



**Submission to the
Productivity Commission's Inquiry into
Disability Care and Support**

September 2010

About National Seniors Australia

National Seniors Australia (NSA) is the largest organisation representing Australians aged 50 and over with some 280,000 individual members.

Our members are from metropolitan, regional and rural areas across all states and territories, and are broadly representative of the three key ageing cohorts: those aged 50-65; those aged 65-75; and those aged 75 +.

NSA works to provide a voice and address the needs of this diverse membership:

- **We represent** – to governments, business and the community on the issues of concern to the over 50s;
- **We inform** – by providing news and information through our website, forums and meetings, our bi-monthly award winning magazine, a weekly E-newsletter and our Australia-wide branch network;
- **We provide opportunity** – to those who want to use their expertise, skills and life experience to make a difference in indigenous communities and on our environmental legacy;
- **We support those in need** – our Charitable Foundation raises funds to provide comfort and support for our most vulnerable older citizens;
- **We provide savings** – through quality insurance, affordable travel and tours, and discounts on goods and services.

Contact:

National Seniors Australia
National Policy Office
23 Torrens Street
Braddon, ACT 2612

P: (02) 6230 4588

F: (02) 6230 4277

E: npo@nationalseniors.com.au

www.nationalseniors.com.au

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Executive summary

National Seniors notes that the *Disability care and support inquiry's* terms of reference bind the Productivity Commission (PC) to investigating funding options that exclude, for the purpose of ensuring the scheme's financial viability:

- disabilities that are not profound or severe;
- disabilities that result from the natural process of ageing.

As part of its inquiry, the PC has also been asked to consider:

- age limits in designing eligibility criteria for the scheme;
- the implications for the health and aged care systems;
- the interaction with national and state-based traumatic injury schemes.

In making its submission, National Seniors has specifically considered the interests of the following membership/constituency subsets:

- People with profound or severe disabilities resulting from the natural process of ageing but aged 65-and-less, e.g. people with dementia;
- People aged 65-and-over who incur a profound or severe disability (i.e. not the result of the natural process of ageing), e.g. people who incur injuries in accidents;
- Ageing parents of adult children with disabilities.

While there is a consensus that the distinction between disability care and aged care is an artificial one, National Seniors appreciates that the underfunding of the disability care sector and the extent of unmet need, which are well documented in the PricewaterhouseCoopers' final report on funding options for a National Disability Insurance Scheme¹, justifies the development and implementation of a funding scheme that targets the areas of greatest unmet need in disability care.

Given the consensus that the distinction between aged and disability care is an artificial one, National Seniors believes that the new National Disability Scheme should be designed in such a way that it can be readily extended at some future date to include further categories of disabilities, including those resulting from the natural process of ageing, not currently contemplated for inclusion.

¹ PricewaterhouseCoopers: National Disability Insurance Scheme - Final Report (October 2009)

Summary of Recommendations

- A National Disability Scheme, rather than impose an age limitation on eligibility, should cover a list of profound and severe disabilities regardless of age to avoid inappropriate admission to aged care.
- A National Disability Scheme should actively engage with the Younger People in Residential Aged Care Program to move people inappropriately placed in aged care facilities on to the NDS.
- A National Disability Scheme should not impinge on national and state-based traumatic injury schemes and jeopardize the benefits available to people aged 65 and over under such schemes.
- The Federal Government should use the success of existing state-based traumatic injury schemes to encourage and promote the creation of similar schemes in states and territories that do not currently have them.
- Relief for ageing parents of children with disabilities should be a priority within a National Disability Scheme.
- A National Disability Scheme should provide individual funding for consumer-directed care following independent, objective care needs assessment.

Disability resulting from the natural process of ageing

The PC's *Disability care and support inquiry*'s terms of reference ask for disabilities which are the result of the natural process of ageing to be excluded from any National Disability Scheme (NDS). National Seniors interprets this description of disability as disabilities common among the frail and old. It is a matter of concern that such as a loose definition of an important category of disability is being used as part of the PC's inquiry. For example, is dementia to be excluded from an NDS if it manifests itself in an older person, but to be included if it affects a person in their 40s? Is loss of mobility due to a fall to be included if the person is young, but to be excluded if the person is old?

Given the importance the terms of reference for an NDS attach to limiting access, the risk is that people who are not ready for federally administered aged care and should be accommodated under an NDS, are excluded because they have a disability common in older, frail people. This is particularly so as aged care for younger people predominantly means residential aged care.

The Aged Care Assessment Program (ACAP) is mainly targeted at frail older people who want to remain at home with support or who are considering living in an aged care home. The Aged Care Act 1997 does not specify an age when a person is considered eligible for aged care, but the ACAP will assess people aged under 65 if it can be demonstrated that there are no other facilities or care services appropriate to meet the person's needs.

It is a measure of the lack of capacity in the disability care system that in 2007-2008 almost 2,000 people under the age of 65 are in residential aged care, with 89 per cent of those over the age of 50.² An equal number of people under 65 receive care through Community Aged Care Packages.³ In other words, if a person with a severe or profound disability is excluded from receiving care under an NDS, there is a fifty-fifty chance that they will end up in a residential aged care facility, which would in most cases be an inappropriate outcome.

There appears to be a strong argument for a list of 'eligible' disabilities adopted under an NDS without regard to age to avoid the inappropriate placement of people under 65 in aged care. Equally, there may need to be formal protocols on how to deal with assessments of certain disabilities that could be judged to fall within the domain of both aged care and disability care to ensure a fair outcome in terms of care made available.

There also appears to be a strong argument for an NDS to actively engage the Younger People in Residential Aged Care Program to move people inappropriately placed in aged care facilities on to the NDS.

² Australian Institute of Health and Welfare 2010. Younger People with Disability in Residential Aged Care program: report on the 2008–09 Minimum Data Set. Disability series.

³ Australian Institute of Health and Welfare 2009. Aged care packages in the community 2007–08: a statistical overview. Aged care statistics series no. 29.

Recommendations

- A National Disability Scheme, rather than impose an age limitation on eligibility, should cover a list of profound and severe disabilities regardless of age to avoid inappropriate admission to aged care of people under 65 and there should be formal protocols for disabilities that could be judged to fall within the domain of both aged care and an NDS.
- A National Disability Scheme should actively engage with the Younger People in Residential Aged Care Program to move people inappropriately placed in aged care facilities on to the NDS.

Ageing and acquired disability

National Seniors is concerned that, in pursuing the legitimate aim of limiting access to the National Disability Scheme to profound and severe disabilities to ensure the Scheme's financial viability, this aim will be achieved by means of a one-size-fits-all age limit for eligibility.

It would not be equitable for someone who has sustained a profound or severe disability in, say, a car accident, but who exceeded the age limit for access to the NDS, to be excluded from the NDS and who would then need to access federally administered aged care.

Population-wide, one in five people have a disability. One in fifteen has a profound or severe disability.⁴ The Productivity Commission estimates that approximately 760,000 people under the age of 65 have a profound or severe disability, and, by implication therefore, approximately 450,000 people aged 65 or over have a profound or severe disability.⁵

National Seniors proposes that, instead, a list of 'eligible' disabilities be used for the national disability scheme to avoid inappropriate placement of people aged 65 and over in aged care. Equally, there may need to be formal protocols on how to deal with assessments of certain disabilities that could be judged to fall within the domain of both aged care and disability care to ensure a fair outcome in terms of care made available.

This approach would be consistent with two existing schemes, viz. the New South Wales and Victorian motor accident authorities' long-term care and support insurance schemes that, quite rightly, place no age limit on eligibility. It is noted here that these two schemes do not feature extensive lists of included disabilities to limit the cost and liability of the schemes, but achieve this by only including disabilities arising from a distinct cause, i.e. road traffic accidents.

⁴ Australian Bureau of Statistics 2004. Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 2003. Cat. No. 4430.0

⁵ Productivity Commission, May 2010, Disability Care and Support Issues Paper.

In relation to national and state-based traumatic injury schemes, National Seniors notes that eligibility for many of these schemes, including the New South Wales and Victorian no-fault motor vehicle insurance schemes, is not age-restricted. Workers compensation schemes, although generally applying an age limit for income compensation, do not restrict compensation for medical and long-term care costs.

National Seniors is concerned that subsuming any of these schemes in an NDS could lead to a loss of benefits for people aged 65 who incur a profound or severe disability.

National Seniors therefore urges the Productivity Commission to ensure its recommendations in no way jeopardize the benefits available to people aged 65 and over under current national and state-based traumatic injury schemes.

National Seniors is also concerned that the creation of an NDS might discourage the further creation of state-based traumatic injury schemes, the prime example being no-fault motor vehicle accident insurance. Currently, only New South Wales and Victoria have such schemes.

National Seniors' preferred option in relation to national and state-based traumatic injury schemes is that an NDS should not impinge on them and that the success of existing state-based traumatic injury schemes should be used to encourage and promote the creation of similar schemes in states and territories that do not currently have them.

Recommendations

- A National Disability Scheme should not impinge on national and state-based traumatic injury schemes and jeopardize the benefits available to people aged 65 and over under such schemes.
- The Federal Government should use the success of existing state-based traumatic injury schemes to encourage and promote the creation of similar schemes in states and territories that do not currently have them.

Ageing parents of adult children with disabilities

Ageing parents of adult children with disabilities are a group that needs to be given special consideration as part of the development of a disability care and support scheme.

According to the ABS's 2003 Survey of Disability, Ageing and Carers (SDAC), there were just over 107,000 full time informal carers in private dwellings, 90 per cent of whom cared for their partner. The majority of these carers would be likely to be providing informal aged care, rather than disability care.

This estimate, by implication, puts an approximate number on carers aged 65 and over who care, full time, for people other than their partners. This group, of about 10,000 people back in

2003 when the survey was carried out, includes and is likely to be predominantly made up of ageing parents caring for adult children.⁶

Ageing parents who care for their adult child with disabilities have carried and continue to carry a heavy load. Many have been in circumstances where they had no choice but to assume the sole responsibility of care for children with disabilities without a real prospect of those circumstances ever ending.

Caring for a child with a disability, particularly an intellectual disability, is a heavy burden for parents of any age. For ageing parents this burden is increased by the realization that their ability to care for their children is diminishing with age and that in the not too distant future their ability to care will have disappeared. This adds enormous anxiety to the already significant anxiety and stresses of their situation.

Recommendation

- Relief for ageing parents of children with disabilities should be a priority within a National Disability Scheme.

Consumer-directed care

National Seniors supports the principle of consumer-directed care and a functional separation in care delivery that ensures care recipients are in charge of the ways in which their needs are met. This entails that responsibility for (1) assessing care needs, (2) funding care, and (3) providing care should be borne by different agencies acting independently from each other. The assessment of care needs should be an objective process and not be influenced by funding considerations or by an interest in providing care services. In addition, the consumer should be placed in control of their individual funding and select the care provider they think will best meet their needs.

Recommendation

- A National Disability Scheme should provide individual funding for consumer-directed care following independent, objective care needs assessment.

⁶ Australian Bureau of Statistics 2004. Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 2003. Cat. No. 4430.0