

28 January 2011

Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

Re: Inquiry into Planning Options and Services for People Ageing with a Disability

Carers NSW thanks the Senate Standing Committee on Community Affairs (the Committee) for the opportunity to provide a submission to the Inquiry into Planning Options and Services for People Ageing with a Disability.

1. Introduction

1.1 About Carers NSW

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- Be the voice for carers in NSW
- Undertake research, policy development and advocacy
- Provide carer services and programs
- Provide education and training for carers and services providers
- Build capacity in the sector.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by the community and by governments.

The goal of all of the work Carers NSW undertakes is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

1.2 Who Carers NSW represents

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful.

Across NSW, there are estimated to be approximately 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

1.3 Submission format

Carers NSW's submission will focus on people ageing with a disability who are supported by their ageing parents, informed by our experience as a provider of the *Support Coordination Program for Older Parent Carers*. It is not the intention of Carers NSW to respond to all of the questions posed in the Terms of Reference.

Carers NSW is aware that the Terms of Reference of the Inquiry have been amended to avoid overlapping with the Productivity Commission Inquiry into *Disability Care and Support*, and as such do not focus on service planning or delivery. However, Carers NSW will make some comment on these areas as we feel it would be remiss to make no mention of issues which are so critical to the carers we represent, and that interrelate so closely with the current Terms of Reference.

The Productivity Commission is conducting an Inquiry into *Caring for Older Australians*, the results of which will also be of significance to this Inquiry. As acknowledged by the Commission, many more people with disabilities are living longer, and many younger people are acquiring disabilities previously associated with ageing. According to the draft report of the *Caring for Older Australians* Inquiry:

In its final *Caring for Older Australians* report, the Commission will recommend the most appropriate funding, assessment and service delivery arrangements for people with disabilities who are ageing, and older people who incur a disability. In defining an appropriate interface between the two systems, the Commission is mindful of the importance of the service provision being seamless for the person receiving care. Services should be drawn from the sector with the most relevant expertise, irrespective of the funding source.¹

The Commission will outline its preliminary preferred option on the split in funding between the aged care and disability sectors in the draft disability care and support inquiry report.²

No doubt the Committee will play close attention to the findings of both Inquiries, including those relating to the interface between the aged care and disability sectors. Carers NSW hopes that the Committee will take into account the recommendations of both Inquiries and the likely future of the aged care and disability sectors when making their findings.

Carers NSW supports the submission provided by Carers Australia to this Inquiry, and the submissions by Carers Victoria and Carers Western Australia.

2. Older parent carers

Older parent carers are people aged over 60 (or over 45 if Aboriginal), who care for an adult son or daughter. Many older parent carers have been caring since they were new parents, often without any support from formal services. Caring for such long periods of time has significant impacts upon the social, emotional, physical and financial wellbeing of the carer. Depending on their parent for care until they themselves are ageing can also have serious consequences for

the person with a disability, particularly when it is time to plan or transition to other care and/or living arrangements.

Older parent carers continually report their anxiety about who will care for their child with a disability when they can no longer continue caring. Many also state that they want a choice about when their caring role ends.

The Australian Institute of Health and Welfare report, *Current and Future Demand for Specialist Disability Service* (based on the user profile of Commonwealth /State/Territory Disability Agreement funded services) provides an insight into older parent carers in NSW. According to CSTDA data, about 44 per cent of ageing carers had been in their role for 30 years or more. Ageing informal carers (aged 65 years and over) were most likely to be mothers caring for a son or daughter (58 per cent).³

2.1. Support Coordination Program for Older Parent Carers

Carers NSW is a provider of the *Support Coordination Program for Older Parent Carers* funded by Ageing, Disability and Home Care (ADHC), Department of Human Services NSW. The objectives of the Program are to identify, engage and support older parent carers to maintain their caring role for as long as possible by providing support and respite opportunities, linking with both formal and informal community supports, as well as planning and preparing for transition from parental care.

The Program aims to achieve the following outcomes for carers:

- access support that assists them in their caring role
- have a break from everyday care responsibilities
- have opportunities to pursue their own interests and build informal networks
- maintain their independence and better manage change as part of more sustainable care arrangements
- have a say in how services are delivered and develop a plan to meet short and longer term goals for themselves and their son or daughter with a disability
- older parent carers are assisted to prepare for the future needs of their son or daughter
- Aboriginal people and people from CALD backgrounds have fair access to support.

Care to Live or Live to Care?, published by Anglicare Sydney in 2010, provides a profile of the older parent carers who access the *Support Coordination Program for Older Parent Carers* delivered by Anglicare. According to this report, one in five of the Program's clients are over 80, more than a third have been in their caring role for more than 40 years, and 96 per cent were living with their adult child. 75 per cent of entrants to the program had no plan in place for the future care of their son/daughter.⁴ This report coincides with Carers NSW own experiences as a provider of this program.

This submission is based upon Carers NSW experiences as a provider of this Program in Sydney, the Mid North Coast and Greater West areas of NSW.

3. Services and choices needed to help people with a disability and their carers to plan for the future

3.1 Access to legal and financial advice

People with a disability and their carers need access to legal and financial advice to assist them to plan for the future. Carers NSW believes that people with a disability and/or their carer should

have access to subsidised legal and financial advice from professionals who specialise in this area. Carers often report that they do not know where to seek the specialist advice that they need and cannot afford the associated fees. Although free or discounted legal assistance is available from some private law firms and through various government and non-government organisations, there is by no means guaranteed or easy access to such services for people with a disability and their carers.

Due to the complexity of the legal and financial issues that are involved specialist advice is often required from practitioners who understand the needs and experiences of people with a disability and their carers. Feedback from clients of the *Support Coordination Program for Older Parent Carers* suggest that generalist legal and financial practitioners do not always understand the situation or needs of people with a disability and their carers and are not familiar with the planning options available to them or their potential implications. Although some individuals prefer to seek the advice of long-standing family solicitors, more complex cases require specialised advice.

Carers NSW believes that there is a need for awareness training for legal and financial professionals, particularly those who specialise in this area. Carers NSW has received reports from older parent carers of legal practitioners who have been highly insensitive in their dealings with the carer, or who have inappropriately provided advice based on their personal opinions and experiences rather than their legal expertise. Specialists in this area should receive awareness training to ensure they interact appropriately, sensitively and ethically with carers and people with a disability. It is important that they are aware of the sensitivity of the issues involved, the vulnerability of some individuals, and the high level of need that exists in some cases.

A directory or register of legal and financial professionals who specialise in this field should be made available, consolidating existing registers/contact lists kept by disability and legal advocacy organisations.

Access to legal and financial advice is not just an issue for older parent carers, or for people who are ageing with a disability. Carers NSW also receives requests for information on these matters from the carers of children and young adults who want to start planning for their future now. Any initiatives that are put into place must not be limited to people already ageing with a disability. Assistance to plan for the future must also be provided for those who are not yet ageing, to enable people to prepare for the future and to avoid repetition of the difficult situation currently lived by many older parent carers and people ageing with a disability.

3.2 Assistance to plan for the future

Carers NSW experience as a provider of the *Support Coordination Program for Older Parent Carers* is that many older parent carers need support and assistance before they can even think of planning for the future. In many cases carers have provided care for several decades with little or no support. In these cases it is difficult for both the carer and the person with a disability to accept and plan for a future in which this caring relationship will change and eventually end.

Older parent carers who have accepted the need to plan for the future often need considerable emotional and practical assistance to do so. For many this is an anxious and challenging time, and emotional support and reassurance is required. More practical support may also be needed, including help to identify what needs to be done, support to understand information they receive from various organisations and agencies, liaison with service providers, and assistance to arrange transport and respite to enable them to attend appointments.

Assistance to plan for the future must recognise the interdependence that often develops between people with a disability and their ageing carer and take a family-centred approach. For

those older parent carers who are experiencing issues related to their own ageing, the dynamic of carer and carer recipient may be shifting, and the care relationship may be becoming more complex.

Assistance to plan for the future will be particularly important in the current context, in which a trend towards individualised funding is evident.⁵ Carers NSW is currently participating in *my plan, my choice: Individualised (Packaged) Support*, a Participatory Action Research Strategy funded by ADHC. In the *my plan, my choice* pilot being conducted by Carers NSW the carer receives assistance from a support planner and a support intermediary. For many carers, similar assistance to plan and arrange support will be needed, particularly under individualised funding models.

3.3 Special Disability Trusts

Special Disability Trusts were established in 2006 to assist families and carers who have the means to do so to make private financial provisions for the current and future care and accommodation needs of people with severe disability.

Take up of Special Disability Trusts has been very low due to their inflexibility and the significant limitations on their use. This issue has been recognised by the Committee, which recommended modifications to the Trusts in 2008. Although some modifications have been made, and the usefulness of the Trusts have improved as a result, serious limitations remain in terms of eligibility for and use of the Trusts. Further modifications will be required if Special Disability Trusts are to become a real option for families and carers planning for the future.

4. Critical importance of accommodation and support services

Although the Inquiry is not focussing on service planning and delivery, the Terms of Reference of the Inquiry cannot be addressed without some discussion of this issue. Improved planning options or services to assist with planning for the future will be meaningless if there is nothing to replace or supplement the care and support provided by carers.

4.1 Supported accommodation

At the core of the difficulties of planning for the future of people ageing with a disability is the critical shortage of supported accommodation that exists in NSW and nation-wide. The significance of this issue has been emphasised by Carers Australia, Carers Victoria and Carers Western Australia in their submissions to this Inquiry. Carers NSW and the network of Carers Associations have raised this issue repeatedly and will continue to do so until there is a significant increase in the number and variety of accommodation options available to people with a disability.

The need for supported accommodation in NSW is urgent. Although there are no definitive statistics publicly available as to the level of unmet need, the Australian Institute of Health and Welfare (AIHW) estimates that around 10,000 people in NSW have unmet supported accommodation needs.⁶ As of July 30, 2010 there were over 1,729 people on the NSW Register of Requests for Supported Accommodation, 723 of whom are identified as needing a 24 hour supported accommodation place and willing to take up a place immediately.⁷ This register represents only a proportion of demand for supported accommodation, as many older parent carers and their families are not in touch with services, have not yet sought alternative accommodation, or their requests for accommodation are not recorded on this particular register.

Through *Stronger Together: A new direction for disability services in NSW 2006 – 2016*, the NSW Government has committed to creating 1,000 accommodation places by 2010-11,⁸ and a

further 1,800 by 2015-16.⁹ According to the NSW Government, capacity in 2005-06 was recorded at 4,700 places. If the places committed to in *Stronger Together* are implemented there will be just 7,500 places in NSW by 2014-16.¹⁰ This figure falls short of current demand, and will certainly not be sufficient for the level of demand that will exist in 2014-16.

Until there is adequate supported accommodation available for people with a disability it will be very difficult, if not impossible, for many families to plan for the future, and to maintain or improve their quality of life. Currently, the effective entry point to supported accommodation is the relinquishment of the person with a disability or the death of the carer. As long as this situation persists there can be no meaningful advances in the capacity of older parent carers to plan for the future, or to maintain or improve their quality of life.

4.2 Residential aged care options

There are also very limited options for those older parent carers who wish to move into residential aged care with the person ageing with a disability. Although several clients of the *Support Coordination Program for Older Parent Carers* have attempted this, very few have succeeded. The few retirement villages who will allow this, do so on the understanding that the person with a disability is a guest, not a resident, and will not provide any assurance that they can remain in the accommodation after the carer passes away.

4.3 Support for people with a disability to age in place

People with a disability should have the same right to 'age in place' as other members of the community if they choose. In many cases, when the older parent carer dies or moves into residential aged care, the family home is available for the person with a disability to live in. Remaining in the home means that not only does the person have somewhere to live, they are in their own home, and can maintain their connections with the local community, social networks and service providers. However, to remain in the home the support and care previously provided by the carer needs to be replaced by long-term, guaranteed formal supports. There must be some guarantee of service for this to be an option for future planning that people can depend upon. The current situation where carers and people with a disability regularly have to reapply or be reassessed for services, creating much uncertainty and stress, is untenable in the context of future planning.

Long-term case management services would also be required if the carer is no longer present to play this role, or no is no longer able or willing. Currently most or all case management services are short to medium term, with a strong focus on supporting clients to transition from case management to greater independence. For some people ageing with a disability, it is long term, continuous case management that is required for them to live in the community.

5. Carers right to choice

Carers NSW believes that carers have a right to choice in their caring role. Better planning options should ensure that carers can choose how they balance informal and formal care as their needs change, and be able to choose how and when their caring role ends. Current policies and programs, such as the *Support Coordination Program for Older Parent Carers*, are based on the expectation that older parent carers will continue in their caring role, regardless of their capacity or willingness to continue providing care. This expectation must not underpin future options and services to help people ageing with a disability and their carers to plan for the future. People with a disability, and their carers, have a right to choose where and how they live.

6. Conclusion

Carers NSW appreciates the opportunity to make this submission to the Inquiry into Planning Options and Services for People Ageing with a Disability. If you require any further information about Carers NSW submission to this Inquiry please contact Alison Parkinson on 02 9280 4744 or email alisonp@carersnsw.asn.au.

Yours sincerely,
(...)

Elena Katrakis
CEO
Carers NSW

Endnotes

¹ Productivity Commission, *Caring for Older Australians Productivity Commission Draft Report*, Canberra, p 8, 2011

² Productivity Commission, *Caring for Older Australians Productivity Commission Draft Report*, Canberra, p XLIII, 2011

³ Australian Institute of Health and Welfare, *Current and future demand for specialist disability services*, Canberra, 2010

⁴ Anglicare Sydney, *Care to live or live to care*, Sydney, 2010

⁵ Australian Institute of Health and Welfare, *Australia's Welfare 2009*, AIHW cat. No. AUS 117, Canberra, 2009

⁶ Australian Institute of Health and Welfare, *Current and future demand for specialist disability services*, Canberra, 2007

⁷ Ageing, Disability and Homecare, 'Submission to the Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care', Sydney, 2010

⁸ Ageing, Disability and Homecare, *Stronger Together A new direction for disability services in NSW 2006 – 2016*, Sydney, 2010

⁹ Ageing, Disability and Homecare, *Stronger Together A new direction for disability services in NSW 2006 – 2016: The second phase 2011 – 2016*, Sydney, 2010

¹⁰ Ibid