



30 July 2010

Caring for Older Australians
Productivity Commission Inquiry
GPO Box 1428
CANBERRA ACT 2601

Dear Sir/Madam,

Carers NSW welcomes the opportunity to make a submission to the Caring for Older Australians Public Inquiry.

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 their communities 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 or linguistic background.

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 is an estimated 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

1.3 Key statistics about caring in NSW

According to statistics on carers from the Australian Bureau of Statistics 2003 Survey of Disability, Ageing and Carers (SDAC):

- Approximately one third of all carers in Australia live in NSW
- 40 per cent of primary carersⁱ cared for a partner, 29 per cent for a child, 32 per cent for other (e.g. sibling, parent)
- Women aged 45-54 years were the largest single group of carers
- 45 per cent of primary carers provided 40 hours or more care per week on average
- 78 per cent of primary carers lived with the person they supported
- 75 per cent of carers were of workforce age although 45 per cent were not in the workforce
- 55 per cent of primary carers relied on a government allowance or pension as their principal source of income.

1.4 The role of carers in the provision of care to older Australians

Carers NSW was disappointed with the exclusion of the role and needs of carers from the Inquiry's Terms of Reference, and with the lack of recognition of their contribution and needs in the *Caring for Older Australians Issues Paper*.

Carers play a critical role in the provision of care in Australia, including in the provision of care to older Australians. The final report by the National Health and Hospital Reform Commission described carers as the 'invisible workforce' and recognised that the health system relies heavily on the care they provide.¹ Carers also underpin Australia's community services system, and provide the majority of the care provided to older Australians.² The economic value of informal care is immense. In 2005, the cost of replacing the care provided by carers with formal services was estimated at \$30.5 billion.³

The contribution of carers will become increasingly critical to the provision of care to older Australians. As acknowledged in the Issues Paper, the population is ageing and the number of older people requiring care is increasing. This growth in demand for care will coincide with a contraction in the availability of informal care, due to a range of factors including increasing workforce participation by women and the decreasing size of families. It is estimated that a 10 per cent reduction in informal care will translate into a 40 per cent increase in demand for formal care.⁴

The importance of making caring more sustainable is evident, and merits greater consideration than it has been given in the *Caring for Older Australians Issues Paper* and Terms of Reference. Any inquiry into the future of the aged care system must make the invisible visible and take into account the unpaid workforce of carers, their contribution and their needs. The Commission must not take the contribution of carers for granted, as the aged care system and the wellbeing of older Australians

ⁱ A primary carer is someone who takes on the main caring responsibilities of a care recipient. Australian Bureau of Statistics defines a primary carer as a person who provides the most informal assistance on an ongoing basis, to another person who is restricted by one or more core activities in the areas of communication, mobility and self care. A secondary carer provides informal care in a supporting role where either another family member or formal services provide the majority of care.

depends upon their continued contribution. If the work of carers is not adequately appreciated a full understanding of the aged care system will not be reached, nor will an effective response be made. Carers NSW recommends that the Inquiry adopts a carer focus to ensure that a full understanding of the aged care system and its future challenges is reached, and that the needs of this invisible workforce are not overlooked.

1.5 Format of this submission

This submission will focus on the role and needs of carers in the provision of care to older Australians. Carers NSW and the Network of Carer Associations were disappointed at the exclusion of carers from the Terms of Reference of the Inquiry, as has been represented to the Commission by Carers Australia. As such, this submission will focus largely on the role and needs of carers in the aged care system, with a particular focus on elder carers (carers of older people) and older carers (older people who are carers) rather than addressing specific items from the Terms of Reference.

2. Elder carers

Elder carers are people who provide unpaid care and support to a family member or friend who is an older person and requires care because they are frail, or because they have a disability, mental illness, drug and alcohol dependencies, chronic condition or terminal illness.

Elder care in Australia is gendered, being provided overwhelmingly by female relatives of the care recipient. In particular, women provide the overwhelming majority of care for aged parents. 91.2 per cent of parents receiving primary care in 2003 were cared for by their daughters.⁵ Often this care is provided in their peak working years of 35 to 54.

In an elder care situation the intensity of the role increases over time and can involve a role reversal between parent and child.⁶ Issues affecting elder carers include the often sudden and intense onset of caring responsibilities, which are likely to require the carer to have greater absences from work and are difficult to plan for due to their unpredictable nature. The needs of elder carers differ from those of other carers, such as those who care for children.⁷

Carers NSW believes that the role of these carers needs to be better supported by the aged care system. Particular interventions are needed to assist these carers to coordinate the care of the person in need of support, as will be discussed in this submission.

3. Older carers

Older carers are older people who provide unpaid care and support to a family member or friend. Older carers may be elder carers, and thus have a double interaction with the system. That is, they may themselves require aged care services, although they may simultaneously be providing care to another older person.

According to the 2003 Survey of Disability Ageing and Carers, in Australia:

- 454,000 persons aged 65 and over were carers – almost 1 in 5 persons
- 391,000 older people provide care for someone living in their household

- People over 65 accounted for 18 per cent of all carers and 24 per cent of primary carers
- 50 per cent of older primary carers spent 40 hours or more actively caring or supervising.

The two most common caring situations for this group are:

- older carers caring for spouse or partner with dementia, chronic conditions, terminal illness or disabilities resulting from ageing
- older parent carers caring for a son or daughter with a disability.⁸

3.1 Older parent carers

Older carers of adult children have often been caring for a very long time, in some cases for as long as 50 years. Caring for such long periods of time, often with little or no formal support, can have significant impacts upon the social, emotional, physical and financial wellbeing of the carer. Older parent carers are still caring at a time when their own health may be deteriorating and they are at risk of a range of age-related issues, in addition to the long-term impacts of their caring responsibilities. When age-related issues present, their caring responsibilities do not necessarily diminish nor does the level of support they receive increase.⁹

In many cases older parent carers are living the consequences of long-term exclusion from the workforce and the accumulated costs of caring over time. Often they have given up on a service system which has failed them in the past, and are receiving no formal support in their caring role. They often lack the resources, such as savings, which would enable them to arrange alternative support for the time when they can no longer care, or to achieve a different balance of formal and informal care.

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

The needs of older carers, particularly older parent carers, need to be better met by the aged care and disability systems. Supports and services to assist older carers in their caring roles, as well as responsive and flexible aged care services which meet their own care needs must be provided. Further, more assistance, information and supports are needed to help older parent carers in particular plan for the future, and make choices about the care they are providing.

4. Community-based services and supports

Over the last twenty years there has been a greater emphasis on community care and on 'ageing in place', in recognition of the desire of a majority of people to live independently in their own homes as they age. 'Ageing in place' means people are cared for with minimal disruption to their situation in the place of their choice, where they live permanently.¹⁰

The Australian Institute of Health and Welfare (AIHW) has described carers as the 'enablers of community care'. For many older Australians, the care provided by formal services is not sufficient to enable them to remain at home. It is the on-going support and assistance provided to them by a carer, supplemented by community care services, which tips the balance in favour of the person being able to age in

place. The AIHW describes the role of the carer as crucial in allowing people to remain living in the home.¹¹ However, carers need supports and services if they are to continue as the 'enablers' of community care. Of particular importance is the timely provision of adequate and appropriate community care services, respite service, transport assistance, and information and coordination supports to assist elder carers to navigate the aged care system.

4.1 Community care services

Increased funding for services that support elder carers is essential. While currently programs such as the Home and Community Care (HACC) and Aged Care Assessment Team (ACAT) programs provide support to people who are frail aged and their carers, in NSW these programs in most cases have considerable waiting lists. Carers NSW continually hears from elder carers who are still waiting for an Aged Care Assessment Team to come to their home or are waiting for a HACC service to become available. Carers NSW believes that to provide appropriate support to elder carers the allocation of funding to programs such as HACC and ACAT must be increased to ensure waiting lists are minimised and that the services are delivered to carers who are in need of them.

Recommendation 1

Carers NSW recommends that funding to services and programs that support elder carer provision such as Aged Care Assessment Teams and Home and Community Care is increased.

4.2 Respite

The provision of adequate and appropriate respite services is crucial to support the role of carers in the aged care system. In our consultations with carers, nearly every carer states that they want more respite. The need for more respite was also evident in the *Who Cares...?* report, and it was one of two services repeatedly mentioned during the Better Support for Carers Inquiry as both critically important and in short supply.¹²

Carers NSW believes that an increase in the respite services available to elder carers is required, and that changes are also needed to the way in which respite services are delivered. To be of benefit to carers, respite services must meet the needs of the carer and the person requiring care. Service users should not be expected to meet the need of the service.

The evidence suggests that demand for respite is increasing. For example, a 2009 progress report for the Commonwealth State/Territory Disability Agreement (CSTDA) on specialist disability services found that funded respite services registered the highest growth in service users relative to target population. In 2007-08, 31,500 people used CSTDA-funded respite services compared with 20,500 in 2003-04, corresponding to an increase from 96 respite users per 1,000 target population in 2003-04 to 137 per 1,000 in 2007-08. Over the same period, government expenditure per respite service user fell by 16 per cent in real terms. Data on hours of respite received show a downward trend from an average of 12.1 per respite user per week in 2003-04 to 10.5 hours per week in 2007-08.¹³

The *Home and Community Care Program 2007-08 Annual Report* indicated that the highest average hours of service to clients by assistance type was for centre-based day care (130 hours) followed by respite care (86 hours). It is important to note, as

stated in the report, that these averages are a rough measure of service provision and do not reflect the experiences of individuals. For example, some clients receive services throughout the entire year and others for only short periods.¹⁴

The evidence suggests that the amount of government funding in real terms for respite per service user has decreased. Meanwhile carers have identified increased respite availability as a high need for their caring role. Carers NSW believes that respite is an essential service for carers and that funding for respite must be provided according to the need for this service.

Recommendation 2

Carers NSW recommends that the Inquiry address the need for increased funding of respite services to align with demand, and with the identified need by carers.

In addition to the limited capacity of respite services, the affordability and flexibility of respite is also a significant issue for many carers. Carers NSW continues to hear concerns from carers regarding respite. Issues commonly raised include;

- lack of appropriate respite places for the person they care for, especially for those with high support needs
- inadequate funded respite which leaves many carers with no respite for actually having a break, as all their respite is used for work and family commitments
- inflexibility of the services provided, which in some cases renders them inaccessible or of limited benefit
- being offered services they don't need but denied the services they do
- lack of transport options between home and respite, and between school or day programs and respite
- considerable out-of-pocket costs
- lack of culturally appropriate respite services for Aboriginal people and people from culturally and linguistically diverse backgrounds.

The Inquiry needs to address the need for better respite provision. In addition to increasing allocation of funding for respite services to align with demand, it is vital that changes are made to the service system so that it is more closely aligned with the needs and choices of the carer and the person requiring care. Respite needs to be more flexible, and driven less by fixed program structures and more by the needs of the people who use it. It is the services who must meet the needs of the people, instead of the current situation where it is the carers and older people who must meet the needs of the service or go without. Better respite is fundamental to making caring, and therefore the aged care system, sustainable.

Recommendation 3

Carers NSW recommends that the Commission address the need to implement a fundamental shift in the delivery of respite services, from an inflexible system to one that responds to the needs and choices of service users.

4.3 Transport

The transport needs of older people are significant. According to 2006-07 Aged Care Assessment Team (ACAT) data, transport assistance was the second largest area of need for ACAT clients, after domestic assistance. 87 per cent of older Australians receiving an ACAT assessment were assessed as needing transport assistance.¹⁵ The 2005 Australian Government House of Representatives Standing Committee on

Health reported that appropriate transport systems for older people were “not optional but essential”.¹⁶

Transport assistance for older Australians is vital for the improved wellbeing and labour force participation of elder carers. Elder carers often spend significant amounts of time transporting the older person to medical, dental and other health appointments, which often occur during business hours and thus can interfere with work commitments in particular. Transport assistance could alleviate the impacts of elder caring on carer workforce participation.

Transport assistance may also increase service utilisation and the benefits for carers of services such as respite. If the carer is required to transport the older person between the home and respite, or respite and other services, the expense, stress and time that may be involved can reduce or negate the benefit of these services to carers and undermine the ‘break’ that they are intended to provide.

Transport is also crucial to improve the social inclusion of older people, and to enable them to retain more independence for longer. Transport assistance would allow older people to continue to go shopping in their local community, to attend the cultural, religious, recreational and social activities of their choice, and to remain engaged and active members of their communities.

Recommendation 4

Carers NSW recommends that the Commission address the need for transport assistance for older Australians.

4.4 Care navigation

Carers have diverse and significant information needs. As has been recognised in the Issues Paper, one of the key reform challenges is the provision of adequate access to information about the services available to older people and their carers.

The *Who Cares...? Report on the inquiry into better support for carers* released in April 2009 identifies access to information about supports, services and assistance as one of the six main challenges faced by carers.¹⁷

The *Who Cares...?* report identified that carers need increased access to information, education, training, family and carer advocacy, case management and care coordination services. Barriers to accessing information for carers included an overly complex and fragmented service system, limited time of carers, language and unawareness of rights to services and the lack of availability of information in specific service settings.¹⁸

For the Australian aged care system to be accessible, the information needs of carers must be met. The provision of information must be simplified and improved so that older people and carers are informed of what services exist and how to access them. Carers should not have to spend time, energy and resources they do not have to find out what they need, nor should they ‘stumble’ upon services and supports long after they are first required. Accessing the necessary services should not depend on chance.

Catering to the needs of elder carers requires a separate and specific policy approach. It also requires an emphasis on early intervention and care coordination.

4.4.1 Awareness raising for potential elder carers

Carers NSW believes that it may be beneficial to develop a promotional and awareness raising campaign aimed at women aged 35-54 years to provide information on what to do if you find yourself in a caring role and what supports are available. Women aged 35-54 years are the group providing the most care to older people, and it is likely that the commencement of these caring responsibilities will be unexpected and intense. Awareness raising and information provision will assist new elder carers in particular to better transition to their caring role and to navigate the aged care system more effectively, ensuring that they access the services and supports that they need, when they need them.

Recommendation 5

Carers NSW recommends that the Commission consider the need for a promotional/awareness campaign targeting the population group women aged 35-54, about what supports are available and what to do in the event that they become a carer.

5. Telecare initiatives

Telecare initiatives could play a vital role in the future provision of care to older Australians. Telecare has been defined by the Scottish Government as;

“the remote or enhanced delivery of health and social services to people in their own home by means of telecommunications and computerised systems. Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs, emergencies and lifestyle changes, using information and communication technology to trigger human responses, or shut down equipment to prevent hazards”¹⁹

Evidence from the Scottish experience of implementing Telecare initiatives indicates that Telecare can have significant benefits for older people, carers and the aged care system. For carers the benefits identified include:

- feeling more relaxed and less stressed
- feeling more confident about the safety and wellbeing of the person they cared for
- having more opportunity to get away from their caring situation and take a break
- feeling better supported in their caring role
- improvements in their relationship with the care recipient
- the ability to remain in paid employment (for some carers).²⁰

A growing body of international evidence suggests that Telecare can also have considerable benefits for the sustainability of the aged care system.²¹ Telecare has been found to:

- enable people to stay in their homes for longer
- reduce the need for acute home care
- delay admissions to residential care
- reduce the number of unplanned hospital admissions
- reduce the number of delayed discharges from hospital.²²

Telecare can result in significant savings. According to the evaluation of the Scottish Government's National Telecare Development Programme, in 2007-08 (the first main year of operation) savings totalling £11.15m were identified. In 2007-2010 the likely savings were valued at around £43 million, an anticipated benefit to programme funding cost ratio of 5:1.²³

It is clear that Telecare, while not a panacea for all of the challenges facing the aged care system in Australia, does have the potential to transform our capacity to care for older Australians in the future, and to make caring more sustainable.

Recommendation 6

Carers NSW recommends that the Commission address the need for further investigation of Telecare initiatives and for funding to implement Telecare initiatives in Australia.

6. Workplace arrangements for elder carers

The Commission has acknowledged in the Issues Paper that one of the key reform challenges is enabling carers to participate in the workforce. If it is envisaged that the future provision of care to older Australians will continue to depend on the unpaid work of carers, caring must be made sustainable. Supporting elder carers to balance their unpaid work as carers with participation in the paid workforce is one of the most crucial elements to make caring, and therefore the aged care system, sustainable.

The need for support for elder carers to remain in the workforce is clear. In 2005, Access Economics reported that the labour force participation rate for all carers was only 56.1 per cent compared to 67.9 per cent for the general population. The labour force participation rate for primary carers is even lower at just 39 per cent, with participation in full-time employment only 19.2 per cent. In other words, the labour force participation of primary carers is less than half that of the general population. This is a particular issue for women, who represent 71 per cent of primary carers²⁴, and a majority of elder carers.

A recent survey of 2,284 Australian workers revealed that 23 per cent of respondents expected to provide elder care in the next five years, which represents a sizeable proportion of the labour force,²⁵ a finding which illustrates the enormity of the issue both for the social and financial wellbeing of individual elder carers, and for the Australian workforce.

6.1 Right to request flexible working arrangements

To enable elder carers to remain in or rejoin the workforce, the right to request flexible working arrangements must be extended. The *Who Cares...?* report recommended that section 65(1) of the Fair Work Act 2009 "...be amended to extend the right to request flexible working arrangements to all employees who have recognised care responsibilities, including those caring for adults with disabilities, mental illness, chronic illness or who are frail aged."²⁶

Carers NSW was very disappointed that the Fair Work Act 2009 and the National Employment Standard effectively excluded the right of all carers to request flexible working arrangements, despite the recommendations made by Carers NSW, the Network of Carers Associations and the Australian Human Rights Commission for this right to apply to all carers, including elder carers.

Recommendation 7

Carers NSW recommends that the Commission support the amendment of the Fair Work Act 2009 and the National Employment Standards to include the right for all carers to have the right to request flexible work arrangements regardless of age or relationship status.

7. Nexus between ageing and disability services

Just as the Australian population is ageing, so too are people with a disability. People with a disability often have a different experience of the ageing process, may have distinct care needs, and may experience the ageing process at an earlier age than the general population.²⁷ There are increasing numbers of people with lifelong disability ageing in our community, as people with lifelong disabilities experience improved life expectancies.²⁸ The Commission must address the need of the aged care system to respond better to the needs of ageing people with a lifelong disability, and consider how the nexus between the ageing and disability services can be improved.

The need for better support for people ageing with a disability was identified by the 2005 Senate Inquiry into Quality and Equity in Aged Care.²⁹ The report from this Inquiry found that often people who are ageing with a disability are not supported effectively by disability services or aged care services. Older people with disability may be excluded from aged care programs by age criteria that do not take into account the relatively early onset of the ageing process that people with disability may experience, while their age also leads to them being deemed 'low priority' by disability services.³⁰

The Commission particularly needs to address the supports and services available to ageing people with a disability who are relying on informal support networks, and their carers, who are likely to themselves be ageing and be experiencing the issues outlined above for older carers. Consideration should perhaps be given to the inclusion of people with a lifelong disability as a special needs group under the Aged Care Act 1997.

Recommendation 8

Carers NSW recommends that the Commission address the nexus between aged and disability services, and the unmet needs of people ageing with a life long disability.

Recommendation 9

Carers NSW recommends that consideration be given to amending the Aged Care Act 1997 to include people ageing with a life long disability as a special needs group.

8. Diversity in aged care services

Aged care services, including residential facilities and home and community-based supports must support the diversity of older Australians and their carers. If services and supports are not culturally appropriate and do not meet the needs of our diverse population, people in need of assistance may not access the services they need or their needs may not be met by those services they do access.

8.1 Aboriginal and Torres Strait Islander people

The experiences, needs and concerns of Aboriginal and Torres Strait Islander older people and their carers are distinct in many ways from other Australians. This is a result of a number of complex factors, including cultural values and beliefs, the disadvantage experienced by Aboriginal and Torres Strait Islander people and their history of loss and dispossession. Aged care services for Aboriginal and Torres Strait Islander older people and their carers must be culturally appropriate, accessible and responsive to the needs of these individuals.

Aboriginal and Torres Strait Islander people are more than twice as likely as the general population to need help with core daily activities because of disability.³¹ They have lower life expectancy and suffer an overall burden of disease that is 2.5 times that of the general population.³² The Aboriginal and Torres Strait Islander population is younger than the general population, with people aged 65 years and over making up only 3 per cent of the Aboriginal and Torres Strait Islander population in 2006. However, due to poorer health and higher rates of disability, care services are often needed at comparatively younger ages. For this reason, the number of Aboriginal and Torres Strait Islander peoples aged 50 years and over is used for aged care planning purposes.³³ This is another significant difference that may impact upon the appropriateness and accessibility of aged care services.

The prevalence of disability and disease in the Aboriginal and Torres Strait Islander population also has implications for the needs of carers. According to the 2006 census, Aboriginal and Torres Strait Islander carers were up to three times as likely as other carers to need assistance with core activities themselves. In total, at least 2,100 Indigenous carers needed help with core activities³⁴. This has obvious implications for the impacts of care provision on their health and wellbeing, their capacity to care, and their own level of need for services and support, both as carers and in their own right as individuals.

The aged care system needs to be responsive and flexible in its delivery of services to Aboriginal and Torres Strait Islander older people and their carers, and respectful of the cultural differences that exist. Carers NSW experience of delivering Koori Carer Yarning Camps for mental health carers has demonstrated the cultural diversity of Aboriginal and Torres Strait Islander people, and has led us to develop the Koori Carer Yarning Resource Manual.

As explored in the Koori Carer Yarning Resource Manual, Aboriginal and Torres Strait Islander people may have different cultural understandings which impact on the accessibility and appropriateness of services. Examples of different cultural understandings may include concepts of kinship and family relationships, community and the individual, disability, place, healing, communication styles, gender relations and protocols. Another significant factor may be widespread mistrust of government or social services within Aboriginal and Torres Strait Islander communities, which has been formed by their communities' experience of these organisations.³⁵

It must be recognised that mainstream aged care services are not culturally neutral, but are founded on cultural tenets of the dominant Australian culture, evident, for example, in the individualistic approach of services and medical understandings of disability. Flexible and culturally appropriate services must be available in all geographic areas, including remote and very remote areas to ensure that services are accessible to older people and their carers from Aboriginal and Torres Strait Islander communities.

8.2 People from culturally and linguistically diverse backgrounds

Older people from culturally and linguistically diverse backgrounds and their carers have distinct needs. While many issues are common for older Australians and their carers regardless of their cultural background or ethnicity, research undertaken by Carers NSW and Down Syndrome NSW in 2007 identified that carers from culturally and linguistically diverse backgrounds experience additional issues and have distinct support needs. These include:

- Isolation of carers even though they belong to a tight knit community. There is often an assumption that people of specific cultural backgrounds rely on strong family ties. However, migration often means leaving behind the family members and friends who would otherwise have provided support.
- Stigmatisation of people with disability or illness is common. This may inhibit carers from self identifying as carers or recognise the need to access services and support.
- Language and communication barriers between carers from culturally and linguistically diverse backgrounds and service providers are a common issue. Often carers cannot access appropriate translated information to assist them in their caring role. Carers need to be able to access bilingual staff as well translated material to assist them to access and use services appropriately
- Cultural concepts of disability, illness, ageing or caring are often different from mainstream Australian perceptions. Flexibility in service delivery is needed to ensure service delivery appropriately addresses the cultural needs of carers.

It is vital that the cultural and linguistic diversity of older people and their carers is supported by the aged care system, and that culturally appropriate and accessible services are provided. The distinct and significant needs of people from culturally and linguistically diverse backgrounds, recognised by their inclusion as a special needs group in the Aged Care Act 1997, must be addressed by the Commission.

8.3 Gay, lesbian, bisexual, transgender and intersex people

Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) older people and carers need culturally appropriate services and supports, which respect and respond to their needs and choices.

Reports from the NSW Anti-Discrimination Board³⁶, the Australian Human Rights Commission³⁷ and Alzheimer's Australia³⁸ detail the discrimination often experienced by GLBTI people in aged care services, and the desperation with which older GLBTI people in particular will avoid using services for fear of discrimination and being "forced back into the closet". These reports also identify the absence of the needs of GLBTI older people in aged care policy, training, research and program guidelines.

The needs of GLBTI carers are also significant, and often overlooked, particularly in aged care services. GLBTI carers are some of the most hidden carers in the community and they require support and services which foster their full inclusion. Often GLBTI carers face challenges because of:

- discrimination and marginalisation
- equity of access to all services
- recognition of their caring relationships, for example, informal friendship networks
- absence of family support

- higher incidences of drug use and depression
- social isolation
- unawareness that mainstream services may be able to offer them support
- non-inclusive language and imagery used to describe services and supports.

Carers NSW is aware that often a GLBTI carer will not feel comfortable accessing mainstream services such as support groups for carers because they face discrimination as a result of their same-sex relationship with the care recipient.

Carers NSW has heard from carers who are often the only person in a support group with a same sex partner and do not feel able or comfortable to share their story with the group. This suggests that some services for carers such as support groups would benefit from being specific to the GLBTI community, and also that there is a need for greater awareness from service providers of, and training in, sensitive and appropriate service provision to GLBTI communities.

Carers NSW was pleased to learn of the funding recently allocated by the Federal Department of Health and Ageing to ACON and the Aged and Community Services Association NSW & ACT. The funding will be used to provide targeted training to residential aged care services to improve their understanding of the needs of older GLBTI people, and hopes that this is an indication of greater awareness of and support for the needs of older GLBTI people and carers.

Recommendation 10

Carers NSW recommends that the Commission address the need for flexible, appropriate aged care services that are responsive to and supportive of the diversity of older people and their carers.

Recommendation 11

Carers NSW recommends that the Commission assess the need for culturally specific information and services for Aboriginal and Torres Strait Islander older people and their carers.

Recommendation 12

Carers NSW recommends that the Commission assess the need for culturally specific information and services for older people and their carers.

9. Dementia carers

An important consequence of the ageing of the Australian population acknowledged in the Issues Paper is the rapid increase of the number and proportion of people who have dementia. Dementia is already the largest single cause of disability in older Australians and is responsible for one in every six years of disability burden for this group.³⁹

The *Making Choices: Future dementia care: projections, problems and preferences* report by Access Economics has projected that the number of people who have dementia will increase from approximately 230,000 in 2008, to 465,000 in 2030 and to over 730,000 in 2050.⁴⁰ This report has identified that there will be a greater need for care for people with dementia, from formal care services and from carers. This need must be addressed in this Inquiry.

One of the issues highlighted by Access Economics was the critical role of carers in caring for people with dementia. Carers may be the only source of care for many

people with dementia, with 37 per cent of people with dementia receiving no formal care. The economic value of the services provided by these carers is considerable. Access Economics estimated that the cost of replacing carers with formal care services at \$5.5 billion per annum.⁴¹

The needs of carers of people with dementia are acute due to the characteristics of the condition, which make the caring role especially challenging. Of the carers surveyed by Access Economics 31 per cent stated caring had a negative impact on their physical health, 53 per cent on their mental and emotional wellbeing and 55 per cent on their lifestyle.⁴² International and Australian studies emphasise that flexible support, information and respite services, together with workplace and community understanding are essential supports for carers of people with dementia.

These carers valued home support services such as shopping, transport and cleaning the most. Respite provided daily or for an extended period was also valued by these carers. A community centre offering counselling, recreational activities, education and information services was also a service type that carers of people with dementia would like to be made available to them.⁴³

9.1 Early onset dementia carers

An emerging issue in relation to dementia carers is early onset or younger onset dementia. Carers NSW continually receives enquiries from very distressed carers and family members who cannot get access to dementia services and care packages as the person with dementia is not eligible for these as they are too young, or the person with dementia has specific needs that are not met by mainstream dementia services.

Another difficulty for people with early onset dementia is being correctly diagnosed to allow them and their carers and families to be directed to the appropriate services, if they are available. Working carers have also reported difficulties in getting services to support them to continue to work full-time to meet mortgages and other financial commitments. Many also report that the cost of care services, if they can access them, is so high that they are forced to use any savings or retirement funds they may have.⁴⁴

Carers NSW recommends that the future needs of people with dementia and their carers are addressed in this Inquiry, and that a special focus is given to the emerging issue of early onset dementia. Carers NSW acknowledges that dementia has been made a national health priority and that Australian Governments have started to address its increasing prevalence through the National Dementia Initiative. However, Carers NSW calls for a greater response from Governments and from the aged care system to the needs of the ever increasing number of people with dementia and their carers.

Recommendation 13

Carers NSW recommends that the Commission address the future need of formal care services for people with dementia, including future workforce needs.

Recommendation 14

Carers NSW recommends that the Commission respond to the need for increased supports and services for dementia carers, including home support services and respite services, in line with both the acute needs of these carers and the increasing size of this group.

Recommendation 15

Carers NSW recommends that the Commission address the need for improved diagnosis of early onset or younger onset dementia, and for increased funding for the provision of appropriate care services.

Key recommendations

Carers NSW recommends the following:

Recommendation 1

Carers NSW recommends that funding to services and programs that support elder carer provision such as Aged Care Assessment Teams and Home and Community Care is increased.

Recommendation 2

Carers NSW recommends that the Inquiry address the need for increased funding of respite services to align with demand, and with the identified need by carers.

Recommendation 3

Carers NSW recommends that the Commission address the need to implement a fundamental shift in the delivery of respite services, from an inflexible system to one that responds to the needs and choices of service users.

Recommendation 4

Carers NSW recommends that the Commission address the need for transport assistance for older Australians.

Recommendation 5

Carers NSW recommends that the Commission consider the need for a promotional/awareness campaign targeting the population group women aged 35-54, about what supports are available and what to do in the event that they become a carer.

Recommendation 6

Carers NSW recommends the Commission address the need for further investigation of Telecare initiatives and for funding to implement Telecare initiatives in Australia.

Recommendation 7

Carers NSW recommends that the Commission support the amendment of the Fair Work Act 2009 and the National Employment Standards to include the right for all carers to have the right to request flexible work arrangements regardless of age or relationship status.

Recommendation 8

Carers NSW recommends that the Commission address the nexus between aged and disability services, and the unmet needs of people ageing with a life long disability.

Recommendation 9

Carers NSW recommends that consideration be given to amending the Aged Care Act 1997 to include people ageing with a life long disability as a special needs group.

Recommendation 10

Carers NSW recommends that the Commission address the need for flexible, appropriate aged care services that are responsive to and supportive of the diversity of older people and their carers.

Recommendation 11

Carers NSW recommends that the Commission assess the need for culturally specific information and services for Aboriginal and Torres Strait Islander older people and their carers.

Recommendation 12

Carers NSW recommends that the Commission assess the need for culturally specific information and services for older people and their carers.

Recommendation 13

Carers NSW recommends that the Commission address the future need of formal care services for people with dementia, including future workforce needs.

Recommendation 14

Carers NSW recommends that the Commission respond to the need for increased supports and services for dementia carers, including home support services and respite services, in line with both the acute needs of these carers and the increasing size of this group.

Recommendation 15

Carers NSW recommends that the Commission address the need for improved diagnosis of early onset or younger onset dementia, and for increased funding for the provision of appropriate care services.

Conclusion

Carers NSW appreciates the opportunity to make this submission to the Caring for older Australians Public Inquiry. 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,



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