



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

May 2010

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education. These rights should be mandated in legislation.

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Title: **CA Submission to the Inquiry into Planning Options and Services for People Ageing with a Disability**

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The issue of 'the future' is currently on my mind. Most of the time I manage to keep it below surface, but now and then it rises to the top and I start worrying, searching, asking questions, and generally end up feeling depressed. Organisations are often vague and lack information, and other families who are normally very sharing of their knowledge tend to keep quiet with anything they know, in case it jeopardises their own chances for support for their child in the future.

Lawyers and accountants promise to "look into" options but don't come back to us, and we don't know whether to try and stretch ourselves financially by buying a unit in case there is any chance of independence, or whether this would also risk any chance of support.

We spend a lot of time thinking about this without any outcome or decisions. We secretly hope this can be put off until much later, but also worry about what if we aren't around to make any decisions. All parents have concerns about their children's futures, but nothing compares to the worries of those who care for their children with a disability.

We need an organisation to help us through this process. Not a project based on a once off grant...I hope the money promised by the government will be used towards practical measures for carers and their families.

- Feedback from a South Australian carer regarding the FaHCSIA Succession Planning for Carers Consultation 2006

Introduction

Carers Australia welcomes the opportunity to respond to this much-needed inquiry which signals a growing awareness of the need for suitable and well-planned care for people with a disability who are ageing. Many people with a disability who are ageing do not have the capacity to plan for their futures without the assistance of their family carer. It is vital that family carers who wish to plan for the future of the person for whom they care are assisted to do so.

People with disabilities are living longer and the demand for disability care is growing at a substantial rate. For example, a recent AIHW report highlights that the number of people accessing services that are funded under the Commonwealth, State and Territories Disability Agreement (CSTDA) aged 45-64 have consistently increased in numbers in the last four years.

Policy and program developments that encourage ageing at home also place a greater demand on the provision of care in the home and often it is family carers who are responsible for this care provision. Carers continue to provide the majority of care to those in the community for the majority of the time. Without the significant contribution of unpaid family carers across the health, community care and aged care systems, these systems would simply collapse.

Supporting carers as they age includes providing them with viable options for alternative care and support. All unpaid family carers need peace of mind about the future of their family members or friends once they are no longer able to provide care for them.

Often, as carers age future planning issues take on a more urgent focus. However, it is never too early for carers to consider future options. Many carers of even young children have the legitimate concern that others would not be able to provide care to the same level because of their intimate knowledge of the condition and relationship to the person they care for.

There is a significant need for a range of information, support, planning services and options that will assist carers to effectively plan for the future, Carers Australia believes that there are potential avenues for support that have not been explored, and that services currently in place could be improved upon to better meet the needs of family carers.

Choice for carers and appropriate support for the people for whom they care should be the end goal of any planning options delivered at a national level.

Carers Australia believes choice, access, and the availability of information and resources which are easy to understand are the most important aspects in enabling family carers to plan for the future of people ageing with a disability.

About Carers Australia

Carers Australia is the national peak body representing those Australians who provide unpaid care and support to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia's members are the Carers Associations in each state and territory that deliver specialist information, counselling and others services to carers in the community through a network of over 60 sites that cover the length and breadth of the country. Carers Australia is informed about carer issues through its member Carers Associations (the Network of Carers Associations) and its participation in national and international forums.

We believe that all carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education.

About Australia's Carers

Australia has almost 2.6 million carers, and nearly 500,000 of these are primary carers – the people who provide the most care.²

Carers are sometimes referred to as 'family carers' to distinguish their role from other caring roles in our society such as paid care providers, foster carers, parents or guardians.

Many carers are termed 'sandwich carers or the sandwich generation' because they care for more than one person – a frail parent, a partner or a child with a disability or chronic condition. Anyone, anytime can become a family carer and the caring journey can last a lifetime. This can be from the birth of a child through to their own inability to continue to provide care because of age or illness.

Carers are the foundation of our aged and community care systems, and the annual replacement value of the vital care they provide is over \$30.5 billion. In 2005 it is estimated that carers provided 1.2 billion hours of unpaid care and the productivity loss of this care is approximately \$4.9 billion.³

Carers are from all walks of Australian society and come into the caring journey at various stages throughout their life. Carers are young, of working age, older, Aboriginal and Torres Strait Islanders, they live in rural and remote areas, and may have been born outside Australia.

Older carers

In 2003 ABS identified:

- 454,000 persons aged 65 and over were carers – almost 1 in 5 persons
- People over 65 accounted for 18 per cent of all carers and 24 per cent of primary carers
- 391,000 provide care for someone living in their household and of these:
 - 48% were caring for someone with a profound or severe limitation in core activities – 187,680 people
 - 36% were assisting someone with a moderate or mild limitation – 140,760 people
 - 8% were assisting someone who had a long-term health condition without disability – 31,280 people

- 50 per cent of older primary carers spent 40 hours or more actively caring or supervising.
- The number of male carers increases with age and there are a greater number of male carers than female carers over the age of 65 (23% and 16% respectively).⁴

The two most common family situations involving older carers are:

- older carers caring for a son or daughter with disabilities, including psychiatric disabilities
- older carers caring for spouse or partner with dementia, chronic conditions, terminal illness or disabilities resulting from ageing.

In 2003 the ABS identified 28,000 older carers (over 65 years of age) who were caring for an adult child. Further, AIHW data shows that over 7,500 carers of CSTDA service users were older parent carers (aged 65 or over) in 2007-08. More than half (57%) were caring for a son or daughter aged 45-64 years.

Older carers of adult sons and daughters have usually been caring a long time, sometimes as long as 50 years. Long-term caring can take its toll, socially, emotionally, physically and economically. Older carers are caring at a time when their own health may be deteriorating and they are at risk of the normal range of health issues that arise for older Australians. Yet the caring responsibilities do not necessarily diminish or the level of support increase as these issues present.

These older family carers have often given up on the service system because it has failed them in the past. Many continue to care out of love and a sense of responsibility and because alternative supports have not been available to adequate standards or levels. Some family carers have attitudes and identities shaped by their struggle for what they felt was right for their child and against the institutional service models that were available when their sons and daughters were children. Many of these carers have had little or no training in supporting their son or daughter and have learnt along the way.

In many cases older carers are living the consequences of long-term exclusion from the workforce and costs of caring over time. They have little savings or resources to call upon to help them arrange alternative support for the time when they can no longer care or to achieve a different balance of care that recognises their current capacity to care.

Key initiatives to improve planning options and services

Lack of information when carers need to plan for the future of the person for whom they care is a significant issue. Often carers are not aware or informed of the options or services available, and as such they do not have the capacity to plan. Carers have consistently reported that searching for relevant information is very stressful, time-consuming and may not eventuate in any clear answers.

Carers have a strong need to be well-informed based on relevant, accessible information and competent advice, particularly with regard to those services already in place.

National Information and Resource Guide

Carers Australia believes that a single, comprehensive information resource that will assist carers to effectively plan for the future is essential. The development of a comprehensive guide to available is crucial to support carers from the beginning of their caring responsibilities.

Government consultations with carers regarding succession planning in 2007 identified the lack of accessible information as the most common issue preventing effective planning for the future. Planning and information services were also identified as the most commonly discussed priority to encourage family carers to make private provisions for the future.⁵

There is currently a range of disparate information available for carers through a number of organisations. The Department of Health and Ageing (DoHA) funded the Carer Resource Kit and the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) funded the development a comprehensive set of brochures, as well as the Young Carer Kit. A lot of this information is outdated, duplicated and rarely available.

Even the recently re-launched *Aged Care Services Directory* supplied by the Department of Health and Ageing (DoHA) does not meet these needs effectively. The main issue for this directory in particular is accessibility for older persons and the relevance of the information for carers. It has not been designed with these two goals in mind.

As such, there is currently no effective and targeted central repository for information regarding planning options and services for carers.

Carers Australia was funded by DoHA to develop a website with information for carers because of our broad reach of carers across the country. We believe this website is the ideal platform to host this information and that Carers Australia is the organisation with the most knowledge and understanding of carers needs to develop this resource.

The resource would provide information on a range of issues including:

- financial arrangements and wills and estate planning
- other legal arrangements such as guardianship, power of attorney and nominated and authorised representatives
- emergency planning
- transition planning involving transition away from family care to other independent living arrangements
- ongoing health care management, eg arrangements with GPs, specialists and other health professionals
- rights when accessing services, eg the Charter of Rights and Responsibilities for Community Care
- complaints processes.

The guide would also contain information on Commonwealth funded programs and services for which carers may be eligible across different government portfolios and the third sector.

There is also a need to ensure that resources are designed to meet the needs of carers in rural and remote Australia and reflect the reality of accessibility of services in these areas. Information also often may not meet the needs of people from diverse cultural backgrounds. It is essential that programs and policies account for cultural and linguistic diversity and are accessible for diverse groups.

To address issues of accessibility, the guide should also be made available in a range of languages and in print and online formats.

Recommendation

Carers Australia recommends that the Australian Government fund Carers Australia to develop an updateable National Planning Information and Resource Guide for carers, available in both print and online formats, outlining planning and support options and available services in one comprehensive resource.

Training

Planning options should not be something that individual carers or families must navigate on their own. Training to accompany the proposed National Information and Resource Guide for those who need it, would also enhance the effectiveness of this resource.

Evidence shows that education and training at the right times in the caring journey is an essential component of carer support.⁶ Education is also shown to be an important psycho-social intervention that can lessen that negative impact and improve the carer's capacity to manage and continue in their caring role.⁷

Planning Workshops on options and services could be delivered through the state and territory Carers Associations and tailored to state and territory specific issues and legislative environments.

Recommendation

Carers Australia recommends that the Australian Government fund planning workshops for family carers.

Accessing legal and financial advice

Navigating the legal and financial issues involved in planning options for people with a disability can be difficult and often requires the input of specialists including financial advisers and legal representatives.

Realistically many carers find their options for planning and service access are limited because of an inability to seek formal advice due to financial constraints. This may especially be the case if they have been caring for some time or their main source of income is a government pension.

Recommendation

Carers Australia recommends that the Australian Government provide financial assistance toward the cost of access to specialist financial and legal advice for family carers.

Time to plan

The very nature of caring means that finding the time to plan ahead is difficult. We know that 64 per cent of primary carers over the age of 15 spend more than 40 hours per week caring for a person with a profound core activity limitation⁸ and for mental health carers this increases to an average of around 105 hours per week.⁹ Because of the intensity of caring situations, many carers are simply rundown, overstressed and overworked, and without enough distance from their current situation (either physical or psychological) and will find planning options difficult to consider.

Given this aspect of caring it is important that any programs and services put in place to assist carers to plan also support carers to find the time to plan ahead. Specialised respite that allows time to put in place planning options may assist in this process.

Recommendation

Carers Australia recommends that the Australian Government fund a program that allocates additional respite hours for the purpose of planning arrangements.

Carer impact

In addition to these initiatives, a considered approach to the outcomes for carers and potential negative impacts in the delivery of new programs and services is important and should be applied to any policies and programs that will affect family carers.

For example, there may be instances where the interests of the person with a disability conflict with the health, wellbeing or safety of family carers. It is essential that this is given full consideration through formal processes.

This can be achieved through the simple inclusion of a 'carer impact statement' in all policies and programs of relevance to carers.

Recommendation

Carers Australia recommends the inclusion of a 'carer impact statement' in all new policies and programs developed at an NGO or government level related to planning options and services for people ageing with a disability.

Consultation

It is essential that wherever policies and programs are proposed that impact on carers, that carers and the organisations that represent them are fully included, informed and consulted.

Recommendation

Carers Australia recommends consultation measures with family carers directly and the organisations that represent them (including carer representation on advisory groups) related to planning options and services for people ageing with a disability.

Other Issues

The following issues can have a significant impact on the ability for carers to access services for the future care provisions of the person for whom they care and have confidence that they will be provided for in their absence. They require further improvements and consideration at a national level.

Supported accommodation

When looking to the future many carers want certainty regarding where the person they care for will reside when carers are no longer able to house them, or whether the person they care for will be able to achieve this kind of independence in the future.

Currently there is a shortage of alternative accommodation for people with a disability. There has been increased attention recently on the need for specialised disability accommodation for adults under the age of 65 who would otherwise potentially be placed in residential aged care facilities that are not designed to meet their needs. Access to suitable housing for adults with mental illness is also a concern for many carers of adults with a mental illness.

In 2008 Carers Australia hosted the Carers Virtual 2020, to learn from carers about issues of concern to them. Housing and accommodation support was one of the topics that attracted considerable interest.

Some of the ideas to come from the discussions included apartment-style accommodation for young adults with disability; little villages with individual living units; and retirement village style accommodation to cater for people with disabilities who needs range from low to high. Overwhelmingly, the major concern was that young adults with a disability may be placed in a residential aged care facility. Another clear message was that one size does not fit all.

Carers Australia believes there is an ongoing need for increased investment in innovative supported housing models for adult children with disabilities. This is in line with the outcomes of the National Disability Agreement 7 (b).

Improved application of universal housing design in the housing market will also increase the potential for those with disabilities to find suitable accommodation in the community.

Recommendation

Carers Australia recommends increased government investment in supported accommodation for adult children with disabilities.

Transport

Transport is an important support service for many people with a disability, particularly where there is reliance on their carers for transport or where carers are unable to provide transport for the person for whom they are caring.

Formal transport assistance can significantly relieve some of the care tasks otherwise provided by family carers. It can also have an impact on the availability of 24 hour respite or other support services particularly in isolated areas where paid care workers rely on these services to deliver care.

Carers Australia has been informed that in the Northern Territory, the available transport is not sufficient to meet current needs, or the increasing demand associated with an ageing population. Further, the transport services provided by the Department of Health and Ageing is limited in terms of use, cannot be shared between clients of different services and often have limited longevity due to the availability of qualified staff to drive the vehicles.

A community transport scheme where vehicles are shared between local services and coordinated through a central NGO has the potential to provide improved support at a community level for people with a disability and their family carers.

Recommendation

Carers Australia recommends that the Australian Government give further consideration to the introduction of new community transport programs and innovative models for transport services, including sharing of services across disability organisations, particularly in areas affected by remoteness.

Special Disability Trusts

The Government has recently committed funding and attention to the improvement of Special Disability Trusts. Despite the improvements implemented to broaden the take-up of these trusts there are still many a number of amendments that could be made to the scheme to ensure it benefits a greater number of carers.

Recommendation

Carers Australia recommends ongoing improvements to the Special Disability Trust process.

Attitudes and caring perspectives

Another significant consideration throughout this process should be the psychological barriers that may inhibit carers from future planning. Many carers recognise the need to plan ahead, but are impeded by attitudes, beliefs or mindsets that prevent them from thinking too far into the future. For many carers contemplating the future can be a confronting and traumatic experience involving the consideration of many worst-case scenarios.

For other carers, their approach to dealing with the challenges of caring is to plan for the short-term and deal with issues as they come to hand. As such, they do not actively seek to plan for the future. The uncertainty that is associated with many illnesses and disorders can also be a significant barrier to planning ahead as these carers may feel that they cannot accurately predict what will happen in the future.

One of the ways of coping with chronic illness is to live it day by day, take it as it comes. Planning is a bit of a challenge sometimes because you're really not sure where the journey is going to take you. — Lois, carer of husband speaking on the issue of 'Planning for the Future'

Older carers may have attitudes that have been shaped by their struggle for what they felt was right for their child and against the institutional service models that were available when their sons and daughters were children. They may have also given up on engaging with service systems or supports because they have failed them in the past.

All of these attitudes and approaches to caring may prevent carers from engaging with planning processes or services. Some carers may need significant assistance, information or even counselling before they can even begin to 'think' long-term.

Conclusion

Carers acknowledge the importance of planning for the future, but many are not properly aware or informed of what is involved in ensuring that the person they care for will be well looked after.

Carers will often be best placed to make these decisions and should be assisted to do so before crises, emergencies or significant life-changes occur. Carers must be supported to engage with this process in the way they feel most comfortable and the provision of information and specialist advice is the best way to achieve this outcome.

Carers Australia understands the needs of carers and is well-placed to develop and deliver informative resources for carers. We would welcome the opportunity to be involved in government funded processes to support carers to access planning options and services for the people for whom they care.

References

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