



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

Dear Sir/Madam

Carers NSW welcomes the opportunity to make a second submission to the Caring for Older Australians Public Inquiry in response to the Draft Report.

## **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 850,000 carers, comprising individuals as young as 8 years of aged through to the very elderly.<sup>1</sup>

### **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 carers 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 Format of this submission**

This submission will focus on the role and needs of carers in the provision of care to older Australians, as well as older Australians who are also caring for others. This submission is intended to supplement the submission already prepared by Carers NSW on behalf of Carers Australia and the Network of Carers Associations, and submitted by Carers Australia. For this reason, Carers NSW will only focus on four groups who are particularly disadvantaged in Australia and whose needs deserve greater consideration: older parent carers, Aboriginal carers, people from culturally and linguistically diverse backgrounds (CALD) and carers of people with younger onset dementia. Due to the importance of the issue of transport in NSW, this submission will also briefly examine this subject.

## **2. Older parent carers**

Carers NSW notes that the Productivity Commission referred to the 'small number' of older people who are primary carers for their adult children with a severe or profound disability. However, Carers NSW believes that this acknowledgement fails to recognise the particular challenges faced by older parent carers and their specific needs in a reformed aged care system. Although the needs of older parent carers may appear to be more relevant to the Productivity Commission's Inquiry into Disability Care and Support, the needs of these carers, who are older Australians, must also be considered by this inquiry.

This section of Carers NSW response is informed by our experience as a provider of the Support Coordination Program for Older Parent Carers. This program is funded by Ageing, Disability and Home Care (ADHC), Department of Human Services NSW.

The number of older people caring for adult children is relatively small at 28,000 across Australia.<sup>2</sup> However, older parent carers are particularly disadvantaged due to their long term caring role and deserve special consideration. Many older parent carers have been caring for their child with intellectual or physical disability, mental illness or other condition for a very long time, in some cases for over fifty years.

The disadvantage faced by many carers is intensified for older parent carers who are particularly at risk of poor health and wellbeing due to caring for an extended period of time, often with little or no formal support. Older parent carers are also more likely to face financial disadvantage due to their limited ability to undertake paid employment and the accumulated costs of caring over time. Older parent carers tend to have had less opportunity to contribute to superannuation and many have minimal retirement savings. These carers are thus more likely to be dependant upon government support in their retirement due to their financially disadvantaged position.

However, while older parent carers are often dependant upon government benefits, it is also important to acknowledge their contribution to society and the billions of dollars in savings to the taxpayer over the many years they have provided unpaid care.<sup>3</sup>

Older parent carers fear for the future of their children and worry about who will care for them when they are no longer able to do so. A 2010 survey of carers by Carers NSW found that for 92 per cent of carers of adult children, the hardest part about caring was worrying about the future.<sup>4</sup> Anxiety about the future increases as the carer and care recipient age and the ability of the carer to continue caring is increasingly at risk.

Due to their particular situation, older parent carers have additional concerns and needs which must be considered in any reform of the aged care system. These include safeguards when calculating the assets of the older person, the need for the disability and aged care systems to be complementary and the need for substantial changes to the disability care system.

It is crucial that the caring situation is considered when calculating the comprehensive aged care means test, particularly in relation to the Commission's proposal to include the family home in this test. This issue is discussed in more detail in the Carers Australia submission to the inquiry. In cases where an adult child is dependant upon the older carer and co-resides with them in the family home, the family home should not be included in the means test. This is important to prevent the care recipient from losing their home and subsequently requiring public housing or supported accommodation.

**Recommendation 1:** The Commission must recommend that any caring situation, especially an older parent caring for an adult child, is considered when calculating the comprehensive aged care means test.

In our previous submission to this inquiry, Carers NSW recommended that the Commission address the nexus between aged and disability services, and the unmet needs of people ageing with a life long disability.<sup>5</sup> From the perspective of the older parent carers of people with disability, there is also a need to ensure that there are strong linkages between the two systems so that older parent carers do not face the additional burden of complying with two care systems which do not complement each other.

**Recommendation 2:** The Commission must ensure that there are strong linkages between the aged care system and the proposed disability care and support scheme, and that the intersection between the two is carefully considered.

The need for major reforms to the disability care and support system is also crucial to the welfare of older parent carers. Older parent carers need to be supported in their caring role and when they are no longer able to care, or no longer choose to care.

They need to be confident that the disability support system will be able to care for their son or daughter. If the disability system is not transformed and remains 'underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports',<sup>6</sup> this will prevent these carers from being able to age with dignity and to look after their own health and wellbeing.

**Recommendation 3:** The Commission must strongly recommend that the disability care and support system be transformed to enable older parent carers to age with dignity.

### 3. Aboriginal carers

Carers NSW was pleased to see that the Productivity Commission recognised the different care needs of Aboriginal and Torres Strait Islander peoples compared to non-Indigenous Australians. This included an awareness of the poorer health outcomes and higher incidence of premature ageing, and consequently higher care needs for the Aboriginal and Torres Strait Islander population. For instance, research has shown that dementia prevalence amongst the Aboriginal community is almost five times the rate as that in the non-Indigenous population and that it presents at an earlier age<sup>7</sup> (see Section 5 regarding the issues faced by carers of people with younger onset dementia).

In addition, Carers NSW was pleased that the Commission also recognised the need for culturally appropriate aged care services for Aboriginal peoples. However, it is important that the Commission also recognises the additional challenges faced by Aboriginal carers compared to non-Indigenous carers.

Due to the demographics of NSW and the experience of Carers NSW, this submission will focus on the needs of Aboriginal communities rather than both Aboriginal and Torres Strait Islander communities. However, many of the issues for Aboriginal peoples apply equally to Torres Strait Islanders.

Aboriginal Australians are more likely to be in informal caring roles than non-Indigenous Australians. Some of the reasons for this include the lower health status of Aboriginal peoples as well as cultural norms that emphasise the needs of the community over the individual and the responsibility to care for those in need, especially elders. There is also a broader understanding of family within Aboriginal communities and thus individuals may be more inclined to care for extended family or unrelated members of their community than non-Indigenous Australians.

However, Aboriginal carers are often 'hidden' because they are less likely to identify as carers and to seek support from formal services. This may be due to a combination of factors including lack of services in the area, lack of awareness of services, mistrust of formal services, cultural inappropriateness and different cultural and social norms.<sup>8</sup>

Aboriginal carers are also more likely to have health problems or require assistance themselves compared to non-Indigenous carers. For instance, 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.<sup>9</sup>

The poorer health outcomes of Aboriginal carers led to Carers NSW developing the 'Looking After Ourselves' training program and DVD to support Aboriginal carers

maintain or improve their own health and wellbeing. This innovative project was based on a tool developed by Carers NT for use in remote communities but was further developed in consultation with Aboriginal peoples in NSW. This training program is an example of a culturally appropriate means of supporting Aboriginal carers and Carers NSW recommends increased funding for initiatives such as these to reach as many carers and communities as possible.

**Recommendation 4:** The Commission should support funding the development of innovative and culturally appropriate carer support projects targeted at Aboriginal carers.

Older members of Aboriginal communities are also more likely to be caring for grandchildren, or even great grandchildren, than non-Indigenous Australians. This includes caring for grandchildren with disabilities, mental illness or behavioural disorders. The needs of older people who are also carers, especially carers for adult children and/or grandchildren were discussed previously in Section 2.

### 3.1 Services for Aboriginal carers

Carers NSW believes that flexible services, including respite, for Aboriginal carers are crucial to uphold the principles in the Commonwealth *Carer Recognition Act 2010's Statement for Australia's Carers*, particularly to ensure that Aboriginal carers are afforded the same rights, choices and opportunities as other Australians. Formal care services allow carers to share their caring responsibilities, and respite services enable them to take a break from their caring role. However, cultural and language barriers as well as a lack of services may prevent Aboriginal carers from accessing care and respite services.

The Draft Report included examples of flexible respite for Aboriginal carers and care recipients, such as the National Aboriginal and Torres Strait Islander Flexible Aged Care Program. Despite these services, Carers NSW believes that there is a serious shortage of appropriate respite for Aboriginal carers, and of other formal care services.

In Carers NSW's submission to the Inquiry into Disability Care and Support, Carers NSW recommended exploring the possibility of direct employment of family members to provide care services to Aboriginal and Torres Strait Islander people with a disability and their carer. Although this recommendation was originally made in relation to care of people with a disability, the concept may also be applicable to aged care.

In the context of the Disability Care and Support Scheme, Carers NSW recommends that the possibility of direct employment of family members be explored, with the incorporation of necessary standards and supports, such as relevant attendant care capacity or training to develop this capacity in family members. Necessary qualifications may include Certificate III or IV in Community Care training, or other training covering areas such as safe lifting, mobility and dealing with challenging behaviours. Appropriate financial accountability measures to ensure that informal carers cannot financially abuse or appear to exploit the older person that they are caring for would also be required.

In the reformed aged care system, where 'cashing out' may not be an option for all (or any) services, allowing service providers to have greater flexibility in the employment of Aboriginal and Torres Strait Islander people will be of great

importance. Flexibility may be required in relation to criminal history checks and education pathways, as discussed in the draft report. Consideration must also be given to allowing the employment of family or community members nominated by the carer or care recipient, to provide services to these individuals. This would ensure culturally appropriate care, alleviate workforce shortages and would prevent violation of cultural restrictions on who can provide care.

**Recommendation 5:** The Commission should recommend greater flexibility in the employment of Aboriginal and Torres Strait Islander peoples, including the employment of nominated family or community members by service providers.

#### **4. People from culturally and linguistically diverse backgrounds**

Carers NSW is pleased that the Productivity Commission examined the needs of older people from culturally and linguistically diverse backgrounds. However, Carers NSW believes that the needs of CALD carers also deserve greater consideration in the reform of the aged care system.

As noted in the submission by Carers Australia, culturally and linguistically diverse (CALD) is a term which is commonly understood to refer to all of Australia's non-Indigenous ethnic groups other than the English speaking Anglo-Saxon majority.<sup>10</sup> This term does not include Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) people and communities, who are not defined by ethnic, linguistic or cultural differences but by sexual orientation, and whose specific needs as carers also need to be addressed by the Commission. Carers NSW supports the use of CALD rather than "non-English speaking background" (NESB), as CALD also recognises the importance of cultural differences. However, Carers NSW also recognises that NESB is the language used in the *Aged Care Act 1997*, since this was enacted before CALD became commonly used.

The Draft Report noted that older Australians from CALD backgrounds are overrepresented in formal community care services.<sup>11</sup> Due to the importance of informal carers in enabling community aged care, it is especially important that the needs of CALD carers are met by the aged care system. It is also important to note that CALD carers of older Australians may also be ageing themselves.

Carers NSW appreciates that the Productivity Commission recognises the complexity of the aged care system for consumers regardless of language, and that the proposed Australian Seniors Gateway (ASG) is intended to make it easier for all members of the community to understand and access the system. However, measures need to be taken to ensure the ASG is accessible to multicultural communities.

**Recommendation 6:** The Commission needs to ensure that the Australian Seniors Gateway is accessible for CALD carers and the older people that they care for.

In order to better support CALD carers and the ageing Australians that they care for, it is important to develop culturally appropriate support services, and to provide services in languages other than English. Although at present service providers can access the Telephone Interpreter Service, Carers NSW believes that it is necessary to employ bilingual and multilingual staff who can communicate directly with consumers. This would allow for ongoing communication with multicultural consumers on a regular basis, without the need for telephone interpreters. Carers

NSW supports the Commission's recommendation in order to attract bilingual staff, providers could consider a language allowance if these skills are used in the course of employment.

**Recommendation 7:** The Commission must emphasise the importance of employing bilingual and multilingual staff in aged care services in order to communicate with CALD populations, rather than relying on the Telephone interpreter Service.

Carers NSW notes that the Draft Report referred to the value of engaging the older person's family in the assessment and service planning process. Informal carers may be in the best position to understand and share the preferences of the older person regarding care. However, it is important that the challenge of navigating the complex aged care system is not left solely to carers and family members, especially since they may have limited language skills themselves or be unfamiliar with the system in Australia.

**Recommendation 8:** The Commission must recommend that CALD carers and family members of older people are supported and properly informed when making decisions regarding future care and services.

## 5. Carers of people with younger onset dementia

Carers NSW is concerned at the lack of consideration given to the needs of people with younger onset dementia and their carers in the Draft Report, as has been highlighted in the Carers Australia and the Network of Carers Association's submission to the Inquiry. Aboriginal Australians are more likely to experience dementia at a younger age and the needs of Aboriginal carers of people with early onset dementia must also be considered.

There is a considerable body of evidence which indicates the significant needs of people with younger onset dementia, and their carers. A 2007 report prepared by Alzheimer's Australia for the Australian Government Department of Health and Ageing, *Exploring the Needs of Younger People with Dementia* found that people with younger onset dementia and their carers experience significant and unique needs. They face issues such as:

- difficulty and/or delays in getting an accurate diagnosis
- family responsibilities including still actively raising a family
- currently working or being only recently retired
- having significant financial commitments based on previous earnings
- needing to revise their expectations of everyday life, such as work, finances and living arrangements
- social and sexual relationships, and independence and responsibility for others
- future plans that are affected at an earlier stage in life
- being more likely to have a rarer form of dementia than Alzheimer's disease or a genetically-based cause
- experiencing difficulty in accessing appropriate services, particularly as younger people with dementia are often otherwise physically strong and healthy.<sup>12</sup>

Carers NSW has worked with carers who have experienced many of these issues, and has borne witness to the very significant impacts that these carers and families

experience. Some carers who care for a partner with younger onset dementia have been advised to divorce their spouse to alleviate some of the financial impacts associated with younger onset dementia. Many carers are placed under great financial strain as they struggle with financial commitments, others face taking on new financial commitments at a time when the mortgage on the family home has been paid off, and they have planned to retire. These stresses come on top of the other significant challenges of caring for a person with younger onset dementia.

Carers NSW hopes that the Commission will take seriously the recommendation made by Carers Australia and the Network of Carers Associations to give greater consideration to the needs of these individuals in the final report, and to ensure that the need for improved diagnosis and age-appropriate care services is addressed, and that potential gaps between the aged and disability care systems are addressed.

**Recommendation 9:** The Commission must give greater consideration to the special needs of people with younger onset dementia and their carers.

## 6. Transport needs of older Australians

The importance of addressing the transport needs of older Australians is an issue already canvassed by Carers NSW in our first submission to the Inquiry, and in the submission by Carers Australia.

Transport disadvantage is a critical issue in NSW, particularly for older Australians and their carers. Carers NSW participates in various interagency groups such as the NSW Aged Care Alliance, the NSW Health Policy Advisory Group and the NSW HACC Issues forum. In recent months, serious concerns regarding transport have been raised at meetings of each of these groups by stakeholders from around NSW. The feedback from these individuals and organisations, which represent a variety of interests, is overwhelmingly consistent. Community transport in NSW is under serious strain, and vulnerable population groups such as older people and their carers are often unable to access the transport they need, which can leave them socially isolated and without access to necessary health services and treatments.

There is a significant body of literature that supports these concerns, including; *No Transport, No Treatment*<sup>13</sup> published by The Cancer Council NSW, Council of Social Service of NSW (NCOSS) and the NSW Community Transport Organisation (CTO); *Closing the transport gap*<sup>14</sup> by Combined Pensioners & Superannuants Association of NSW; *Transport and access to health care services for older Australians*<sup>15</sup> by the National Aged Care Alliance and discussion papers from Alzheimer's Australia NSW<sup>16</sup> and the NRMA.<sup>17</sup>

This submission will not repeat the discussion and recommendations included in Carers NSW first submission to the Inquiry, and the Carers Australia submission. However, due to the significance of this issue in NSW in particular, we feel it is necessary to restate that we have significant concerns regarding the lack of attention transport was given in the Draft Report, and refer the Commission to the section on transport in the *Sharing the Care* submission and the literature mentioned here.

**Recommendation 10:** The Commission must give more attention to the transport needs of older Australians, and the significant implications these needs have for carers, particularly working carers and carers without access to private transport.

## Summary of recommendations

1. The Commission must recommend that any caring situation, especially an older parent caring for an adult child, is considered when calculating the comprehensive aged care means test.
2. The Commission must ensure that there are strong linkages between the aged care system and the proposed disability care and support scheme, and that the intersection between the two is carefully considered.
3. The Commission must strongly recommend that the disability care and support system be transformed to enable older parent carers to age with dignity.
4. The Commission should support funding the development of innovative and culturally appropriate carer support projects targeted at Aboriginal carers.
5. The Commission should recommend greater flexibility in the employment of Aboriginal and Torres Strait Islander peoples, including the employment of nominated family or community members by service providers.
6. The Commission needs to ensure that the Australian Seniors Gateway is accessible for CALD carers and the older people that they care for.
7. The Commission must emphasise the importance of employing bilingual and multilingual staff in aged care services in order to communicate with CALD populations, rather than relying on the Telephone interpreter Service.
8. The Commission must recommend that CALD carers and family members of older people are supported and properly informed when making decisions regarding future care and services
9. The Commission must give greater consideration to the special needs of people with younger onset dementia and their carers.
10. The Commission must give more attention to the transport needs of older Australians, and the significant implications these needs have for carers, particularly working carers and carers without access to private transport

## Conclusion

Carers NSW appreciates the opportunity to make this submission to the Caring for older Australians Public Inquiry. It is again noted that the recommendations in this submission supplement the detailed response prepared by Carers NSW on behalf of Carers Australia and the Network of Carers Associations, and submitted by Carers Australia. 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](mailto:alisonp@carersnsw.asn.au).

Yours sincerely,



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## Endnotes

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- <sup>1</sup> Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2009*, 2011.
- <sup>2</sup> Australian Bureau of Statistics, *A Profile of Carers in Australia*, Canberra, 2008.
- <sup>3</sup> Access Economics, *The economic value of informal care in 2010*, Report for Carers Australia, 2010.
- <sup>4</sup> Carers NSW, *Carers NSW 2010 Carer Survey*, Sydney, 2010.
- <sup>5</sup> Carers NSW, Submission to the Productivity Commission Inquiry Caring for Older Australians, Sydney, 2010.
- <sup>6</sup> Productivity Commission, *Disability Care and Support*, Draft Inquiry Report, Canberra, 2010.
- <sup>7</sup> Rachele Arkles, Lisa Jackson Pulver, Hamish Robertson, Brian Draper, Simon Chalkley & GA Broe, *Ageing, Cognition and Dementia in Australian Aboriginal and Torres Strait Islander Peoples*, Neuroscience Research Australia and Muru Marri Indigenous Health Unit, University of New South Wales, 2010.
- <sup>8</sup> Carers NSW, *Koori Carer Yarning Resource Manual*, Sydney, 2010.
- <sup>9</sup> Australian Bureau of Statistics, *Summary of findings: 2006 ABS Census of Population and Housing, the Health and Welfare of Australia's Aboriginal and Torres Strait Islander People*, Canberra, 2008.
- <sup>10</sup> Pooja Sawrikar & Ilan Katz, *How useful is the term 'Culturally and Linguistically Diverse' (CALD) in Australian research, practice and policy discourse?* [Online] Social Policy Research Centre, University of NSW, Available at: <http://www.sprc.unsw.edu.au/media/File/Paper276.pdf>, 2009.
- <sup>11</sup> Australian Institute of Health and Welfare, *Older Australia at a Glance*, 4th edn, Canberra, 2007.
- <sup>12</sup> Alzheimer's Australia, *Exploring the Needs of Younger People with Dementia in Australia*, report to the Australian Government Department of Health and Ageing, Canberra, 2007.
- <sup>13</sup> TCCNSW, NCOSS and NSW CTO, *No Transport, No Treatment: Community transport to health services in NSW*, Sydney, 2006.
- <sup>14</sup> Combined Pensioners & Superannuants Association of NSW Inc, *Closing the transport gap: Meeting the transport needs of the transport disadvantaged in NSW*, Sydney, 2010.
- <sup>15</sup> National Aged Care Alliance, *Transport and access to health care services for older Australians*, Canberra, 2006.
- <sup>16</sup> Alzheimer's Australia NSW, *Driving and Dementia in New South Wales*, Discussion Paper 1 2010, Sydney, 2010.
- <sup>17</sup> NRMA, *Transport and Mobility Needs of Ageing Australians*, Discussion Paper, Sydney, October 2010.