



The Royal Australasian
College of Physicians

Submission to:
Australian Government Productivity Commission
Disability Care and Support Issues Paper
on behalf of
The Royal Australasian College of Physicians
August 2010

The Royal Australasian College of Physicians (RACP) would like to thank the Productivity Commission for the opportunity to respond to the Issues Paper on 'Disability Care and Support'. The RACP is highly supportive of measures to improve the support and care for people with disabilities, and of the development of a National Disability Long-term Care and Support Scheme. We congratulate the Australian Government in looking forward towards solutions for what is widely acknowledged as an important and complex issue.

Executive Summary

The Royal Australasian College of Physicians considers that Disability Care and Support is an area which would benefit from a review highlighting the most effective means to improve the provision of appropriate, timely and well maintained support and care for all individuals with disabilities. The RACP is highly supportive of measures to improve the support and care for people with disabilities. A disability support and care scheme will allow people with disability to contribute to society more effectively, and to improve their health and quality of life.

Key aspects of a scheme should include:

- universal coverage for people with severe and profound disability irrespective of its cause;.
- the age of the person with disability should not impact upon eligibility and provision;
- should the new scheme target those less than 65 years, then there must be consistency with, and a seamless transition to, schemes that cater of those 65 years and over;
- a broad definition of the elements of "support and care", which includes all factors that assist people with disability to function as fully as possible. These include healthcare services of all types, education, rehabilitation, equipment and, where necessary, specialised accommodation needs.

The principle risk in establishing a scheme is that it becomes financially unsustainable. This can be minimised with:

- careful targeting of the scheme to people with severe and profound disabilities, regular review;
- strong appeals procedures, and;
- a method of funding that will increase with the CPI and is not open to political interference.

The RACP is able and committed to supporting the development of a scheme through its education and advocacy roles.

The Royal Australasian College of Physicians

The Royal Australasian College of Physicians is a Fellowship of more than 10,500 specialist and generalist physicians and 4,000 trainees who practice in more than 25 medical specialties including rehabilitation medicine, public health medicine, cardiology, respiratory medicine, neurology, oncology, occupational and environmental medicine, palliative medicine, paediatrics, geriatric medicine, sexual health medicine and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the well-being of patients. The College works to establish and achieve the highest standards of contemporary knowledge and skill in the practice of medicine and to promote the health and well being of the community. The College, in collaboration with affiliated specialty societies, is the provider of frameworks and standards of education for specialist physicians and trainees. The College is a key stakeholder in the Australian health system, advocating for improving the health and wellness of individuals and communities and reducing disparities across population groups.

We congratulate the Australian Government in looking forward towards solutions for what is widely acknowledged as an important and complex issue, and provide comments and recommendations below on some of the issues raised in the Issues paper regarding the development of a National Disability Long-term Care and Support Scheme, as well as specifically the inquiry's terms of reference

The Inquiry Terms of Reference

Disability and ageing

As noted by the Commission in the Issues paper, the terms of reference for the Inquiry *'specify that the scheme should cover disability present at birth, or acquired through an accident or health condition, but not due to the natural process of ageing.'* The College has some concerns about the implication that disability in old age will naturally occur and is even unavoidable, and believe that such a comment is discriminatory towards older people. With improved health care, and better community living standards, people can anticipate better health as they age, and specific incidences of disability should not be excluded from this review on the grounds of age. Though the College understands the Commissions inclination to distinguish between support for disability care and older peoples care, this distinction is not considered appropriate.

The College would also like to raise the concern that the distinction between "young" and "old" appears to be against the principles of the United Nations Convention on the Rights of Persons with Disabilities. There is an implication in the terms of reference that the 'young' and the 'old'

are two distinct groups of people with disability. It is particularly troubling that the Inquiry *“mainly emphasises people with disability aged less than 65 years”*. The Australian government has already announced that the retirement age for benefit eligibility will be arbitrarily set at greater than 65 years. Any Scheme should be consistent with overall government policy and societal expectations. Development of the National Disability Long-term Care and Support Scheme (the Scheme) should not be influenced by the existing, but outdated, Commonwealth / State concepts enshrined in the National Disability Agreement.

The College does recognise that pragmatic decisions must be made in defining a Scheme’s target population, and also that the needs of people with intellectual and developmental disability, and those with acquired impairment under the age of 65 years, are not being catered for under the range of programs currently in place in Australia. Some alternative options for eligibility with reference to chronological age, health conditions and disability are discussed below.

Additional issues for consideration in the Inquiry

Further issues that should be considered by the Inquiry are:

- The extent to which the concepts of manifest disability (for example spinal cord injury), self-reported disability and assessed disability can be used, particularly in relation to scheme eligibility assessments.
- A Disability Care and Support Scheme should include incentives for disability minimisation.
- There should be an expectation that some people with disability will be able to exit the Scheme due to improved functioning as a result of rehabilitation, or following natural recovery which might occur with some types of acquired disability.
- Disabled students should be specifically considered. The government’s equity agenda in education implies better opportunities across the full spectrum – from school to higher education – for disabled students. Profound physical disabilities are beyond the scope of most schools to address and seriously stretch the resources of tertiary institutions as well. Education is a critical productivity issue.

The Proposed Scheme

Rationale for and objectives of long-term disability care and support

The RACP believes that the primary aim of a National Disability Long-term Care and Support Scheme (the Scheme) should be to provide care, support, education and rehabilitation / habilitation for people with permanent disabilities, as well as the equitable provision of

equipment and assistive technology (including home modifications) to help people with disabilities increase their participation in society.

Key design elements of a new scheme

The Scheme should include an eligibility assessment, a provisional eligibility period in which services are available based on a needs assessment, a lifetime eligibility assessment, and regular needs re-assessment (see below).

Who should be eligible?

The basis of eligibility should be people with core activity limitations. Specifically, people with severe or profound core activity limitations should be eligible. Other factors such as carer status or geographical location should not be part of eligibility.

A relatively “narrow” scheme is preferred if it is focused on people with profound disability. Preference should be given to people with truly “long-term” disability and hence the two year provisional eligibility period is supported. The period of interim eligibility will need to be longer for children and adolescents (and probably to 18 years of age).

Reassessments of needs should be conducted second yearly from scheme entry for ten years and then five yearly. Major life changes should also trigger reassessment.

Eligibility assessment must be based on objective and valid methods. It will be possible to identify criteria for which eligibility will be manifest, for example based on specific health conditions, for some participants. There will also be a need for an objective assessment of activity limitation for the majority of participants. The Functional Independence Measure (FIM™) is one tool likely to be suitable for this purpose and, for children, the Vineland Adaptive Behaviour Scales is another. Other tools which examine the ability of the person to participate in domestic and community activities will also be necessary.

Eligibility criteria should not be too restrictive. The exclusion of people with a disability who are employed, and the absence of alternative strategies, causes financial hardship, particularly for those who require high-cost care or numerous equipment items.

Current schemes generally have waiting lists, so that care and support are often provided only after a lengthy delay. Children and young people, with their particular developmental and growth patterns, can require changes in support needs in rapid succession. Sometimes the delay in

provision is so great that they outgrow their original assessed care and support needs before the required service / equipment becomes available.

Means testing should not be applied as it will create disincentives for employment and wealth accumulation. However, there may need to be a system of co-payment as wealth increases.

An eligibility criterion based on chronological age is discriminatory and arbitrary. Eligibility based on health condition is also discriminatory. The ideal is to have a universal scheme (that is not age, or health condition, based).

Setting appropriate eligibility criteria that do not entrench, or create, inequities should be the goal. The Terms of Reference perpetuate the two tier system that operates at the current time. Depending on the perspective of the observer, either the current disability services system, or the aged care system, is less adequate and effective for people with disabilities.

There is no easy compromise, but one which would cause least disadvantage overall would be to have an agreed age criterion. Disability acquired beyond this age would be supported through aged care services and Scheme participants who reach this age would exit the Scheme and be supported by aged care services.

The ideal 'Scheme' would have the same eligibility, assessment and access criteria for those under, and those over, the age criterion. For the individual there would need to be a seamless transition from one Scheme to the next with increasing age.

Who makes the decisions?

Eligibility decisions will need to be made by the Scheme Authority but must be open to appeal.

The Scheme participant, or the person legally responsible to make decisions on their behalf, should manage an individualised funding package. This package is to have nominated components. Funding is not transferable between components, for example nominated educational funding is not transferable to equipment purchase.

The nature of services available

As well as personalised care and support, additional types of services that should be included as specific categories are:

- education and training
- rehabilitation services (including vocational rehabilitation)

- specialised equipment and assistive technology
- home modifications and specialised accommodation
- respite

Quality indicators are to be applied for each service type.

Incentives are to be present for work and community participation. A “no disadvantage” test should be developed to ensure that participants do not have a reduction in support services as a result of workforce participation, or increased community participation.

Participants should be able to make co-payments to extend service provision.

“Natural” day to day living costs are not part of the scheme. Therefore, generally, accommodation, food and basic transportation costs are not part of the Scheme.

Waiting times for the provision of specialised equipment and assistive technology need to be short to ensure rational prescribing. Excessively long waiting periods for equipment, a feature of current state-based services, leads to the individual being without necessary equipment for extended periods of time, or to the prescribing of equipment well in advance, to account for the waiting period, whether new equipment may be needed at that time or not. In the ideal scheme, once a person is deemed to be eligible, supply of equipment is timely.

Planning and predictions of service use

It will be difficult to predict service use over time for individuals and particular efforts are required to encourage independence and community participation.

To assist with planning, more accurate data about the likely make up of Scheme participants, and their activity profiles, are needed. In particular, the number of participants with profound disability onset during the adult years is not clear at present.

An entitlement based scheme is unlikely to be viable. The Scheme should be needs-based with service provision based on available resources.

The Scheme should commence catering for people with new profound core activity limitation, then be progressively extended to all people with profound core activity limitation and finally, if sufficient resources are available, to people with severe core activity limitation.

Data on the prevalence and incidence of disability

At present, the ABS Disability Survey provides the best population level data about people with disabilities in Australia. However, for the purposes of a Scheme, better data about people with core activity limitations is required, including a longitudinal view of these limitations over the lifespan. Some health and disability service data are available and existing agencies, such as the Victorian Transport Accident Commission and the NSW Lifetime Care and Support Authority, could provide relevant information.

Financing options

A population based levy is supported, that is the “Medicare and Disability Levy”.

Workforce issues

The major workforce requirements may be difficult to meet, especially in regional, rural and remote areas. To meet workforce requirements there could be a strategy of joint development of the disability and the aged support workforce, as there will often be overlap of service provision. However, workforce will need the capacity to cater for the specific needs of children and adolescents. The overarching philosophical strategy is that effective support in the setting of activity limitation is required and core skills are developed in these areas to assist all people with disability.

Governance and infrastructure

An Australian Disability Authority is supported. This operates throughout Australia and has a regional structure.

Appraising costs, risks and benefits

The Scheme could conduct public awareness activities designed to provide information relating to the availability, benefits, appropriateness, and costs of care and support. The Scheme could provide for a national information and referral system designed to meet the needs of individuals. The Scheme could deliver information on services and the availability of resources, including funding to obtain such care and support, for example workplace modifications. The Scheme could deliver information to government and community on the benefits of care and support in enhancing the capacity of individuals with disabilities of all ages to perform activities of daily living.

Measurable goals should be integral to the Scheme and could include:

- education and training completion
- study, employment and community living outcomes

- appropriate provision of aids and equipment, including telecommunication and information technology, care and support

Costs could easily increase beyond levels that are sustainable. This has been the experience with insurance schemes in the past. If this occurs there will be a loss of confidence in the Scheme, political pressures for changes and disadvantage to Scheme participants.

These risks are minimised with careful targeting of the Scheme to people with severe and profound disabilities, regular review, strong appeals procedures, and a method of funding that will increase with the CPI and is not open to political interference.

Benefits of the Scheme are obvious. The greatest benefits will accrue if Scheme participants maximise participation, particularly workforce participation.