SACOSS
South Australian Council
of Social Service

Submission to the Senate Inquiry into Planning Options and Services for People Ageing with a Disability

---

May 2010

Submission to the Senate Inquiry into Planning Options and Services
for People Ageing with a Disability
May 2010

ISBN 978-0-908293-77-3

First published in May 2010 by the
South Australian Council of Social Service

47 King William Road
Unley, SA, 5061 Australia
Ph (08) 8305 4222
Fax (08) 8272 9500
Email: sacoss@sacoss.org.au
Website: www.sacoss.org.au

Written by Kate Braham, Policy & Research Analyst, Kari Bowling, Policy & Research Support Officer, and Ross Womersley, Executive Director, South Australian Council of Social Service.

Contents

Executive Summary

The Australian Institute of Health and Welfare's (AIHW) 2009 report titled *Australia's Welfare* highlights that the current number of people aged 65 and over who are living with severe or profound core activity limitations, 705,000 people, will more than double over the next two decades. In the context of the UN Convention on the Rights of Persons with Disabilities and the recent considerations of a National Disability Insurance Scheme in Australia, this issue has been shown to clearly cross economic, employment, health, housing, social and human rights boundaries.

As people who live with a disability age, so do those family members who throughout history have often found themselves cast into a role as the primary source of support for their loved one. In the main this will be a parent(s), who if, at least 20 years older, is also likely to be struggling with age related issues. This typically amplifies any existing difficulties the person who has a disability may have in terms of access to: adequate support and healthcare; employment; personal support services; and, to community life more generally.

The South Australian Council of Social Service (SACOSS) welcomes this inquiry and the opportunity to contribute on behalf of its members. SACOSS notes that there are a myriad of state and territory, federal and international reports and inquiries, which are already available to the Senate Community Affairs References Committee.

SACOSS believes this vast body of research and analysis speaks to four overarching considerations detailed below. SACOSS believes these should therefore guide thinking, recommendations and any actions arising from the inquiry.

The first is our desire, willingness and need as a nation, to give life to the UN Convention on the Rights of Persons with Disabilities by committing to the idea that people who live with a disability belong at the heart of our community and should be valued for the contribution they make, and indeed, can be supported to make to the life of our community.

The second is the knowledge that in order to achieve this ambition, people who live with a disability need to be supported in a manner which is highly personalised and that ensures the support available is based on a sincere understanding of their individual needs.

The third is the vast body of evidence right throughout our nation that points to the reality that:

a) The way many of our current service arrangements are structured probably directly competes with achieving this ambition.

b) There is a chronic mismatch between support which is actually available to people who live with a disability and where relevant for family members and others in informal caring roles and the need for this support

The fourth is that action on all these issues is imperative and yet another compelling report confined to libraries for the future will do nothing to address the genuine hardships, exclusion and rejection currently being experienced by people who live with a disability and the people who love and care for them.

SACOSS submits that in addition to these overarching issues there a number of other considerations and recommendations detailed in the body of this paper that must be considered in order to ensure a better future for people who live with a disability and who are ageing.

These embrace:

- *Including Key Carer Issues in Planning Options and Services*
- *Pursuing the National Application of Universal Design Standards*
- *Facilitating People's Mobility, Access and Social Inclusion*
- *Improving Mechanisms for Supporting Ageing Parents as Primary Carers*
- *Giving Greater Consideration to Retirement Options for People who live with a Disability and their Carers*
- *Increasing Support for 'Ageing in Place'*
- *Reviewing the Age Criteria for Residential Aged Care*
- *Increasing Accessibility to Information and Resources*
- *Improving Coordination of Government Responses*
- *Improving Communication between Commonwealth and State Governments*
- *Moving Towards Individualised Planning*
- *Addressing Discrimination and Poor Access to Services*

Background to SACOSS and our interest in this Inquiry

SACOSS is the peak body for social services in South Australia. SACOSS is a not-for-profit independent organisation and our members represent a wide range of interests in social welfare, health and community services. SACOSS is also part of a national network assisting low-income and disadvantaged people. SACOSS and its members have the *vision of justice, opportunity and shared wealth for all South Australians.* In addition, SACOSS is an independent non-Government organisation with a proud sixty year history of advocating for disadvantaged and vulnerable consumers.

SACOSS welcomes the Senate Community Affairs Reference Committee's *Inquiry into Planning Options and Services for People Ageing with a Disability*. In our role as a peak body for community services in South Australia we cover a broad range of policy areas including the impacts of disadvantage on the most vulnerable South Australians. Advocating for the needs and interests of people who live with a disability is a focus of SACOSS' work, highlighted by the recent establishment of our disability policy and advocacy group.

Our submission to this inquiry is based upon the perspectives, knowledge and experience of our membership, informed by the fact they might live with a disability and/or work and advocate on behalf of people who have a disability and those who care for them. SACOSS recognises that many people who live with a disability are considered to be amongst the most vulnerable and disadvantaged in our community.

SACOSS is encouraged by the growing awareness of the many implications associated with the changing profile of our ageing population. The establishment of the Disability Services National Minimum Data Set and the Functioning and Disability Unit, and more recently the Productivity Commission's inquiry into a long-term care and support scheme for people with disability in Australia are all evidence of this.

Introduction

The Australian Institute of Health and Welfare's (AIHW) 2009 report titled *Australia's Welfare* highlights that the current number of people aged 65 and over who are living with severe or profound core activity limitations, 705,000 people, will more than double over the next two decades. In the context of the UN Convention on the Rights of Persons with Disabilities and the recent considerations of a National Disability Insurance Scheme in Australia, this issue has been shown to clearly cross economic, employment, health, housing, social and human rights boundaries.

It is generally accepted that the prevalence of disability increases as people age. For example, the commonality of certain disabilities such as vision impairment and deafness dramatically increase with ageing. This is especially of concern in Australia as the numbers of our ageing population are increasing. So too is the age of family members who often find themselves thrust by default, into a caring role for a family member who has a disability. This is typically in the absence of adequate support for the person who lives with a disability from other sources. In addition to the needs of the person they care for, they often find themselves facing increasing health issues, social isolation and often denying their own needs. SACOSS believes all people should have access to the same opportunities for 'active' ageing as the rest of the population, however there is a clear disconnect between the level and variety of need and the types and quantity of government programs to meet this need.

We know that people who live with a disability and who are ageing are vulnerable to premature and inappropriate admission to residential aged care in lieu of receipt of services and assistance appropriate to their age and condition. The Australian Institute of Health and Welfare report, *Disability and Ageing*, highlighted various groups as unlikely to be able to access appropriate services to meet their needs through the ageing-disability interface, including; those with an early onset disability who have minimal living skills; people ageing with disability acquired during adulthood who have greater support needs as they age; people with an intellectual disability who become frail, possibly acquiring dementia and needing increasing health care. The report also referred to the difficulty likely to be faced by people with a disability retiring from Federal-funded employment programs.

Social isolation is a reality for many people with disabilities as indeed it can also be for family members where they are conscripted to provide large amounts of informal care. Prejudice, negative community attitudes and a lack of understanding are seen in the small and often highly restricted social networks of people with disabilities and the people who provide informal care for them.

While people who live with a disability may now, more than ever, be 'physically' present in the community, they far too often remain socially excluded and lonely, as interactions remain generally confined to other people with disabilities, service workers and family members. People who live with a disability and who are ageing lack sustained meaningful relationships which are characterised by the presence of intimacy and friendship, other than (and then not always) with family. This has an increasingly poignant impact on the capacity of people who live with a disability to remain and live in their local communities as they age.

Key Considerations/Recommendations for the Inquiry

SACOSS welcomes and applauds this inquiry. The amount of attention afforded to disability, in terms of the number of inquiries currently in progress and seeking to address issues facing people who living with a disability, is promising. Furthermore, the Australian government's renewed policy focus on social inclusion and the acknowledgement that as a community, we haven't been as inclusive as we ought to have been, is also welcomed.

However the biggest challenge facing this inquiry is that it must sincerely look to deliver much more than considered, compelling reading. In practice, its ambition **must be** to give effect to **real action** on many longstanding issues of concern.

SACOSS believes that there are a number of actions that need to be closely considered as a part of this Inquiry, which will lead to improved planning options and services for people who live with a disability who are ageing and where appropriate, to improvements in the lives the hundreds and thousands of family members and other people who provide care out of love and concern. These actions and recommendations are discussed below.

Commit to ensuring people who have a disability are valued as members of our community.

At the core of any discussion about the needs and interests of people who live with a disability must be a clear commitment about where as a nation we collectively see these people belonging. The UN Convention on the Rights of Persons with Disabilities (to which Australia is a signatory) clearly identifies that this is in the centre of our community, participating equally as citizens, with support to make a contribution and that enables people who live with a disability to enjoy challenging, rewarding, and vibrant lives.

It remains vital that this vision guide any actions we take as a community relating to people who are ageing and who live with a disability. Any actions proposed in support of people who live with a disability who are ageing should be tested against these same criteria.

Ensure people have access to the day to day assistance they need in a manner that is highly personalised, maximises their control and is designed around their individual needs.

There is a wide body of research which repeatedly identifies that the quality of the assistance a person who lives with a disability obtains, will directly relate to the degree in which it is designed for, and as much as possible controlled by, that person themselves. As we move to explore providing excellent support to people who live with a disability and who are ageing these learning's should remain at the forefront of any actions we take

Assist existing services to evolve towards enabling people to exercise control and design support around their own needs and interests.

In Australia today the great majority of services and as a result, the great majority of support available to people who live with a disability, is still not designed around and delivered with these principles in mind.

In practice a huge number of services are still oriented to serving people who live with a disability in ways and means that see them grouped together with other people who have a disability and often congregated away from other community members.

Providing support in this way confirms in the minds of other community members that people who live with a disability are different from them and indeed must need support and assistance that is substantially different to the support that any other community member requires.

This marks who live with a disability apart and ensconces a form of apartheid – rather than on the basis of race, it is on the basis of disability.

It is therefore imperative that as we think about the interests of people who live with a disability and who are ageing we turn our minds to designing new services and support structures which go closer to meeting these principles while also assisting existing services to evolve in ways which help them move toward this.

Ensure there is a sincere investment in funding so as to ensure these supports and services are actually available.

SACOSS believes that the inquiry needs to acknowledge at the outset, the gross unmet need for support and assistance that currently exists in our community today. This too has been repeatedly calculated, and its impact widely documented, although lamentably, has never been afforded an adequate response.

If we are to support people who live with a disability and who are ageing well, we need to address this sometimes devastating reality.

Address Discrimination and Poor Access to Services

Discrimination remains to this day a significant barrier for people living with a disability both in accessing services and being active members of a community. Long standing prejudices and misconceptions are difficult to alter, and greater public campaigns and community education programs are needed to ensure discrimination does not remain yet another barrier TO people who live with a disability living normal lives and fulfilling meaningful roles in their communities.

Comprehensive community education campaign to reduce the stigma still attached to people who live with a disability should be based around the momentum in the sector and internationally around valuing the contribution of people who live with a disability. One of the key ways to overcome stigma is to demonstrate the value and contribution to society and our local communities of people living with disabilities. Starting in schools, young people with disabilities should have access to educational experiences that are positive and inclusive. Children not living with disabilities should grow and learn alongside children with disabilities, supported in ways that encourage interaction, support good relationships with each other and ensure understanding that disability is a natural part of life and okay.

Move Towards Individualised Planning

Individualised or person-centered planning has gained momentum as a means of enhancing the quality and appropriate control of services for people who live with a disability.

Under this approach, support is tailored to fit the individual, rather than the opposite – having the individual fit into a defined system model. Such an approach is able to better meet the changing support needs of a person with a disability, its flexibility allowing assistance for the individuals based on their own goals and helping them to lead a more enriched and self-directed life.

Currently the systems in place across Australia do not allow for this sort of flexibility and tailoring of service models to individual needs, but instead slot individuals into predefined service models. The adoption of a system that makes space for individualised planning and programs to facilitate and implement such programs across all Commonwealth and state programs would greatly improve the capacity and ability of people living with disabilities to plan for their future.

There is a great need for government to work with people who live with a disability and their families where involved along with the disability sector to design and put in place such flexible approaches, with a focus on building capacity of individuals and their carers and communities to manage and plan beyond crisis responses. In working together, non-paid non-service solutions such as circles of support and family networks could also be explored as to the way they can be incorporated into individuals service and life plans.

Improve Communication between Commonwealth and State Governments

There are a number of difficulties and barriers experienced by people ageing with disability and their carers in securing suitable support arrangements, including the interaction between and differences in systems and approaches between Federal and State programs.

SACOSS is sincerely concerned with how the recent National Health and Hospitals Network Agreement may impact on people ageing with disability, as the Commonwealth will assume responsibility for community care services and specialist disability services under the National Disability Agreement for people aged 65 years and over, and the states will assume like responsibilities for those under the age of 65 years. It is imperative that, with the introduction of the NHHA, a system of service provision that allows a seamless transition from and to services for people with disabilities turning 65.

There are significant levels of unmet need for services across the nation. A greater level of investment and a more robust approach to service provision is urgently needed. SACOSS welcomes the inquiries into a long term care and support system and is supportive of such an initiative. It is imperative that all tiers of government agree and support a funding mechanism that guarantees adequate and flexible lifetime support and care for people with disability.

Improve Coordination of Government Responses

The support needs of people with disability usually increase as they age. The history of government programs suggests that responses to such changes are often crisis-driven and problematic.

It is important that all levels of government, the sector and service providers work co -operatively to ensure new and existing programs are well coordinated and their roll-out smooth. The roll-out of responsibilities under the National Health and Hospitals Network Agreement will be a useful indicator, and may set the framework as to how various jurisdictions and agencies can best work with each other to meet desired outcomes.

Increase Accessibility to Information and Resources

As people who live with a disability are living longer, additional resources and supports are needed to help these people and their families wherever appropriate, address the myriad of planning tasks involved. Some such activities are complex, may be difficult to navigate and can be emotionally draining for those involved.

It is important that there is relevant and easily understood information available to those who require it regarding the scope of government programs and various support arrangements available to them, especially for those who have not used the service system before. Such resources should also cover respite and emergency care, as well as longer term support arrangements.

Review the Age Criteria for Residential Aged Care

The government's initiative to reduce the number of inappropriate placements in residential aged care is welcomed, but focuses on those under 50 years of age. SACOSS recommends that consideration be given to the raising of the age criterion to 65 years, an age more aligned to other programs and agreement criteria.

Increase Support for 'Ageing in Place'

There are many people who live with a disability and their families who want to maintain their present family interactions and relationships but need appropriate support and assistance. The 2002 AIHW report titled *Unmet Needs for Disability Services* highlighted a number of pertinent concerns relating to transitional arrangements, potential feelings of guilt about not continuing to support their family members and the need for flexible services and supports. The report also highlighted that funding received by such families is primarily used for crisis response and minimal long-term planning takes place.

It is important that future planning takes into account the overall benefits that ensue from people being supported to live in their own home and 'age in place' - not just in terms of economic considerations but also from social, personal satisfaction and choice perspectives. Cost factors should not be the key determinant to move older people with disabilities from community living arrangements to residential aged care.

There are also restrictions on the ability of supported accommodation residents to access certain community care services to enable them to age in place in their existing accommodation. It is important that any such limitations be reviewed and amended to allow these residents to age in place in their existing homes.

SACOSS believes more creative financing and support options must be explored and developed in order to enable aging parents and carers to secure the future of their sons and daughters with disabilities through the provision of access to lifetime care/support within the family home. New models and concepts, such as home sharing, should be explored to ensure a full range of options are available to suit the range of need.

Just as importantly, SACOSS recommends that increased support for ageing in place should be provided concurrently with additional support for people in informal caring roles. The (2008) Profile of Carers in Australia report cited figures showing that 3/5 of carers aged over 65 are themselves living with disabilities (while likely less severe than the children/partners they care for), compared with just 1/3 of carers generally.

Give Greater Consideration to Retirement Options for People who live with a Disability and their Carers

Like most other people, employees who live with a disability face the dilemma of what to do once they are confronted with retirement. For many such people, work is not merely a form of income generation and meaningful activity/contribution to society; it forms a crucial part of their support structures, social networking, relationships and sense of belonging and identity. In practice retirement often means they find themselves thrust back into having an elderly loved one (typically a parent) provide them with the continuing informal care and guidance they require on a day to day basis. Therefore, people who live with a disability retiring at 65 need to have supports and programmes in place that allow them to retire to "something" that allows them to continue to live as meaningful and active members of society.

Employment often provides significant and much needed respite for ageing carers who, when those they care for cease work, are not supported with funding or opportunities for further (essential) respite.

Furthermore, at such times carers often have to give up employment and therefore income and social networking opportunities. Carers face myriad additional challenges as those for whom they care leave work and furthermore when they pass away, such as difficulty in finding work and an income, and struggling with social isolation that often comes with caring for people with disabilities.

It is recommended that comprehensive programs and supports are developed to assist people who live with a disability and their carers when the time comes for retirement or work is terminated. Such supports should cover issues such as finding further/future employment, tackling social isolation issues and ensuring adequate income remains.

Improve Mechanisms for Supporting Ageing Parents as Primary Carers

Ageing parents of adult children who are getting older themselves may have been caring for many years and are concerned about who will care when they cannot. Assisting with transition of care is central for parents who are themselves ageing. These people are desperately concerned about the end for ongoing care for their son or daughter and aware of the poor availability of housing and support options. They often feel abandoned by the state and distrustful of formal services. They need information about options for, and the legal and financial requirements of, permanent care arrangements as well as ongoing respite and other support.

Many ageing parents do not have a fall back carer. Many will need to be engaged in planning housing and other support for their son or daughter prior to their own frailty or death. There is currently no clear easily accessed mechanism to register a future need for housing and support. SACOSS is adamant that mechanisms which provide families with options to combine family and formal resources for future support must be considered or developed.

Facilitate People's Mobility, Access and Social Inclusion

Transport and mobility issues, community attitudes and accessibility and cultural differences all enhance the sense of social isolation faced by people with disabilities. With ageing, these problems become magnified, as social networks diminish or move into care and mobility becomes an even greater challenge.

For individuals who live with a disability from indigenous and CALD backgrounds (many of whom already face increased health related issues at younger ages and higher levels of social and cultural isolation), the lack of well designed culturally appropriate disability services becomes more obvious as they age and require increasing levels of assistance.

Campaigns aimed at promoting disability as a 'natural' part of life and that portray people who live with a disability as active and effective community members, are desperately needed to start to change long-standing undervaluing and acceptance by the wider Australian community. Concurrently, programs aimed at enhancing community participation, mobility and accessibility options for people who live with a disability, and targeted programs in these areas for the population of ageing people with disabilities, would not only reduce levels of depression and isolation, but enhance the ability of people who live with a disability and their carers to be active as they age and participate in the activities afforded to the wider (ageing) population.

Furthermore, a continued lack of ability to access both transport and buildings remains discriminatory, with social inclusion objectives remaining unmet in this area. While continual talk of a whole-of-government approach to transport and access ensues, little has actually happened to improve accessibility to transport and ensure people who live with a disability are able to be physically mobile in the community. The transport system still is not designed in a way that allows people who live with a disability to access public and other transport systems.

SACOSS recommends that disability services which are culturally relevant and meaningful for people with disabilities from Aboriginal and CALD backgrounds should be developed in consultation with Aboriginal and CALD carers, people who live with a disability and organizations. These services should be flexible and responsive to the needs of these communities and individuals rather than prescriptive of the ways in which they will be assisted.

Pursue the National Application of Universal Design Standards

While some progress has been made in working toward a set of design standards more needs to be done to ensure there are vast improvements in access to buildings of all types, public transport and general community activities and services for people who live with a disability and who have impaired mobility.

It is also important that design takes account of the needs of people who live with a disability who are ageing with regard to adaptive technology, aids and equipment, as the needs of this cohort are likely to increase and change as they grow older. Furthermore, it is important that Government ensures the necessary infrastructure and funding support is available and part of longer term planning considerations.

Include Key Carer Issues in Planning Options and Services

To complete our submission, SACOSS reminds the inquiry that there is an army of sometimes willing but often conscripted family members and others, who provide huge amounts of informal care to someone who lives with a disability and who are a fundamental part of disability services. We believe it is important that in considering planning options and services for people who live with a disability, it is also crucial that we consider planning options and services for the large number of people who provide them with informal care.

Key issues that SACOSS highlights as needing ongoing attention include:

- The effects and impact of long term care on the ageing process in terms of health and wellbeing of the older person.
- The effects and impact of becoming a carer as an older person, especially when becoming a carer but in need of some care themselves.
- The nexus between ageing and disability, including where carers have a disability themselves. This relates to the interface between ageing and disability services.
- The availability of community based resources, from care navigation to transition support, underpinning appropriate levels of support for ageing carers.
- To research and examine how an ageing population will impact on carers. Including looking at issues such as ‘can we anticipate the extent of the future carer challenge’?
- The need to examine the future impact on working carers (especially women), as both the carers and those being cared for live longer.
- The need to continue to and invest more in identifying current and future gaps in carer support.