



Caring for Older Australians

**CARERS WA
SUBMISSION**

July 2010

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1. About Carers WA

Carers WA is the recognised peak body for carers in Western Australia. Since 1996 Carers WA has provided systemic advocacy and grassroots support to the more than 307 000 family members and friends in WA who provide the overwhelming majority of care and support to those who need assistance to live in the community.

2. Carers in Western Australia

A Family Carer is someone who provides care and support to a parent, partner, child, relative or friend, who has a disability, is frail aged or who has a mental or chronic illness. Carers cut across all aspects of West Australian society: from ages 5 to 95 years of age, they can be from any ethnic group; they live in both urban and rural communities within the state; they care for people who live with the whole spectrum of illness, disability or age-related frailty; they comprise almost 307 000 West Australians. They are your neighbours, friends and relatives and they are unpaid.

Western Australia was the first State in Australia – and only the second Government in the world – to legislate an Act recognising carers. The WA Carers Recognition Act 2004 has been a significant and positive step forward in the recognition of the important role that carers play in our society.

3. Responses to select questions

Question 1. Systematically examine the social, clinical and institutional aspects of aged care in Australia, building on the substantial base of existing reviews into this sector.

Family Carers as partners in the care of older Australians

The ageing of Australia's population is clearly placing an increased demand on the provision of aged care services, and on the family carers who provide the majority of care to older people. This inquiry presents an opportunity to identify and provide funding for alternative, sustainable and community based responses to the needs of older people and their families.

Carers WA believes the overarching goals of a system of care for older Australians should be consistent with Australia's commitment to human rights, to the United Nations Convention on the Rights of Persons with Disabilities and with the Australian Government's Social Inclusion Agenda. Older people, as with any other segment of the population, are a diverse group with a diverse set of needs, preferences and aspirations. This diversity is reflected in their preferred care arrangements and should be supported with the provision of flexible and appropriate services.

Carers WA promotes the rights of carers to have a greater say in how the services they require, both in the community and in residential care, are designed and delivered. For those who desire it, a self managed or self directed care model should be available. A family centred approach to determining needs is necessary to ensure that both the care recipient and their family carers are adequately supported. A family-centred approach can reveal mixed care needs, for example, where older carers are caring for an adult child with disability. This review should therefore examine opportunities for a greater interplay between health, disability and ageing services.

Our focus is on unpaid family carers

The role of family carers in supporting older Australians is well documented in *Who Cares...? Report on the Inquiry into Better support for Carers* (HRSCFCHY 2009). Many family carers are older Australians. This submission will respond to the questions posed by the inquiry with a focus on those areas where carers are restricted in their ability to meet the needs of care recipients and in their ability to meet their own needs. Typical family care arrangements relevant to this inquiry include an adult child caring for ageing parents, older carer/s with responsibility for a co-resident adult child with disability or illness, or an older couple where one cares for the other for example.

Family carers and community based care for older people

The issues relating to carers and community based care supports for older people were highlighted in *Who Cares...?* (HRSCFCHY 2009). Carers are required to negotiate support services for the care recipient, which can be time consuming, administratively difficult and expensive where out of pocket costs are not covered by entitlement. Carers are not always recognised for the caring role they have, let alone their own need to retain aspects of their own life. If their input and observations are overlooked, the impacts on the care situation can be detrimental.

Family carers and residential aged care and palliative care

Family carers often continue to carry out their caring role when the care recipient enters residential aged care. It is vital that their knowledge of the care recipient's needs and preferences is understood by nursing and support staff for an effective handover. For this reason, formal recognition of family carers should be given and resources should be available within residential aged care to allow the family to continue their personal and private interactions with the care recipient. Carers and their family experience a range of emotional needs and may experience a strong sense of grief and loss during the transitional periods associated with and following the move to residential care, particularly when this occurs in association with degenerative illness and dementia.

The needs and contributions of unpaid carers and the impacts of this on the paid workforce

The value of the unpaid contribution of family carers was estimated at \$30.5 billion annually if this care was to be replaced with formal paid care (Access Economics 2005). It is therefore important to deal with workforce issues in an holistic manner, acknowledging both the unpaid and paid workforce, in order to better plan for care needs in the long term (Glendinning et al 2009:133). Support for family carers is necessary to ensure the ability of carers to continue in their caring role without this being to the detriment of their own health and emotional and financial wellbeing. This is particularly the case as the ratio of available family carers to care recipients in the future continues to tighten.

Commonwealth versus state jurisdiction and the role of legislation in supporting carers

As noted in previous inquiries, carers are often required to work across jurisdictions in seeking support for the care recipient. It is important that where jurisdictions may change as a result of the recommendations of this inquiry, appropriate legislative amendments provide for and protect the role of carers.

Recommendations

- The Commonwealth Government to develop a National Carers Strategy and a National Carer Recognition Framework.

- As part of the National Carers Strategy, family carers should be included within decision making forums alongside consumer, community and industry representatives.

Question 2. Develop regulatory and funding options for residential and community aged care (including services currently delivered under the Home and Community Care program for older people). The Commission has been specifically requested to address the interests of special needs groups.

Residential aged care

Family Carer recognition and family inclusion

Even when in residential care, family carers play an ongoing role in ensuring that the needs of the care recipient are met. Many families and carers have reported feeling excluded and ignored by paid staff, and have reported that paid staff may be too busy to fully involve the family (Cameron 2007). Currently, there is no acknowledgement of the role of family carers in the Charter of Residents' Rights and Responsibilities. It is not clear whether the proposed Carers Recognition Bill 2010 will address this situation.

Recommendations

- Clarify the interactions between the Charter of Residents' Rights and Responsibilities, which is within the Aged Care Act, and the yet to be passed Carers Recognition Bill 2010, to ensure consistency and adequacy in the provisions relating to carer recognition.
- Ensure the provisions of the Aged Care Complaints Investigation Scheme allow for carers to lodge a complaint regarding family carer issues.
- Implement an education and awareness program to promote the Carers Charter within aged care residences with the passing of the Carers Recognition Bill 2010.
- Consider the findings of the report by Cameron (2007) into the experiences of family carers with a family member in residential aged care.
- Staff, in conjunction with the care recipient and the family should develop a care plan and family carer inclusion plan on entry to the aged care residence to be reviewed on an ongoing basis.
- Family and family carer inclusion should be included in accreditation requirements.

Family Carers and special needs aged care residents

The well being of special needs groups in residential aged care, including CALD, Indigenous, GLBTI residents and residents with mental health issues or intellectual disabilities, is intrinsically connected with the support provided by their family carer. This is even more the case when those needs may not be widely understood by paid staff (Birch 2009).

For partners of non-heterosexual aged care residents, there can be greater difficulties in being recognised as a partner and a

family carer by both the partner's family and by paid support staff.

'...getting older for many GLBTI people can mean an increased fear of being 'outed' after a lifetime of avoiding disclosure of their sexuality, or fear of lack of understanding and support as they age and seek supported care...Some older GLBTI people fear that going into residential aged care will render them socially and emotionally isolated from their communities' (GRAI 2010:2-3).

Elmes (n.d.) and Birch (2009) cite case studies where these issues were not able to be resolved in ways consistent with the rights of the resident or their family carer. When the care recipient is affected by dementia, the complexities increase for all concerned.

Recommendations

- Explore the option of adding GLBTI residents to the list of special needs groups under the Aged Care Act 1997.
- Assess the Australian Aged Care Accreditation Standards with the view of implementing the Best Practice Guidelines developed by GRAI (2010).
- Assess the Australian Aged Care Accreditation Standards to ensure the provision of private space within aged care residential facilities for the continuation of family life and family interactions between residents and their family carers.

Older carers with caring responsibilities

The move to residential aged care is a significant and stressful life transition for the older person, as well as for their family carer/s. This is made all the more stressful when the ageing person is a carer (Carers Victoria 2005). In some cases entry to residential aged care is delayed out of concern for what will happen to their adult disabled child. The move to residential care causes the physical separation of these families. The design of many aged care residences does not support the continuation of family roles. Older carers, particularly those reliant on public transport, have reported spending much of their day travelling to and from the aged care residence to visit their partners who have been offered a place in suburbs far from their home and social networks.

Recommendations

- Funded education and awareness program to promote advance planning or 'futures planning' for carers (ASLARC 2010, 2008; FAHCSIA 2009).
- Investigate models for family-centred accommodation to support the continuity of families with mixed care (ageing, mental health and disability) needs.
- Research the preferences people have for the provision of residential aged care.

- High priority should be given to providing an aged person with access to an aged care residence in close proximity to their natural caring and support networks.

Where one aged partner is caring for the other partner, entry to residential aged care of the care recipient causes the physical separation of the couple.

Recommendation

- Investigate the provision of couples accommodation in cases where only one partner is eligible for residential care.

Community aged care

Previous inquiries have detailed the difficulties associated with accessing adequate and appropriate services (for example, HRSCFCHY 2009). Often, the services that are provided by aged care providers are not flexible enough to fit with the needs of the household, or are not available. This is not client-centred or family-centred service; rather the client has to fit with the service model. Similarly, HACC clients are not provided with any incentive to move to CACP or EACH, especially if their HACC provider does not provide such packages. The portability of the package also needs to be considered, as people move from one suburb or State to another for personal reasons.

From a carers' perspective, the *Report on the Inquiry Into Better support for Carers* (HRSCFCHY 2009) very clearly showed the lack of access to innovative, flexible and meaningful supports for carers themselves. Family carer needs can change through employment commitments, other family members' needs, and their own personal requirements, among others. Hence, the family needs must be taken into account, alongside the care needs of the care recipient.

The Wellness Approach being rolled out through HACC in Western Australia is beginning to see a culture shift with staff involving carers more in the assessment and provision of services, however, there is still quite a way to go to seeing carers as clients in their own right.

Recommendations

- Provide the option of self managed care packages which allow the carer or care recipient to manage their own care services when and if they choose to.
- Remove the barriers to moving between HACC, CACP, EACH and EACH-D. This may incorporate attaching the funding to the client, not to a service provider or health area, so that it is transportable and the care recipients' services remain flexible to need.
- Adopt family centred assessment processes when determining needs and eligibility, acknowledging that circumstances are likely to change and will need to be reassessed.

- Develop and implement a carer needs assessment framework as part of a broader National Carer Recognition Framework.
- Clarify the interactions between the Charter of Rights and Responsibilities for Community Care which is within the Aged Care Act, and the yet to be passed Carers Recognition Bill 2010, to ensure consistency and adequacy in the provisions relating to carer recognition.

Palliative care and death

Some family carers spend years in the caring role. In many cases they have reorganised their lives around the needs of the care recipient, including their residential, financial and employment arrangements. The cessation of the caring role therefore impacts heavily on carers who, in some instances, will lose the financial support of a carer's payment, along with the pension of the care recipient and will now be required to seek employment.

Recommendations

- Ensure that paid support staff receive adequate training to support the care recipient *and* family carers in end of life situations
- Continue to conduct ongoing research to identify the needs of people who are dying, as well as the needs of their family carers.
- Research the emotional, financial and other practical impacts of death and dying on family carers with a view to identifying post death needs of family and family carers

Question 3. Systematically examine the future workforce requirements of the aged care sector, taking into account factors influencing both the supply and demand for the aged care workforce, and develop options to ensure that the sector has access to a sufficient and appropriately trained workforce.

Family carers currently provide the bulk of in-home care to older Australians. This care is not only delivered at less cost than formal care services (Access Economics 2005), it also delays or prevents the entry of the care recipient into residential care. The extent to which unpaid family carers are able to continue to supply care is therefore a crucial factor influencing the future demand for and supply of paid support workers. Research indicates that for planning purposes '...closer links are required between policies on informal care and paid professional care, so that both are treated as parts of an integrated long-term care workforce' (Glendinning et al 2009:133). As part of this integrated approach, family carers as well as paid staff should be able to access training in all aspects of the care they are expected to deliver.

Carers WA has heard from carers who have been denied access to services due to staff being unwilling or unable to deal with the challenging behaviours exhibited by the care recipient. This is

of great concern, particularly as it is the family that are then left to try to cope with sometimes violent or inappropriate behaviours. Access to respite has also been left wanting where staff are not adequately trained to provide medications such as insulin injections.

Carers often have their own employment requirements. It makes good financial sense to keep carers supported to continue their employment rather than having to leave the workforce and rely on government payments so that they can continue to care.

Unpaid family carers also require other practical support to continue in their caring role and to assist them to recover from their period of caring. 'Given the high personal costs that informal carers may experience, support mechanisms will play an important role in encouraging and ensuring that informal care services continue to be provided' (Productivity Commission 2008:159).

Recommendations

- Develop workforce training policies that identify and address the skill needs of family carers as detailed in Recommendation 42 of *Who Cares...?* (HRSCFCHY 2009:xxix).
- Extend the provisions of the Fair Work Act to ensure flexible working arrangements for carers caring for people over 16.
- Fund a Carer Superannuation Scheme for family carers unable to participate in paid work due to their caring responsibilities.

Training required for paid support workers

Recommendations

- Ensure that paid support staff receive training in family centred communication models.
- Ensure that paid support staff receive training in communicating and working with people who exhibit challenging behaviours, or may have additional medical requirements.

Question 4. Recommend a path for transitioning from the current regulatory arrangements to a new system that ensures continuity of care and allows the sector time to adjust.

Current care recipients and family carers will also require time to adjust to a new system.

Recommendations

- Conduct consultation processes with community, consumer and carer groups and their representatives on the details of the new system and the transition mechanisms.

- Develop informational material and deliver appropriate training to carers so they remain informed and assist care recipients in decision making and in gaining access to services.
- Ensure appropriate legislation is in place to maintain carer recognition should jurisdiction shift from state to Commonwealth.

Question 5. Examine whether the regulation of retirement specific living options, including out of home services, retirement villages such as independent living units and services apartments should be aligned more closely with the rest of the aged care sector, and if so, how this should be achieved.

The World Health Organization (2007), as part of its recommendations for creating Age Friendly Cities, has suggested inclusive housing models that encourage and support older people to remain in their communities where they have existing links and supports. While some people may prefer to live in communities based on retirement or age, family-centred accommodation located throughout suburbs can provide options that allow people to age in place while still being able to carry out their caring role. Social housing that is fully accessible can provide for a variety of family and carer needs, including ageing parents caring for an adult child with disability. On the death of the parents, the person with disability could still remain in the residence with the provision of paid support as required.

Currently, carers' recognition, with regard to community aged care services, is delivered through state-based legislation, namely the Carers Recognition Act 2004. Should the Commonwealth take over regulation of services delivered in retirement villages and other retirement-specific living options, the recognition of family carers may need to be sought through appropriate Commonwealth legislation.

Recommendations

- Consult with consumers and carers regarding their preferred living and accommodation options with a focus on the provision of family-centred supported accommodation models.
- Engage the community to tender for alternative accommodation support models.
- Should jurisdiction change from state to Commonwealth, investigate the provisions of the proposed National Carers' Recognition Bill 2010 to ensure that carers are adequately recognised with regard to their caring role.

Question 6. Assess the medium and long-term fiscal implications of any change in aged care roles and responsibilities.

The ageing population, and the weaknesses of the existing aged care 'system', demand a rethink of what services are required and how they can be delivered. The submission to this inquiry by the Seniors Alliance provides a cogent argument for reassessing the 'system', and emphasises the importance of greater coordination between the levels of government involved.

Carers WA encourages the Commonwealth Government to explore the options for the coordinated delivery of services to meet the needs of people who are ageing, people with mental illness and people with disabilities. In the case of ageing carers, these needs often co-exist within the family. From the perspective of those seeking services, and for carers who seek services on behalf of the care recipient, navigating complex bureaucratic and administrative pathways can be time wasting, confusing, deflating to the spirit and there is always the risk of failing to locate appropriate services. There may be cost savings identified as a result of reducing multiple assessment tools and duplications in bureaucracy and administration. Further savings could be made in the provision of services that are responsive to the consumer's changing needs, as well as the changing needs of their carers. Supporting carers with the provision of flexible respite services can save a later, much more costly, crisis-driven response such as early entry to residential aged care or into hospital.

The following recommendations are offered with a view to identifying alternative, sustainable and community based responses to the needs of older people and their family carers.

Recommendations

- Conduct research into the flexible models of care provided under the National Aboriginal and Torres Strait Islander Flexible Aged Care Program to determine their effectiveness and the appropriateness of replicating this model in other areas.
- Conduct research the aged and disability models currently utilised in the UK, New Zealand and Europe to look at their strengths and areas for improvement.
- Investigate a greater role for local governments in delivering accessible social housing that would support sustainable accommodation options for mixed needs families within their existing communities.

4. References

- Aged Services Learning and Research Collaboration (ASLARC). 2010. *Future Planning for Older Carers of Adults with Disabilities: Phase 2*. Report to NSW Department of Ageing, Disability and Home Care.
<http://aslarc.scu.edu.au/Futures%20Planning%20for%20Older%20Carers%20of%20Adults%20with%20Disabilities%20Phase%202,%20January%202010.pdf>
- Aged Services Learning and Research Collaboration (ASLARC). 2008. *Future Planning for Older Carers of Adults with Disabilities*. Report to NSW Department of Ageing, Disability and Home Care.
http://www.dadhc.nsw.gov.au/NR/rdonlyres/08E45F97-0A09-4915-9FE4-AB6E1CC4243E/4025/Futures_Planning_report.pdf
- Australian Institute of Health and Welfare. 2010. 'Ageing and aged care', in *Australia's Welfare 2009*. AIHW, Canberra, pp. 81-135.
- Birch, Heather. 2009. 'Dementia, Lesbians and Gay Men'. *Alzheimer's Australia Paper 15*. Alzheimers Australia.
- Cameron, Jill. 2005. *Who Will Look After Her When I Die?: Report on the Ageing Carers of People with a Disability Project*. Commonwealth Carer Respite Centre/Carer Links West. Carers Victoria, Footscray. Available at
<http://www.carersvic.org.au/Assets/Files/who-will-look-after-her-feb-2005.pdf>
- Carers Victoria. 2007. *Still Largely on the Outside: The Caring Experiences of Relatives and Friends of Older People Who Live in Aged Care Facilities in Victoria*. Carers Victoria, Melbourne.
- Commonwealth of Australia. 2009. *Social Inclusion Principles*. Available at
<http://www.socialinclusion.gov.au/SIagenda/Principles/Documents/SIPrinciples.pdf>
- Elmes, Gen. n.d. 'Caring Diversity: Same Sex Relationships'. Pamphlet. Carers Victoria.
- Edwards, Ben, Matthew Gray, Jennifer Baxter and Boyd Hunter. 2009. *The Tyranny of Distance?* Carers Australia, Australian Institute of Family Studies and Commonwealth Financial Planning, Canberra.
- FAHCSIA. 2009. *International Review of Future Planning Options*. Available
http://www.facs.gov.au/sa/carers/pubs/Documents/international_review/default.htm
- FAHCSIA 2007. *Planning for the Future: People With Disability*. Commonwealth of Australia. Canberra.
- GLBTI Retirement Association Inc (GRAI) and Curtin Health Innovation research Institute. 2010. *We Don't Have Any of Those People Here: Retirement Accommodation and Aged Care Issues for Non-Heterosexual Populations*. Curtin University, Perth.

GLBTI Retirement Association Inc (GRAI) n.d. Best Practice Guidelines: Accommodating older gay, lesbian, bisexual, trans and intersex (GLBTI) people. GRAI, n.p..

Glendinning, Caroline, Frits Tjadens, Hilary Arksey, Marjolein Morée, Nicola Moran and Henk Nies 2009. *Care Provision within Families and its Socio-Economic Impact on Care Providers*. Working Paper No. EU 2342 Social Policy Research Unit, University of York in collaboration with Vilans Centre of Expertise for Long-Term Care, Utrecht.

Government of Western Australia. 2004. *Carer Recognition Act 2004*. Available at http://www.austlii.edu.au/au/legis/wa/num_act/cra200437o2004243/

House of Representatives Standing Committee on Family, Housing, Community and Youth (HRSCFCHY). 2009. *Who Cares...?: Report on the Inquiry Into Better Support for Carers*, Commonwealth of Australia, Canberra.

Productivity Commission. 2008. *Trends in Aged Care*. Commonwealth of Australia. Canberra.

Senate Standing Committee on Finance and Public Administration (SSCFPA) 2009. *Residential and Community Aged Care in Australia*. Commonwealth of Australia, Canberra.

World Health Organization. 2007. *Global Age Friendly Cities: A Guide*. WHO. Available at http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf