CATHOLIC HEALTH
Australia

Catholic Health Australia

Submission to Senate Community Affairs Committee Inquiry into Planning Options and Services for People Ageing with a Disability

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About Catholic Health Australia

21 public hospitals, 54 private hospitals, and 550 aged care facilities are operated by different bodies of the Catholic Church within Australia. These health and aged care services are operated in fulfilment of the mission of the Church to provide care and healing to all those who seek it. Catholic Health Australia is the peak member organisation of these health and aged care services. Further detail on Catholic Health Australia can be obtained at www.cha.org.au.

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Introduction

Many CHA members are providers of services for both frail older people and people living with a congenital or acquired disability needing long term care and support, including people ageing with a disability.

Our members have direct knowledge and experience of the fragmented nature of the current arrangements for caring for people with an acquired or congenital disability as they age. The fragmentation in current arrangements is accompanied by:

- inadequate resourcing, gaps in services and uneven access to services across different locations and States and Territories;
- inequity of treatment and eligibility;
- most importantly, lack of certainty of continuity of services as care and support needs change with age; and
- lack of choice of services.

These issues also pertain generally to the total population of people living with a profound or severe disability.

The inadequacy of services for people with a disability as they age is gaining prominence not only because improvements in clinical and care arrangements is seeing a welcome increase in people with disabilities living longer, but because the carers (mostly parents) of people with disabilities are also ageing and are experiencing or foreseeing difficulties in sustaining their caring role .

The above issues are not only reflective of the current chronic under funding of disability services, but also the complexities of the current interface between aged care and disability programs and how they are funded and administered.

Current Program and Funding Arrangements

Services for people with congenital or acquired disabilities are currently provided through a range of Commonwealth, State/Territory and joint Commonwealth/State programs. The Commonwealth is solely responsible for policy, funding and administration of disability employment and support programs, in recognition of the policy and budgetary inter-relationships between employment programs and the Commonwealth's disability support pension scheme. On the other hand, the accommodation, care and support programs are a mix of Commonwealth and state programs, many of which also encompass aged care for the wider population.

The accommodation, care and support programs include the Home and Community Care program (HACC), programs under the Commonwealth State and Territory Disability Agreement (CSTDA), residential respite under the *Aged Care Act 1997*, respite services under the National Respite for Carers Program and the Carer Payments and Carer Allowance programs.

All except the CSTDA target both the aged care and disability community and their administration is spread across multiple agencies at both Commonwealth and State levels, with varying program guidelines

and complex transparency and accountability arrangements, resulting in inconsistencies in eligibility, access, level of service received and personal contributions (fee policies).

As well as complexity around accountability and responsibility, disability services, when compared with aged care services, are characterized by chronic under funding and unmet need. Estimates of unmet need vary, but all estimates indicate a significant level of unmet need.[1]

Unlike aged care, growth funding for disability services is not linked directly to measures of disability prevalence. Instead, funding levels are periodically reviewed in the context of Governments' budgetary processes against other competing priorities. In contrast, growth funding for services under the *Aged Care Act 1997* is automatically linked to a population based formula (113 aged care places per 1,000 people aged 70 years and over) which ensures that aged care services increase in line with the growth in the number of older people.

One result of the underfunding of disability services is that a large number of younger people with disabilities continue to be cared for in aged care homes as a last resort even though, for the most part, aged care homes do not offer younger people with an appropriate environment.
While there have been attempts through COAG to address this matter, it is likely to remain unresolved while ever there is unmet need in disability services and limited choice of service options.

Principles Underpinning Services for People Ageing with a Disability

Catholic Health Australia considers that any framework for the provision of care and support for people ageing with a disability should embody the following principles:

- People with disabilities, as they age, should have the same entitlements as other citizens to access age related services that recognize and meet their changing needs, and accommodate the full range of human experience.

- Age barriers to disability services should not exist.

- The needs of individuals should be central to the funding and design of services, rather than services being constrained on the basis of a person's chronological age, or disability.

- Older people with disabilities should have the right to access services that are available for the general population, as well as to receive specialized disability related services where needed to maximize their independence, social inclusion opportunities and function.

- The principle of "ageing in place" should apply to people with disabilities as it does to the general population. Needs should be capable of being met in the same community settings as for others who are ageing, including in people's existing residence. For people in a specialized accommodation service (their home), the choice to remain with that service should be available.

- People with disabilities are entitled to the same level of choice of services and provider as other ageing people.

[1] Issues Paper: Inquiry into a National Disability Long Term Care and Support Scheme (Productivity Commission May 2010)

Consistent with these principles, all services should:

- deliver quality outcomes for individuals, develop a culture of partnership in the pursuit of continuous improvement, and be staffed by practitioners with appropriate training and expertise;
- be individually planned and negotiated, recognizing consumer sovereignty, with direct involvement of the consumer and/or advocate or family member as appropriate, or where requested by the consumer;
- be flexible enough to allow changes in services over time and provide a variety of support options;
- reflect the functional needs of people with disabilities as they are ageing; and
- be flexible enough to meet the diverse needs of the individual, regardless of cultural and linguistic background and geography.

In meeting the needs of individuals, the role of families and carers must be considered, and the needs of both for ongoing social involvement, leisure pursuits, spiritual well being and continuing self-development.

Options to Manage the Disability /Aged Care Interface

There are two basic options to address the current fragmented arrangements. The effectiveness of either option, however, would be compromised without adequate funding to meet need which avoids the necessity to ration services. The two options are:

a) Create a national aged care and disability program which would encompass all people with long term care needs irrespective of age and the cause of frailty and disability.

b) Create two national parallel programs to address disability and aged care services separately, with the former designed to ensure lifelong care and support for people with congenital or acquired disabilities, and the latter designed to ensure care and support for people assessed in need of care due to frailty as a result of ageing.

Currently Australia operates a hybrid system. While there are separate disability and aged care programs, there are also some programs which cover both groups. Added to this is the significant complication that the disability programs are even more underfunded than the aged care programs.

The advantage of separate parallel national programs is that it would provide the opportunity to create a universal entitlement-based national disability scheme which has common needs based assessment and funding entitlements based on need, consistent eligibility criteria, consistent client contribution policies based on standardized capacity to pay criteria and consistent quality assurance , accreditation, reporting, transparency and accountability arrangements, to mirror that which is more evolved in the aged care sector under the *Aged Care Act 1997* (which also has some way to go to reach its full potential).

The existence of national policies on these issues would not preclude administration of the program at State and Territory level.

A national disability program would need to ensure lifelong care and support as people's needs change, including due to ageing. There would be one system clearly responsible for lifelong care. To be effective, however, a national program would need to be underpinned by a nationally agreed funding system, such as a form of social insurance which is presently being examined by the Productivity Commission.

Under the National Health and Hospitals Reform proposals, the Commonwealth and most of the States and Territories have agreed that the Commonwealth will assume full funding responsibility for all aged care, including full funding responsibility for care and support services for all people aged 65 and over. This is a practical policy response to the problematic issue of apportioning dependency and frailty (and funding responsibility) between ageing factors and acquired and congenital related factors. The policy could be accommodated by the Commonwealth under a parallel programs structure simply by transferring funding annually to the States and Territories to compensate them (or a national funding authority under a social insurance arrangement) for the cost of caring for people with disabilities who are 65 and over.

The compensation would apply irrespective of the settings in which the care is provided. The settings should embrace 'ageing in place' principles which would allow people to continue living in their current accommodation as their needs change, but also allow people to choose to move to dedicated residential aged care services if preferred, including services which are collocated with 'mainstream' aged care homes in order to share common support systems.

Importantly, with funding certainty, the administering authority would have the flexibility to allow care recipients and their carers to plan for and exercise choice of care setting and providers that best meet their needs, thereby ensuring continued quality care and support for people with disabilities as they and their carers age. It would also allow care providers the flexibility to tailor their services to meet client preferences.

Recommendation

Australian Governments create a separate universal entitlement based disability care and support scheme funded through social insurance arrangements which would provide lifelong care and support for people with a profound or severe disability, with the Commonwealth having funding responsibility under the *Aged Care Act 1997* for the care and support of all people aged 65 and over who are assessed in need of care, regardless of care setting.

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