

# Disability Care and Support

Productivity Commission Inquiry Report

No. 54, 31 July 2011

Plain English version

#### © COMMONWEALTH OF AUSTRALIA 2011

#### ISBN 978-1-74037-371-5

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, the work may be reproduced in whole or in part for study or training purposes, subject to the inclusion of an acknowledgment of the source. Reproduction for commercial use or sale requires prior written permission from the Productivity Commission. Requests and inquiries concerning reproduction and rights should be addressed to Media and Publications (see below).

This publication is available from the Productivity Commission website at www.pc.gov.au. If you require part or all of this publication in a different format, please contact Media and Publications.

#### **Publications Enquiries:**

Media and Publications Productivity Commission Locked Bag 2 Collins Street East Melbourne VIC 8003

Tel: (03) 9653 2244 Fax: (03) 9653 2303 Email: maps@pc.gov.au

#### **General Enquiries:**

Tel: (03) 9653 2100 or (02) 6240 3200

#### An appropriate citation for this paper is:

Productivity Commission 2011, Disability Care and Support: Plain English Version, Report no. 54, Canberra.

#### The Productivity Commission

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

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

Further information on the Productivity Commission can be obtained from the Commission's website (www.pc.gov.au) or by contacting Media and Publications on (03) 9653 2244 or email: maps@pc.gov.au

### Disability support and care

#### What it means for you (Plain English version)

The Productivity Commission was asked by the Australian Government to look at the costs and benefits of replacing the current system of disability services. We were asked to suggest new arrangements so that all Australians who have a significant and ongoing disability would be able to get essential care and support.

This paper tells you about the Commission's ideas for a new way of meeting the care and support needs of people with a disability. The Commission makes recommendations to the Australian Government, but it is up to the Australian Government to decide what it wants to do.

#### The Commission is recommending two schemes.

The largest scheme would be called 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.

This document sets out how the scheme would work, what services would be available, and how supports could be provided. There are also some examples of people with different disabilities and how the scheme might help them. If you want to know more about how the scheme might be funded, who would do what in government and so on, please look at the website (http://www.pc.gov.au/projects/inquiry/disability-support).

A second, smaller scheme would cover the lifetime care and support needs of people who get a catastrophic injury from an accident. The smaller scheme would be based on the motor accident compensation schemes that operate in the states and territories. This scheme would be called the National Injury Insurance Scheme. We set out how the injury scheme would work at the end of this paper.

You can find a lot more detail about how both schemes would work in our report.

#### The current system does not work well

The current disability support system is very poor. The system **is unfair and does not work well**. Not enough money is provided to help people with disabilities. It does not give people with a disability much choice, and they cannot be sure they will get the supports they need.

#### Some comments from participants

Many of the people who participated in the inquiry pointed to big problems with the way things work now.

People said that the system is underfunded and has long waiting lists and that they have to waste time filling in lots of forms. This is just some of the things we were told:

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

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

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

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

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

## People with a disability told us they do not have enough say and often get supports that do not match their needs:

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

This particular agency has extremely set rules about what they can give, it's a maximum of three showers a week ... (Ms McKenzie-Christiansen, transcript of Adelaide hearings, p. 302)

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

#### No national coverage makes it hard for people to move between states:

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

#### People said they are left to find their own way through a complex system:

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

## Some people told us that lack of government funding now just means pushing costs on to other people or into the future:

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

### People are worried about what might happen to them and their families in the future. They have no peace of mind:

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

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

## In some cases, poor arrangements cause isolation, loneliness and feelings of helplessness and despair:

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

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

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

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

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

#### A new system is required

The Commission believes that big changes are necessary. The current arrangements are underfunded, inefficient and unfair. They also make it hard for carers to cope since the system relies too much on their informal support. We think that a new scheme is required and that the costs of the scheme **are manageable and justified**.

The Commission considers that there will be significant benefits from the new scheme. People with disabilities and their carers will be much better off and the organisations providing supports will run more efficiently.

But if the scheme is to work well over the long-run it will need to have:

- clear rules about who is entitled to what
- careful processes for assessing the needs of people with disabilities
- much more choice for people with disabilities and carers
- careful management of the costs of the scheme
- good arrangements for managing and supervising the scheme
- better jobs and conditions to encourage more people to work in disability care and support
- arrangements to help service providers operate in a new system based around the needs of the person with a disability.

## **Key features of the National Disability Insurance Scheme** (NDIS)

#### What kind of scheme is proposed?

A national scheme to provide insurance cover for all Australians who have a *significant and ongoing* disability. The scheme would pay for long-term high quality care and support. It would also provide referrals to other services that are required, ensure the quality of services, and encourage best practice care and support.

#### Who would be covered?

All Australians would be insured. Packages of assistance would be provided to all people with *significant and ongoing* disability, whose needs could not be met without taxpayer funding. Anyone with, or affected by, a disability could ask for information and referrals.

#### What would the scheme 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 not be covered by the NDIS, but the NDIS would provide referrals to them.

#### How it would be funded?

The Australian Government should make payments into a 'National Disability Insurance Premium Fund', according to rules set in legislation.

#### What would be the cost?

The total cost would be about \$13.5 billion per year, but governments already spend money on disability support. The new amount of money needed is much less. The scheme would cost about \$6.5 billion more each year than is currently spent. This would cost about \$290 per Australian.

#### How many people would receive funded packages?

Around 410 000 people would receive direct funding from the scheme. The scheme would cover existing and new cases of disability.

#### When would the scheme start?

The NDIS would not be able to provide help to everyone immediately. We recommend that it begin in a few regions of Australia in July 2014. It would then extend across Australia from mid-2015. To start with, the scheme would cover those most in need, and then continue to expand until all cases of significant disability were covered by mid 2019.

## The three tiers of the National Disability Insurance Scheme

The NDIS would have three main functions and associated with them, three different groups of 'customers':

- Tier 1 this would involve efforts to increase social participation by people with disabilities, and to minimise the impact of disability; this would be targeted at all Australians (22.5 million people).
- Tier 2 this would involve information, referral and web services, targeted at all people with disability (4 million) and their primary carers (800 000).
- Tier 3 this would involve providing funded support to all people up to the pension age with a permanent disability, where they had sufficient need for ongoing support and/or early intervention; it would mainly be made up of
  - people with significantly reduced functioning in self-care, mobility, communication and self management who require significant ongoing support (330 000 people)
  - people in an early intervention group (80 000 people).

The total number of people who would receive funded support from the NDIS would be around 410 000.

## People with a disability would be at the centre of the system

Their needs and approved spending plan will determine the types and nature of services they receive. People could choose to have their needs met by a range of service providers including:

- private firms
- not-for-profit organisations

- paid individuals, for example, neighbours
- specialist disability service providers.

If people with a disability wish, they could choose an intermediary to be a service broker, provide management services, personal planning etc. Disability support organisations could act as intermediaries.

The NDIA would supervise needs assessment, support packages and planning at the local level. NDIA local area coordinators would provide case management services and liaise with the NDIS and other government services.

#### What supports would the NDIS provide?

The NDIS would fund a broad range of supports:

- Aids & appliances and home & vehicle modifications (including artificial limbs and communication aids)
- **Personal care** that helps 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,
  - eating and/or drinking
  - mobility and transfers
  - health maintenance, such as oral hygiene, medication use or regular and routine exercises and stretches.
  - nursing care when this was a key element of the care of the individual (for example, when meeting the care and support needs of a quadriplegic who is on a ventilator).
- Community access supports so people could enjoy their full potential for social independence. We think that people should have a lot of choice in this area. Supports would focus on learning and life skills (for example, self-help, social skills and literacy and numeracy) Supports would also focus on 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 much shorter periods of support.

- **Respite** to provide a short break for people with disabilities, families and other voluntary carers of people with a disability. These services are designed to help support and maintain the relationship between the primary carer and the person with a disability, while at the same time providing a positive experience for the person with a disability. It could include:
  - respite care provided in the home of the person with a disability
  - respite care provided in a community setting similar to a 'group home' structure
  - respite provided by 'host families' who are matched to the age, interests and background of the person with a disability and their carer
  - 'recreation/holiday programs' where the primary purpose is respite.
- **Specialist accommodation support**, such as group homes and alternative family placement.
- **Domestic assistance** to enable people with disabilities to live in the community and live on their own. This assistance could involve 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 help 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). This also includes coordination and development activity within a specified geographical area. These services aim to help people increase their independence and participation in the community.
- **Crisis/emergency support**, following, say, the death of a family member or carer, including emergency accommodation and respite services.
- Guide dogs and assistance dogs, including the reasonable costs of being assessed for a dog, a dog, user training and veterinary costs.
- Whole-of-life personal planning, for those who need more wide ranging or intensive assistance with planning in order to achieve more personal aspects of well-being such as with relationships, aspirations and achievements, employment, financial security as well as succession planning.

PLAIN ENGLISH

The NDIS will not meet *all* of an individual's needs. Mainstream government services (like health and education) and state and local government providers will continue to play a role.

#### Impacts of the scheme

#### What it will mean for all Australians

- long-term coverage for their care and support needs if a person or their family acquire a significant and ongoing disability
- peace of mind: a better and fairer system that will cost an additional \$290 per Australian each year.

#### What it will mean for people with a disability

- twice as much funding for care and support services
- individualised packages of supports based on meeting reasonable needs
- more choice of providers
- for those willing and able, self-directed funding
- national coverage of reasonable needs for those meeting the eligibility criteria
- incentives to focus on early intervention and improved outcomes for people with disabilities
- support of a local area coordinator; electronic records, so you will not have to tell your story over and over again; a national body, so your entitlements can be used anywhere in Australia; the agency will use plain English
- a way to make complaints, and protection from abuse.

#### What it will mean for carers

- care and support of their loved ones
- certainty about the future
- more respite and supported accommodation
- a way through the maze: not only better information but someone that will work with you to find the right service
- more choice of providers including mainstream services
- counselling support.

#### What it will mean for providers

- increased resources, but also increased competition
- for those that do not already do this, a focus on the consumer and their choices, and away from block funding
- support to adjust to the changes, and a special fund that can be used to demonstrate and promote new approaches.

#### What it will mean for workers

- increased need for workers
- greater incentive for employers to offer better wages and conditions; more opportunities for part-time and casual workers to work longer hours if they wish
- more opportunities to work in a new system that gets better results for people with disabilities.

#### What are the benefits worth?

The Commission has assessed the economic benefits and we believe that the net benefits are large. They mainly arise from better wellbeing for people with disabilities, their carers and the community as a whole. Our calculations suggest that the net gain to Australia would be equivalent to many billions of dollars.

There are also some employment gains. While the scheme will cost governments more, they will get some of the costs back as people with disabilities lead a better life and participate more in the community and in the economy.

#### How the new system would address current problems

**Problem** — Poor national insurance. People without a disability have no clear coverage if they acquire a disability.

**Solution** — Full coverage of all Australians of the costs of long-term disability care and support, so people without a disability could feel confident that they or their families would be supported in the event of a significant and ongoing disability.

**Problem** — Unfair and inequitable. For example, what you receive in assistance depends on where you live.

**Solution** — National schemes with national standards and entitlements that would cover all people with disabilities who have high needs.

**Problem** — Underfunded with long waiting lists.

**Solution** — Funding would be doubled.

**Problem** — Failures to provide help early enough. For example, people stuck in hospital because there is not enough money for minor home modifications.

**Solution** — The scheme would have a strong incentive to undertake early intervention where it is cost-effective. The scheme would spend dollars to save more dollars and people would not have to wait for basic supports like wheelchairs and personal care.

**Problem** — Fragmented with people getting the support they need from lots of different programs.

**Solution** — National schemes with:

- strong regional management with local area coordinators to help people connect to services
- disability support organisations to assist people with disabilities and their families to get the best outcomes
- services for which you had funding would continue to be provided if you chose to move to another state or to another service provider.

**Problem** — Lack of clear responsibilities.

**Solution** — Assessments for assistance under the NDIS would include referrals to suitable supports that are provided outside the NDIS.

**Problem** — People with disabilities and their families have little power and little choice.

**Solution** — People would be able to choose their provider or providers. They could choose to have a disability support organisation manage their funded packages or to act in other ways on their behalf. They would be able to manage their own funds if they wish and within rules.

**Problem** — Economically unsustainable. The current crisis-based system means that some carers do not get the help they need, when the need it. This leads to the costly withdrawal of informal supports by carers who can no longer cope.

**Solution** — Additional funding would help support informal care.

**Problem** — Inefficient with weak governance.

**Solution** — The new scheme would be run by an independent body — the National Disability Insurance Agency. It would follow insurance principles by a commercial board of directors with strong and constant monitoring by Treasury. All Australian

governments would have a hand in the way the new agency was set up, so it would not just be a decision made by the Australian Government. The board would get advice from a council of stakeholders (people with disabilities, carers and providers). People with disabilities and their families would have more control over the services they would receive. They would have a strong incentive to get the best outcomes. They would have a direct stake in cutting out waste and unnecessary services. The scheme would have many safeguards to ensure costs did not get out of control. The performance of the NDIS could be checked against the National Injury Insurance Scheme (NIIS) as well as schemes overseas.

**Problem** — People have no confidence about the future including what services will and will not be available.

**Solution** — A scheme that would focus on long-term care and support needs. People would have clear entitlements to their assessed needs. Strong complaints, appeals and advocacy arrangements. Strong financial reserves. The scheme funds would not be tied to an annual government budget cycle, but would have mandated funding to a separate fund.

**Problem** — Poor information (a 'maze' for people with a disability); poor data collection for disability services to ensure efficient management.

**Solution** — Information to be provided through web and other means by a single national organisation, disability support organisations to act on behalf of people, availability of information to measure and compare supplier performance. Careful collection of data by the scheme to manage costs and to assess outcomes.

**Problem** — Poor evidence base.

**Solution** — There would be a research function, and the scheme would be guided by evidence as to best practices.

#### How much will the NDIS cost and who will pay for it?

Currently, governments spend around \$7 billion on disability services and supports. Of that, about \$2.3 billion is Australian Government spending and about \$4.7 billion is state and territory government spending.

Under the NDIS, spending would be around \$13.5 billion. The Commission has considered two funding options:

• Option A, with one funder. In this option, state and territory governments would lower tax rates (reducing their tax take by \$4.7 billion). The Australian

- Government would provide funding of \$2.3 billion (the existing value of its funding contribution) *plus* a further \$11.2 billion.
- Option B, with nine funders. The state and territory governments would transfer \$4.7 billion (the value of their existing funding contribution) to the National Disability Insurance Agency. The Australian Government would provide funding of \$2.3 billion (the existing value of its funding contribution) plus a further \$6.5 billion.

Option A is the Commission's preferred funding option because we think it is likely to provide more certainty of funding, and because the Australian Government has more ways of funding the scheme than do states and territories.

#### When might the NDIS start

#### **July 2014**

The NDIS would start in a few regions and have about 10 000 clients per region in its first year. That would allow the operation of the scheme to be properly tested. At the same time, it would start providing high quality services to thousands of people.

#### Mid-2015 to mid-2019

Over the next few years, the scheme would be expanded across Australia. In the early stages, it would include all new cases of significant and ongoing disability and some of the groups most disadvantaged by the current arrangements.

All current and new clients would be receiving NDIS services by mid-2019.

#### **Cameos**

#### 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.

#### From a service provider's perspective

At present Carecom Incorporated is a medium sized disability support provider that 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).

#### The National Injury Insurance Scheme

A second scheme, the National Injury Insurance Scheme, would cover the lifetime care and support needs of people who get a catastrophic injury from an accident. This smaller scheme would be based on the motor accident compensation schemes that operate in the states and territories.

#### **Key features of the National Injury Insurance Scheme (NIIS)**

#### What kind of scheme is proposed?

A federated model of separate, state-based schemes providing lifetime care and support to all people newly affected by catastrophic injury. The schemes would be 'no-fault', that is, people who get catastrophic injuries would be fully covered irrespective of who, if anyone, was at fault in the accident. It would provide for consistent, national minimum care and support arrangements.

#### Who would be covered?

All causes of catastrophic injuries, including those related to motor vehicle accidents, medical treatment, criminal injury and general accidents occurring within the community or at home. Coverage would be provided irrespective of how the injury occurred, and would only cover new cases.

#### What would the scheme provide?

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 would include reasonable and necessary attendant care services; medical and hospital treatment and rehabilitation services; home and vehicle modifications; aids and appliances; educational support; help for people to have a greater role in the workforce and socially; and domestic assistance.

#### What would be the cost?

The net annual costs of a comprehensive no-fault scheme covering all catastrophic injuries could be around \$830 million (around \$35 per Australian).

#### How would it be funded?

The additional funds required for the NIIS would come from existing insurance premium income sources and from local rates.

#### How many people would receive funded packages?

The NIIS would cover new cases of catastrophic injury (around 900-1000 each year), but over the long-run, about 30 000 people would be in the scheme.

#### When would the scheme start?

To begin, states and territories should set up no-fault catastrophic injury schemes for motor vehicles by the end of 2013. The NIIS should cover all catastrophic injury by the end of 2015.

#### Impacts of the scheme

#### What it will mean for all Australians

- national coverage for catastrophic injury for lifetime care and support needs
- peace of mind: a better and fairer system that will cost about \$35 per Australian each year.

#### What it will mean for people with a disability

• care and support, no matter who was at fault.

#### What it will mean for carers

- care and support of their loved ones
- certainty about the future.

#### Key dates for setting up the NIIS

#### Second half of 2011, or early 2012

At a COAG meeting, the state and territory governments would agree to set up accident insurance schemes for long-term care of new cases of catastrophic injury.

People who get catastrophic injuries would be fully covered, whether or not the accident was their fault.

Governments should agree to have these arrangements in place everywhere for motor vehicle accidents by the end of 2013, and all other forms of accidents by 2015.

#### What has changed in our report

The Commission heard many views about our draft report, and we did more work to understand the issues better. We changed our mind in some cases. The big differences between the draft and the final report are that we:

- examined the benefits of implementing the NDIS and found convincing evidence
  that the benefits are sufficiently large to well exceed the estimated costs of the
  scheme
- proposed some ways for getting greater community engagement with people with disabilities
- suggested some options to reform the Disability Support Pension so that it had
  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. We think people with disabilities have got more potential to
  contribute to Australia than many people think
- widened the group of people who could get funded support from the NDIS. They
  would now also include people who have significant and enduring psychiatric
  disabilities, and who have scope to be supported in the general community. For
  example, that might be someone with schizophrenia
- removed any payment for services provided by the NDIS. We originally suggested that a small upfront payment might be a good idea, but we changed our minds.