD benchmark — a highly achievable target given the proposed reforms — employment of people with mild to profound disabilities would rise by 100 000 by 2050.

In fact, the package of measures, including through reforms to the Disability Support Pension (DSP), would be likely to raise employment by considerably more than 100 000. Under a reasonable scenario, the Commission estimates that there could be additional employment growth of 220 000 by 2050 (including for people with less severe disabilities).

By 2050, the collective impact of these two employment gains would be around a one per cent increase in GDP above its counterfactual level, translating to around \$32 billion in additional GDP (in constant price terms) in that year alone.

However, it is important to note that some of the economic impacts of the NDIS measured in official statistics of employment and output do not include the offsetting reductions in unmeasured informal employment and output.

There would also be fiscal gains from reductions in DSP beneficiaries and an increase in part-rate DSP payments. These gains materialise slowly, but the value rises steeply. Taking account of the benefits over the longer run, the reforms would be equivalent to reducing budget pressures by around \$2.7 billion (in constant prices) per year over the next 90 years.

# 1.8 Financing the NDIS

Four principles drive the structure, governance and financing recommendations of the report:

- the requirement for certainty of funding (like the age pension)
- financial sustainability
- equity
- efficiency.

These are best achieved through having a strong insurance framework with the Commonwealth to fund the NDIS based on a legislated formula. Only the Commonwealth has the revenue base to provide certainty. Accordingly, the Australian Government should be the single funder of the NDIS. It should direct payments from consolidated revenue into a National Disability Insurance Premium Fund, using an agreed formula entrenched in legislation that:

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

The states should reduce inefficient states taxes (their stamp duties) by the amount of own-state revenue they used to provide to disability services (a 'tax swap').

#### What if the states refuse a tax swap?

If state and territory governments refuse to reduce their taxes, but want to participate in the scheme, there are alternative ways of the Commonwealth recovering a quid pro quo contribution. Given the staged rollout of the scheme, the Commonwealth could gradually reduce, or not increase, some special purpose payments.

# What are the alternative means of the Commonwealth funding the NDIS?

We have looked at alternative sources of Commonwealth funding for the scheme, but these are inferior options. The Australian Government could legislate for a levy on personal income (the National Disability Insurance Premium), with an increment added to the existing marginal income tax rates, and dedicated to the full revenue needs of the NDIS. The rate would need to take sufficient account of the pressures

of demographic change on the tax base and to create a sufficient reserve for prudential reasons.

A dedicated tax is not as efficient as the legislated contribution from the consolidated revenue fund because it does not exploit the opportunities for funding the scheme through spending reductions elsewhere and for future tax reforms to deliver a more efficient source of revenue. A dedicated tax would not be a future-proofed arrangement.

# What if the Australian Government does not want to be the sole funder?

If the Australian Government does not follow the Commission's most preferred financing option and instead adopts a joint funding arrangement with the states, it should be based on agreed shares of the legislated formula. It would be critical to use a clear funding framework based on a long-run formula, since shorter-term arrangements, with re-negotiated co-contributions would be likely to ultimately break down, losing the required certainty of funding.

## 1.9 What are the essentials of the NDIS?

While it would be ideal to have all states and territories participate in the NDIS, this is not essential. Under a second-best option, the Commonwealth should reach agreement with participating governments and move ahead. It should not wait for any state or territory that does not want to participate.

Any arrangement for funding and organising the NDIS should have some key features to ensure the financial sustainability of the scheme and an equitable and efficient system:

- the same national eligibility criteria, assessment toolbox, arrangements for assessors, and access to the full range of necessary supports. That would mean that regardless of location, people with equal disability status and traits/natural supports would receive the same entitlements based on need
- certainty of future resourcing based on a legislated formula for funding
- the model and management of an insurance scheme, including the sophisticated collection and analysis of data to measure the outcomes and performance of the system, and a national research capacity. That would maximise efficiency and underpin a framework for decision-making that considers the whole-of-life costs

of support for a person, with the capacity to make early investments that save future costs

- a shift from block funding and a service-centred model to one in which people with disabilities and their carers would wield the greatest control, whether that be to cash out their package, or to have it met in flexible ways by providers. Under any arrangement, people could choose their providers, which would have to conform to common quality standards, compete on a competitively neutral basis and be remunerated using efficient prices. Informed choice would be supported by providing nationally consistent and publicly available measures of the performance of service providers
- a focus on individual needs and outcomes, allowing people with disabilities to reach their potential through funded supports and/or active interaction with the community. In many cases, this will include supporting individuals in understanding how to take advantage of choice and options
- the inclusion of local area coordinators, disability support organisations and a wider community role for current not-for-profit specialised providers
- a national service provider strategy (capacity building and attitude change) and workforce development strategy.

The Commission's strong view is that these core features would be best organised using a single agency — the National Disability Insurance Agency — that would oversee a coherent system for all Australians, regardless of their jurisdiction. The national model and its overseeing agency would learn from the best arrangements in place around Australia (such as local area coordinators in Western Australia and the accident schemes in Victoria, NSW and Tasmania).

#### What about a federated model for the NDIS?

Some say that devolved management (a 'federated' model) is appropriate because the states run the systems now. However, the present arrangements are severely flawed, and a new system and approach is required. A federated model that included *all* of the core elements above (including a legislated formula for funding) would be better than present. The Commission considers it a third-best option. The major problem with a federated model is that achievement of nationally-agreed critical design features would not take place or could disintegrate into the fragmented arrangements typical of the current system. In contrast, the Commission's most preferred option — a national scheme with a single funder — would be stable and coherent, and would still have a strong regional presence and flexibility.

The worst of all worlds would be joint funding based on the vagaries of all jurisdictions' budgets and preservation of what amount to haphazard governance arrangements, varying eligibility criteria, and low degrees of power to people with disabilities (Only a few states provide people with much choice and genuinely individualised packages — block funding still rules in most places.)

# 1.10 The National Disability Insurance Agency

The National Disability Insurance Agency would not deliver mainstream services or provide specialised services, since it would be unlikely to be proficient at this and it would be inconsistent with a consumer choice model.

A new form of organisation, 'disability support organisations', would offer people brokering services, the skills and confidence to practically exercise choice, management services (such as dealing with the administrative aspects of self-directed funding, were a person to go down that route), personal planning, and orientation supports for people who are suddenly faced with the unfamiliar world of severe disability. They would also develop linkages with mainstream local community groups (such as Scouts or Rotary) so that these were receptive to the inclusion of people with disabilities generally — in effect, a community capacity building role. Disability support organisations and local area coordinators would then be able to match specific people to such community groups, depending on the preferences and personal plans of the person.

People with disabilities and service providers would need to be able to complain to, and contest the decisions of, the National Disability Insurance Agency. The Commission proposes that there would be an Office of the NDIS Inspector—General to hear complaints by people with disabilities and providers about the conduct of the Agency, and reassess contested decisions on a merit basis.

While located within the NDIA, the legislation for the National Disability Insurance Agency would ensure the independence of the Office. The Inspector–General would be separately appointed by the Australian Government, and the legislation would specify that that Inspector–General be independent (an 'independent statutory officer'), would act fairly and impartially, would base decisions on the available evidence, and could not be directed in his or her decision-making. The Inspector–General would be required to follow complaints made, and would have the power to undertake investigations and to direct the National Disability Insurance Agency to alter contested decisions. The legislation would require that regard be given to the legal entitlements of the individual.

#### The structure of the NDIS

#### Functions controlled by the NDIA

#### Governing board

- Appoints CEO
- · Sets corporate plan
- Oversees the performance of the NDIA
- Ensures financial sustainability and good governance
- Seeks advice from Independent Advisory Council as to how well the NDIA meets the needs of its stakeholders
- · Reports to Minister and the community

#### National Disability Insurance Agency

- Assesses needs and determines individual plans and budgets
- · Authorises funding of services and supports
- NDIA local area coordinators oversee system at local level
- Web and information services for people with disability, carers and Australians generally
- Assist people in contacting other government service providers
- · Help build capacity among participants and providers to work within the scheme
- Help build local community capacity for inclusiveness, including encouraging not-forprofits to take on this role, and through small grants to local community groups
- Determines efficient prices for supports
- Central purchasing of some goods & services
- Manage costs and future liabilities
- Collect and analyse data about services used, outcomes, efficacy of interventions and provider performance
- Research function
- Provides advice to and monitors fund holder
- Innovation fund
- Interacts with and reports to the board
- Create a stakeholder group that advises the NDIA on ways of controlling compliance burdens on services providers and people with disabilities, and to ensure plain english forms

#### Internal but independent review process overseen by Inspector-General to:

- Manage complaints about suppliers
- Review NDIA decisions where a person appeals
- Provide mediation services
- Oversee quality assurance of service providers

#### Functions controlled outside the NDIA

#### Government disability & mainstream services outside the **NDIS**

DSOs

- Provides other government-funded services to people with disability
- Provides income support
- Agreements with NDIA about respective responsibilities
- Referral of clients to the NDIA
- Provides data to NDIA

# -unctions focused on people with disabilities (intermediaries)

- Provide personal planning services & individual guidance
- · Links people to the community
- Assembles 'packages' of supports from specialist and mainstream providers
- Undertakes administrative tasks for people using self-directed funding
- Provides data to NDIA
- Innovation in coordinating services

#### Disability service providers

- · Supplies & promotes services to people
- Coordination of a specific provider's services
- Internal complaint mechanisms
- Provide data to NDIA
- Innovation in service delivery

#### Private mainstream providers

Supplies services to people

#### The wider community (not-for-profit organisations, local councils, businesses)

- Community awareness of disability issues
- Economic and social inclusion of people with disability
- A compact with the NDIA to improve outcomes

# Governments

- Form policies
- Appoint Board
- Monitor sustainability
- Guarantees collection of funds (Australian Government)

# Courts

Hears appeals on matters of law

# Treasury

- Assesses scheme performance • Reports to governments about problems with performance

# manager

NDIA-focused functions

# Fund

- Manages funds on behalf of the NDIA
- Provides advice to NDIA
- · Responds within constraints to advice from the NDIA

#### Auditing

 Provides professionally independent audits and accounting reports on the NDIA to the government and public

# 1.11 What would it mean for providers?

The NDIS would change the way services are supplied and funded. There would be:

- more resources (and more satisfaction in being able to meet people's needs).
   Notably, despite the inevitable changes that the NDIS would have for service providers and the greater risk they would face in a world where block funding had virtually disappeared most service providers endorsed the Commission's proposed model
- a change in philosophy for some no longer a service-led model, but one in which people with disabilities would hold the reins
- a greater capacity for innovation
- more competition and an expectation of good performance (outcomes would be published — for example, do support workers turn up on time? What is the hospitalisation rate for people prone to bed sores?)
- a coherent system for data collection and portable records for people to reduce duplication of information requests
- a special advisory group for the NDIS to keep red tape burdens as low as possible.

## 1.12 What would it mean for the states and territories?

It would mean:

- a better system for people with disabilities in their jurisdictions. Many governments agreed their own arrangements were heavily rationed and not working well
- relief of growing budgetary pressures. It would not be fiscally feasible for states and territories to fund the NDIS alone (given the need for a 90 per cent funding increase)
- a different role a contribution to the governance arrangements of the NDIS and a role in forming the legislation. But they would have no ongoing role in managing the disability system in their states
- the potential to continue as service providers but on a competitively neutral basis with other providers.

## A cameo for a service provider under the NDIS

At present *Carecom* Incorporated is a medium sized disability support provider that is block funded to supply attendant care services, day programs for people with an intellectual disability and manages two group homes.

As *Carecom* has a proven track record of quality service provision, with its state government disability authority, after a few basic checks it is quickly granted approval under the NDIS. Before the rollout of the NDIS, the NDIA provided *Carecom* advice about managing customer accounts and billing processes.

As the NDIS is gradually implemented, block funding is slowly withdrawn, and *Carecom* moves to primarily bill the NDIA per service user. *Carecom* also bills a small number of clients using its attendant care services directly, as they have undertaken self-directed funding. *Carecom* no longer has to juggle multiple contracts and reapply for funding at funding rounds. So long as its services are good enough to attract customers, its funding is secure.

Annually, the NDIA checks that *Carecom* is compliant with the national disability services standards through surveying its clients, talking to local area coordinators about its performance and in other years through occasional audits. Community Visitors periodically check on the welfare of the people staying in its group homes.

With the rollout of the NDIS:

- customers can find Carecom through the internet database of service providers, as well as from lists provided by local area coordinators and disability support organisations
- Carecom can access relevant information about its clients through the electronic record (with their permission)
- if customers have complaints with *Carecom* that are not being addressed, they can lodge a compliant with their local area coordinator or complain directly to the Inspector-General (and independent office that hears complaints).

# 1.13 What would it mean for people with disabilities and carers?

Most families and individuals cannot adequately prepare for the risk and financial impact of significant disability. Everyone would have insurance for themselves or their loved ones.

People's reasonable needs would be met across all the appropriate kinds of support, with certainty over people's lives. As one person said, even small amounts of support can make life more comfortable and dignified:

A few more hours a week [of assistance] would decrease the strain on my body and allow me to go the toilet when I feel like it, and not necessarily when the schedule dictates. ... There are often instances during the day when I do not eat at certain times because I know it will adversely affect my toileting patterns. (Todd Winther sub. 346)

Carers would get the support they need to continue their role as informal carers, and to have better paid employment prospects. Older carers would no longer have to worry about what would happen as they become frail or die.

There is compelling evidence that people with disabilities and carers have high levels of psychological distress — and this should be significantly allayed.

The Commission has recommended some changes to the Disability Support Pension so that it has the same goals of maximising people's economic and social participation as the National Disability Insurance Scheme. Two major proposed changes would be that people could more easily get the DSP while working, and would get bonuses for working. Combined with the NDIS and improvements in disability employment services, reform of the DSP would mean that people with disabilities would be more likely to obtain jobs and to keep them, and to play an active role in the community.

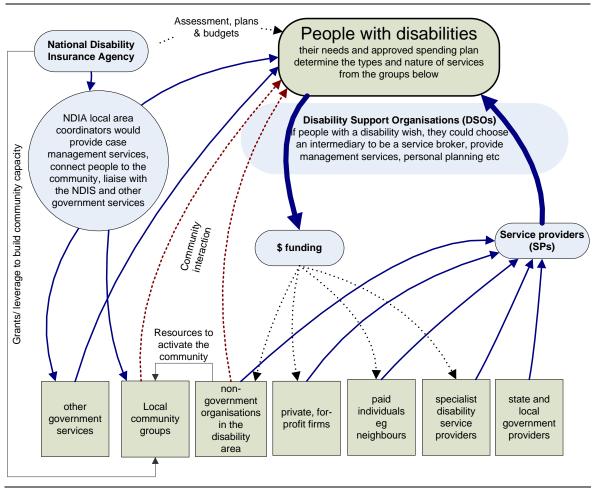
## People would be able to exercise more power and control

People would get packages tailored to them.

They would be able to choose a provider or get a disability support organisation to broker a deal or help them manage their packages

If they want and are able, people could cash out their packages, and subject to a plan and oversight, manage their own disability support needs, including employment of support workers ('self-directed' funding). Empirical evidence from multiple studies shows that self-directed funding has significant benefits, but that it also takes time before many people take advantage of it.

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



The cameos below provide concrete examples of how the NDIS should work for people with disabilities.

## A young adult with an intellectual disability

Emily is 27 years old with Down Syndrome and lives at home with her mother, Kathy, in an outer suburb of a capital city. Kathy works, so she can only provide support in the evenings. Emily completed her education in a mainstream high school, but has not gained any other educational qualifications since, and has never had a job.

Emily can manage most of her personal care requirements, such as bathing and dressing herself, but she has difficulty in managing her weekly schedule, like remembering to exercise, getting out and about, going to appointments or cooking properly. Although Emily can catch public transport from her home to the day centre, she has trouble navigating the city's broader public transport network. She goes to a day activity with other people with intellectual disabilities, but she finds the activities boring, and feels she is constantly being ordered about.

Emily loves to act and would like to take drama classes. She would also like to have a job, so she can earn some more money and meet other people.

Following a discussion with Emily and her mother, the NDIA completes an assessment of Emily's needs. She is given a package that includes provision for work training, community access (like a day centre), a weekly visit by someone who helps organise a diary for her week, and some one-off assistance about how to use the public transport system, and to use a mobile phone in case she gets lost or upset.

Kathy is attracted to the idea of self-directed funding and the flexibility and choice that it offers for her and Emily. The family is able to manage self-directed funding, so the NDIA gives Emily and Kathy a budget. Kathy and Emily prepare a personal plan and funding proposal, with its key goals being to get a job for Emily and for her to be 'out and about' in the community at large. Emily does not want to go to the local day centre anymore, but would like to attend drama classes at the local community centre in her suburb and to learn to swim. She also wants to use a program to develop her independence and self-help skills, and to attend a transition to work program in the city. The personal plan and funding proposal are accepted by the National Disability Insurance Agency, and cost less than the original package because the drama and swimming classes are much less expensive than the disability-specific day centre.

At first, Kathy handles all the administrative and accountability requirements associated with Emily's self-directed funding package, but it gets too hard, and she pays a small fee for a disability support organisation to do it on their behalf.

In nine months time, at the completion of her transition program, the NDIA local area coordinator helps her get in contact with employment services so she can find a job.

## A newborn with a severe disability

Susan has given birth to a boy called Jack who has a major congenital birth defect, which has led to profound intellectual and physical disabilities. Jack will not be able to walk or talk, will need a wheelchair as he grows, and will require lifelong assistance with personal care, including eating, drinking, bathing, and toileting. He has an unknown life expectancy.

Susan contacts the National Disability Insurance Agency to make an appointment with an assessor to discuss Jack's needs. Like all babies in the first two years of their life, Jack's personal care needs will be largely met by his parents. However, Susan and her partner are struggling with the emotional impacts of caring for Jack and this is also affecting their other children.

The assessor determines a package of supports for Jack and his family — which is signed off by the NDIA. The package provides some physiotherapy to improve Jack's 'floppiness', counselling for the parents, and some respite services so the rest of the family can periodically take some time off together. The NDIA also arranges for an NDIA local area coordinator to visit, and the manager puts the family in contact with a local support group. The parents are also told about the support they will be able to get as Jack grows older, so they know with certainty that they will not be left to manage by themselves.

Susan and Mark choose a local respite service, but they are unreliable and not very empathetic. They tell the NDIA, and using the information it provides, choose another respite service that has a good reputation for families in their circumstances.

## An adult with disabilities resulting from illness

Angela is 35 years old and lives on her own in a two-story house in a large country town. She contracted bacterial meningitis twelve months ago, which resulted in partial blindness, severe balance problems and a slurring of her speech. There is little potential for her physical disabilities to improve with time.

For now, she is unable to walk without a Zimmer frame. She requires assistance with aspects of her personal care such as bathing and toileting, with domestic duties such as cooking, cleaning and gardening, and assistance with transport as she is no longer able to drive. She needs handrails in her bathroom to make it safe for her to use, and a stair lift to enable her to go up and down the stairs in her house. She has short-term memory problems and suffers from depression because of her condition. Before her illness, she was an editor of a small newspaper. However, she is not interested in returning to work yet, but is focused on improving her health.

The assessor at the National Disability Insurance Agency determines a package of supports for Angela to cover her needs for personal care, domestic assistance, home modifications and transport. The assessor also arranges an appointment for Angela to see an officer in a mental health agency for counselling sessions to assist her with her depression.

Angela is visited by her local area coordinator, who makes her aware of the service providers in her area and their different skills. Angela chooses a disability support organisation to manage her package for her and to put her in contact with the service providers that can meet her needs. The local area coordinator will be in contact again in six months time to stay in touch, and to check that Angela is getting the support she needs, and to the right standard.

## An adult with a newly diagnosed degenerative disease

Jane, who is single and 52 years old, has just been diagnosed with Multiple Sclerosis (MS). Jane is still able to live independently in her home, drive her car, and work as a secretary in a large city firm. Jane's depression and anxiety has been aggravated by her diagnosis.

She contacts the National Disability Insurance Agency for information about what supports she could obtain under the National Disability Insurance Scheme. When she initially contacts the National Disability Insurance Agency and tells the officer she has MS, Jane is advised that a local area coordinator will visit her and will make an appointment for a formal assessment.

Subsequently, at her appointment, the assessor tells Jane that the National Disability Insurance Agency has developed a protocol on early intervention for people with MS. Following a discussion with Jane about her needs, and guided by the protocol, the assessor determines a package of early intervention supports for Jane, consisting of information sessions on how to best manage the disease and a prescribed number of physiotherapy and occupational therapy sessions over a specified period of time.

Jane and her local area coordinator discuss the options available for her, and Jane elects to choose her own service providers (from a list set out in the early intervention protocol). If Jane chooses to have more therapy sessions than would be regarded as clinically justifiable, she will have to pay for these herself. To address Jane's depression and anxiety, the assessor refers her to a contact officer in a government mental health agency to arrange counselling sessions. The assessor advises Jane to return to the National Disability Insurance Agency if she suffers any deterioration in her condition that require further supports, noting that in six months time, the local area coordinator will arrange a meeting to see how she is going.

# 1.14 The National Injury Insurance Scheme (NIIS)

This would be state-based and funded by premiums from insurance policies, local government, state and territory governments and other sources. It would:

- be a 'no-fault' scheme, so that people would be covered even if they could not find another negligent party. For example, that might occur if a kangaroo jumped out in front of a car
- be targeted at catastrophic injury (mainly spinal cord injuries, acquired brain injuries, severe burns and multiple amputations)
- provide lifelong funding people would be able to access supports funded by the NIIS until they died. (This would be different from the NDIS where funding arrangements switch at the pension age, though care and support arrangements would continue under the NDIS if people wanted that.)

- be 'fully funded', so that all new cases of catastrophic injury would have an amount equal to their expected lifetime care and support costs put into the scheme fund. (Existing cases would be covered by the NDIS.)
- extinguish common law rights to sue for lifetime care and support, but not other heads of damage
- not cover cerebral palsy. However, people with cerebral palsy would get full coverage of their needs in the NDIS (and much more quick and secure benefits than now). The main reason for the NIIS not covering cerebral palsy is that most instances are not accidents, but more like other chance events causing disability. Coverage of cases of cerebral palsy by the NDIS means that pressures on medical indemnity insurance costs would probably go down, and at worst be modest. People acquiring cerebral palsy would still be able to sue for income loss and pain and suffering if a negligent party was identified.

Table 2 **Implementing the NIIS** 

	P
Date	Milestone
Second half of 2011, or early 2012	<ul> <li>COAG would:</li> <li>agree to the establishment of the NIIS, whereby states would implement no-fault accident insurance schemes for long-term care of new cases of catastrophic injury</li> <li>agree to have these arrangements in place in all jurisdictions for motor vehicle accidents by the end of 2013</li> <li>establish a full-time high level taskforce to help implement this</li> <li>The taskforce would report back regularly to Heads of Treasuries meetings and COAG on milestones reached</li> </ul>
end 2013	NIIS to cover catastrophic injuries from motor vehicle accidents in all jurisdictions on a no-fault basis
2015	People suffering catastrophic injuries from other causes should be covered by at least 2015
2020	Independent review of the NIIS

## Box 1.1 What are the main changes since the draft report?

The economic benefits of implementing the NDIS. The scheme would substantially increase the personal wellbeing of many people with disabilities and their carers. Such benefits are economic gains, even though they cannot be measured with any accuracy and do not show up in conventional measures such as GDP. There would also be beneficial employment effects, increased efficiency and fiscal offsets (which would grow over time). The benefits are sufficiently large to exceed the estimated costs of the scheme.

The benefits of greater community engagement with people with disabilities. There should be concerted efforts to support 'community capacity building' and 'social inclusion' initiatives.

Options to reform the Disability Support Pension to align its goals with those of the NDIS.

Special arrangements for cerebral palsy. The NDIS should fund all cases associated with pregnancy or birth that meet the NDIS eligibility criteria. Most cases of cerebral palsy cannot be avoided through clinical practices, and it is very hard to determine whether clinical care was the cause.

Revised criteria for obtaining assistance under tier 3. The NDIS should provide supports for people under the pension age who have significant and enduring psychiatric disabilities, and who have scope to be supported in the general community.

The criteria for eligibility do not separately identify people with intellectual disabilities. They are grouped with other people with 'significantly reduced functioning in self-management' (this criteria would also capture some people with acquired brain injuries and those with significant and enduring psychiatric disability). There is full coverage of intellectual disability.

There is no longer a requirement for a front-end deductible. However, one should be considered if, after the implementation of the NDIS, small claims cloq up the NDIS assessment process.

Qualifications for the disability services workforce. Professional development involves both experience and formal training, but while formal training is important, it should not be compulsory for all employees.

Revised estimates of the numbers of people likely to be receiving supports, and of the costs of the scheme. About 410 000 people would meet the criteria to receive funded individualised supports under tier 3 of the scheme. The increase principally reflects the inclusion of people with significant and enduring psychiatric disability, who would benefit from community supports. When fully operational, the scheme would cost about \$6.5 billion more than is currently spent by all governments.

Net costs of the NDIS. Despite the inclusion of people with significant and enduring psychiatric disability, overall net costs have only risen slightly compared with the draft. This mainly reflects greater analysis of the spectrum of people's needs and associated costs.

Approaches to funding of the NDIS. The Commission's first preference remains that the Australian Government should finance the entire costs of the NDIS by directing payments from consolidated revenue into a 'National Disability Insurance Premium Fund', using an agreed formula entrenched in legislation. An alternative but inferior option would be that all governments could pool funding, subject to a long-run arrangement based on the above formula, and with pre-specified funding shares.

Governance models. The Commission still strongly favours a national approach through the NDIA, in which all governments would play a role. The NDIA should still be used as the model if some governments decide not to participate. An alternative but inferior option would be a 'federated' NDIS. This would give state and territory governments control over their own systems, but with some common core features. The risk is that disagreements could see it revert to a broken and inequitable 'system'.