



**Aged & Community
Services • Australia**



ACSA Submission

Planning Options and Services for People Ageing with a Disability

Submission to the
Senate Community Affairs References Committee

MAY 2010

Introduction

Aged and Community Services Australia (ACSA) welcomes the opportunity to contribute to the discussion process on planning options and services for people ageing with a disability.

ACSA is the national peak body for aged and community care providers representing faith-based, charitable and community-based organisations providing residential and community care services, housing and supported accommodation to almost 1 million older people, younger people with a disability and their carers.

We fully support the COAG initiatives announced in November 2008 to improve and expand services for people with disabilities, their families and carers. In the words of Senator Stephens in her speech to the International Not-for-Profit Convention (17 November 2008), it's "not just about words but real action".

ACSA's interest in this discussion results from our members providing HACC services to people with disabilities; younger people with disabilities living in aged residential care facilities and the fact that more people with disabilities are ageing and accessing aged care services. ACSA has been proactive in this area and works cooperatively with NDS on disability issues.

All people, no matter what their circumstances or location, should be able to access the support they need. This requires a system of funding, which enables people who need assistance, and their carers, to live optimally in the home and community of their choice. For those with disabilities, it requires a structure that recognises that "one size doesn't fit all", and that differing levels of need and choice will be required across the wide spectrum of disability.

Under current funding arrangements the access to planning options and services is restricted with people often forced to take what's on offer rather than have no service at all. As the number of people with disabilities increases and they live to an older age, without action the situation can only get worse.

Under the recently released National Health and Hospitals Network Agreement¹, from 1 July 2011 the Commonwealth will assume funding and program responsibility for basic community care services in line with its responsibility for the rest of the national aged care system (packaged community care, respite care, and residential care); and specialist disability services delivered under the National Disability Agreement for people 65 years and over (50 years and over for Indigenous Australians). It is essential that this change in funding occurs as seamlessly as possible for both people with disabilities and providers with no onerous bureaucratic and accounting requirements attached. The details of the transition are still to be established and it is essential that all stakeholders are consulted in the process.

This Senate Inquiry needs to take the changes into account in considering how adequate funding can be effectively provided into the future, so that planning options for those with disabilities are a reality and no-one is denied the support services they require.

This submission focuses on the need for a coordinated, inclusive approach to supporting people with disabilities as they age.

¹ National Health and Hospitals Network Agreement, Appendix 3 – Home and Community Care and Related Programs P.47

Disability and Ageing

As the Australian population ages, the number of people with disabilities, either long term or acquired, is increasing and they often require access to both disability and aged care services.

11,845 or 4.8% of the users of Commonwealth State/Territory Disability Agreement (CSTDA) funded services were over 65 in 2007-08². As a result of poverty; loss of family, peers and networks; restricted access to primary health care and limited and poor retirement options these people are amongst the most isolated and vulnerable in the community. It is also well known that the health profile of people with disabilities is poor by comparison with the general population, yet there are few strategies in place to ensure that older people with lifelong disabilities can be supported to age well.

On the other hand, over 5% of care recipients under the Community Aged Care Program (CACP) were aged less than 65 years and of these, 25% identified as Aboriginal or Torres Strait Islander peoples - a group who more commonly access aged care services at younger ages than the rest of the population.³

While disability services are generally not equipped to manage the ageing process, conversely, aged care services are generally not able to meet specific disability support needs. The funding formulae and administrative arrangements that govern the disability and aged care service systems seem to assume that a person is either disabled or aged, but cannot be both. In reality, a growing proportion of the population need both services. In 2007-08, around 831,500 people received services through the HACC program, of whom around 70 per cent were older Australians and around 30 per cent were younger people with a disability.⁴ Under the new post June 2012 environment⁵, it is unclear how these crossover client groups will be serviced; however, many providers will need assistance adapting their services accordingly. Agencies and staff may have to acquire new skills and capacities to deliver responsive services and form new partnerships.

People living in supported disability group homes and aged residential care facilities should be able to 'age in place' in the same way as other older people. This includes provision of leisure and recreation services more in keeping with a younger profile than the traditional aged care resident. (Over half (55%) of the residents in aged care services at 30 June 2008 were aged 85 years and over, and over one-quarter (27%) were aged 90 years and over.)⁶ The focus in policy and funding should be to create a positive third age with service models mirroring what typically happens to people in their 50s and 60s as they retire, with recognition that people with disabilities require access to extra services. So in addition to the usual range of physical and domiciliary supports, would be added social activities, hobbies or even holidays.

Ageing in place should also extend, where practical, to private residences. Most people want to live independently in their own homes for as long as possible. Building houses with some simple universal design features will make them liveable and visitable for everyone, regardless of age or ability. "It's internationally accepted that well-designed housing reduces the risk of injury, ill-health and institutionalisation. Badly-designed housing however costs government – and taxpayers -

² Disability Support Services 2007-08, Australian Institute of Health and Welfare 2008 Table 2.4 P.17

³ Aged Care Packages in the Community 2007-08, Australian Institute of Health and Welfare P. 24

⁴ Report on the Operation of the Aged Care Act 1997 2007-08, DHA P.20

⁵ COAG has announced a change of Government funding arrangements with the Commonwealth responsible for people aged 65 years and over and the State responsible for younger people. This will see the disaggregation of HACC program funding.

⁶ Residential aged care in Australia, 2007-08, AIHW June 2009 P.39

millions of dollars each year in hospital admissions, home care, early aged care admissions and expensive modifications, many of which would be unnecessary if houses were built to universal design standards.⁷ Enabling people to stay in their own homes assists in maintaining community and family networks close to established support networks and familiar surroundings.

To ensure adequate access to planning options and services to people with disabilities:

- Provide additional aged care packages funded at a higher level to meet the additional demands that extending eligibility to people ageing with disabilities will create.
- Ensure that age-based eligibility criteria do not prevent the provision of appropriate services to people experiencing conditions arising from premature ageing e.g. Indigenous Australians, Downs Syndrome and Cerebral Palsy.
- Encourage partnerships between aged care and disability services at the local level to support people with disabilities who are ageing.
- Enable clients to raise appropriate issues and remain active partners in the development of services that specifically meet their needs and enhance their quality of life.
- Amend the Building Code of Australia to adopt the principles of adaptable housing in line with AS 4299.
- Phase in Universal Design and sustainable living planning criteria.
- Develop a policy framework for funding public housing for disabled and older people.

Young People with Disabilities Living in Aged Residential Care

Of major concern are the over 6800 younger people with disabilities who live in aged residential care homes. Many of these young people have high and complex support needs, which cannot be appropriately supported in aged care facilities that are neither funded, resourced or designed for this purpose. The new Commonwealth, State and Territories Disability Agreement includes \$901 million for more accommodation, respite and in home care which will enable a small proportion of people to move out of residential aged care. However, the YPINH program is coming to an end and the amount budgeted will have little impact on the overall numbers involved. Those that have been moved are costing an average of \$120,000 per annum to support, which is more than double the highest level of funding provided by the ACFI.

It is important that those who remain in aged care services receive the support and care they require. They come from a widely varying age group, usually have acquired disabilities and require complex clinical and support needs. While their placement in aged care is undesirable, the fact that they are there and deserve the very best support shouldn't be ignored. Under current funding models, there are definitely insufficient funds for providers to provide adequate disability services.

To ensure adequate access to planning options and services to people with disabilities:

- Increase the provision and monitoring of long term residential accommodation specific to the needs of younger people with disabilities.
- Extend and broaden the current COAG initiative to reduce the number of young people with disabilities in aged residential care to include all younger people, including anyone under the age of 65.
- Increase resources for residential aged care to enable the needs of disabled residents with high and complex needs to be adequately supported. This should take the form of an individualised assessment and funding scheme, which would be in addition to the ACFI funding normally associated with aged care.

⁷ Victorian Universal Housing Alliance

- Appropriate equipment presently unable to be accessed in residential aged care should be provided. This includes electric wheelchairs, pressure mattresses and other aids that YPINH or older residents with disabilities are presently unable to access.
- The issues of jurisdictional responsibility should be resolved to ensure funds are available to providers to meet the level of care required.
- Strategies should be developed focusing on the additional training and education to support the aged care workforce working with younger residents.

Retirement

People with disabilities who are ageing and living in supported accommodation where all the residents go out to work, often find it difficult to retire from employment, despite their wish to do so. The accommodation is usually unstaffed during the day and to employ a carer to care for only one resident is not financially viable. The options for these individuals are very restricted and usually result either in having to continue working or move into inappropriate accommodation such as a residential aged care facility. The former may place unnecessary mental and physical demands on the individual, while the latter results in a totally inappropriate placement similar to the issues outlined in the section above. Aged care day centres are also inappropriate.

People living at home with their parents often face similar dilemmas. Parents may themselves be working during the day and not be available for caring duties at that time. Ageing parents may find the ability to continue with their care role being dependent on not having to be available 24 hours a day.

The number of people facing these dilemmas will only increase over time as people with a disability age along with the general population.

To ensure adequate access to planning options and services to people with disabilities:

- Review support employment programs and provide employees with disabilities specific case managed support to transition to retirement.
- Fund appropriate retirement and community living/social programs for people ageing with disabilities.
- Ensure supported accommodation residents get access to Commonwealth funded community care packages when required.

Workforce

There is general agreement and evidence that Australia has an ageing workforce and a national shortage of Registered Nurses, allied health workers and carers. However, the ageing of the workforce is more acute within the disability and aged care sectors.

Greater sharing of knowledge and skills across the two sectors should be facilitated to enable workers to support both disability and aged care clients.

Generally the wages and conditions able to be offered by service providers in disability and aged care make it difficult to attract and retain staff at a time when demand is at its highest level ever and rising. High turnover increases provider costs and workloads for existing care staff.

The agreement to establish a National Disability Workforce Strategy (which is nearing completion) was welcomed and should be linked in with a similar strategy for the aged care workforce. Without urgent action, the current labour shortages in disability, combined with similar workforce shortages

in aged care, will become highly critical. Given the two sectors are often trying to recruit from the same pool of people, both strategies need to achieve complimentary positions.

Another significant feature of Australia's post-war demographics has been the influx of migrants from many different parts of the world. As these people with disabilities age, the proportion of older people from non English-speaking backgrounds requiring assistance will also rise. Providing services to disabled people of Aboriginal and Torres Strait Islander descent also presents its own distinct issues and challenges. Specific strategies to enable support of these populations need to be developed and resourced.

To ensure adequate access to planning options and services to people with disabilities:

- The inadequate funding that results in a low paid workforce in the disability and aged care sectors must be addressed.
- Strategies for the attraction and retention of staff must be developed.
- Requires a change in the perceived poor profile of a career in disability and aged services. The NSW advertising initiative is a good example of how this can be achieved.
- The need for ongoing training and career paths.
- A major focus is required to encourage the employment of Indigenous and culturally diverse people within the disability and aged services sectors.

Carers and Respite

There is not enough respite available to assist one of Australia's most valuable resources – its carers. While there are many support programs and a growing recognition of their needs, many Carers don't get the real support they require. Respite care, when available, is often patchy with no planned breaks.

Many people who are ageing with disabilities are cared for by their parents who are also ageing and often suffering from their own aged related disabilities. So we have the aged caring for the aged and often the disabled caring for the disabled. This is an enormous load, and as their caring role becomes increasingly physically difficult, they have the added mental stress of having to plan for the future care of their child. Many suffer from anxiety and guilt, which may accelerate their own ageing/disability process. Often their greatest concern is what happens when they die or get sick?

All carers require access to information to assist them not only in the physical aspects of caring, but to support their emotional wellbeing. Information on mental health services should be included. Information hubs may be useful in helping to disperse valuable information and bring carers together to share experiences.

The problems for some culturally and linguistically diverse (CALD) and Indigenous carers are magnified beyond the norm. Often they have been isolated and unaware of the availability of special services. It is only when they become ill or a crisis occurs that they and their disabled child accidentally fall into the system.

Carers living in rural and remote areas suffer even greater hardship due to the lack of services and poor access because of the long distances they have to travel and limited public transport.

To ensure adequate access to planning options and services to people with disabilities:

- A wider range of options must be developed to support these ageing carers, including the transition arrangements needed in relinquishing care.

- Options should include access to community based respite in small home-like environments, in-home respite and emergency overnight and weekend respite.
- The availability of respite and other support services must be increased to allow for regular, planned care and not just crisis or emergency breaks.
- Older carers must be given assurances that their child will be looked after when they can no longer do it. This will need to involve transition arrangements so that parents can witness and adjust to the changing situation.
- Elderly Carers should have ready access to HACC support (or its future equivalent).
- Easy access to information and case managers and stream lining and simplifying access to services will alleviate some of the anxiety suffered by carers.
- Provision of rural and remote services should take into account the extra distances, timeliness and other difficulties associated with gaining access to these services.

Aids and Equipment Programs

Many Australians with disabilities, both older and younger people, rely on aids and equipment or assistive technology to assist with their daily living in order to maximize their independence. In some instances, this technology enables them to function with reduced or no expensive personal support services.

Although all the states have aids and equipment programs, there is no consistency between them and they are all inadequately funded. Long waiting lists and the provision of inappropriate equipment, which once accepted by the client usually can't be exchanged, is forcing people to accept items that are unsuitable in order to make do as they can't wait any longer. Alternatively, they may be forced to hire or purchase equipment at retail rates they can ill afford. Lack of access to equipment and programs is impacting on the ability of disabled people to participate in society as fully as they could. Such isolation may also lead to other long term problems.

Computer or communication technology is often twice as expensive as technology for the non disabled and is often out of reach due to the expense involved.

The agreement by COAG⁸ in November 2008 to a National Disability Agreement to bring about a renewed focus on early intervention and a "more consistent access to aids and equipment by the end of 2012"⁹ is an admirable step. However, we are still to see the detail. Programs between states do vary considerably and there should be no lowering of standards in order to bring about consistency, nor should the provision of aids or equipment become a substitute for personal care.

To ensure adequate access to planning options and services to people with disabilities:

- The lack of consistency around the country in relation to aids and equipment programs must be addressed. Access to these programs shouldn't be reliant on the state in which you reside.
- The introduction of timely access to relevant aids and equipment based on need rather than age related and/or disability specific criteria must be introduced.
- People with disabilities must have the freedom to change residency between states without fear of losing their equipment or entitlements.
- Promote and explore the use of technology in the provision of aids and equipment that promote a person's independence.

⁸ Council of Australian Governments' Meeting 29 November 2008

⁹ National Disability Agreement 2009 P. 9

Conclusion

It would be wonderful to assume that people ageing with a disability could plan their care, taking into account a range of services and lifestyle options. The reality is that for the majority of people this is a mere pipe dream.

There are major issues in relation to the provision of disability services, including:

- Underfunding
- Over regulation
- Difficulties in negotiating the system
- Inconsistencies
- Workforce shortages and
- The capacity of services to work together in a coordinated way to meet the often complex and changing support needs of people ageing with a disability.

Any future government strategies must address these issues before it will be possible for people to confidently and universally plan for their future.