

Carers WA Pre-Budget Submission 2016-2017

*Working in partnership with
Western Australian carers and their families,
service providers, peak bodies and
government agencies*

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“We care
because you do.”

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Pre-budget Submission 2016-2017

Introduction and background

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged¹. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour. Illness and disability are non-discriminatory and the caring role can be borne by any individual at any given time, regardless of socioeconomic status, age or location.

Key demographic trends point to a significant increase in the demand for carers. With advances in healthcare people are living longer including those with frailty, chronic illness or disability. According to the Australian Government's Taskforce on Care Costs, established in 2007 "The proportion of Australia's population aged over 65 years is set to increase from 13.4 per cent to 20.5 per cent by 2027"¹ The number of people aged over 65 is expected to double by the year 2054. As such there will be fewer people of working age. The number of people of working age compared to those 65 and over is reducing and is expected to fall from 7.3 in 1975 to 2.7 people in 2054². Demographic trends strongly indicate that the demand for caring is going to increase. The economic and social sustainability of this situation will depend upon the ability of carers to combine work and care and to enter or re-engage with the workforce when their caring role ceases or is reduced.

Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems. A recent report undertaken by Deloitte Access Economics determined the replacement value of the care undertaken by carers in Australia to cost \$60.3 billion per annum³. Providing supports to carers is an effective means to reduce the financial costs to the Government and taxpayers as well as the social costs to the wider community.

In order to address these challenges cultural shifts are required within the community as well as across government, non-government services and the private sector. Such shifts require workplaces and other services to be aware of the role and needs of carers. In order to achieve this, it is necessary to provide appropriate and flexible supports to assist carers during the course of their caring role, whilst also meeting their needs if and when their role reduces or ceases. In addition to the benefits to service improvement there is considerable opportunity to improve community and workforce participation through state and regional initiatives that target and improve service availability, particularly in the regions. Such initiatives could have additional benefits, by stimulating growth, improving

¹ Taskforce on Care Costs 2007, The hidden face of care: Combining work and caring responsibilities for the aged and people with a disability

² Treasury Intergenerational Report 2015, Commonwealth of Australia, page viii

³ Access Economics. 2015. The Economic Value of Information Care in 2010. Deloitte and Carers Australia, Canberra.

productivity and enabling the development of a more sustainable economy and equitable communities statewide.

Carer Statistics:

- There are 2.86 million unpaid carers in Australia. More than 825,000 carers are primary carers⁴.
- There are more than 310,000 family and friends in a caring role – 1 in 8 Western Australians⁵.
- Almost 80,000 carers live outside of the metropolitan area in Western Australia⁶.
- 53.6 percent of primary carers aged 15-64 years in Australia are employed, compared to 79.4 per cent of non-carers⁷.
- The Australian Government 'Intergenerational Report' noted that in 2007 there were 5 people of working age in Australia to support every person 65 years and over. The report also notes that this will decrease to 2.4 by the year 2047⁸.
- It has been estimated that an extra 3 percentage points of participation among workers aged 55 and over would result in a \$33 billion boost to GDP – or around 1.6 per cent of national income⁹.
- Researchers suggest that only 4% of young carers between the ages of 15 to 25 are still in education, compared to 23 % of their peers¹⁰.
- 24.1% of Carer Payment recipients are on incomes below the poverty line¹¹.
- Almost 45% of carers in very remote areas are Aboriginal and/or Torres Strait Islanders¹².
- Over 69.7% of primary carers are women¹³.
- More than 17,100 carers in Western Australia are under 18 years of age¹⁴.
- An estimated 42,900 carers in Western Australia are 65 years of age or over¹⁵.
- Across Australia, research suggests more than a third of carers have severe or extremely severe depression. In the largest ever study of carers in Australia, carers recorded the lowest levels of wellbeing of any social group¹⁶.

⁴ Access Economics.(2015). The Economic Value of Information Care in 2010. Deloitte and Carers Australia, Canberra.

⁵ Edwards, Ben, Matthew Gray, Jennifer Baxter and Boyd Hunter. 2007. *The Tyranny of Distance? Carers in Regional and Remote Areas of Australia*. CA, AIFS and CFP, Canberra.

⁶ ABS. 2009. *Survey of Disability, Ageing and Carers*. ABS, Canberra.

⁷ ABS, (2012) *Survey of Disability Ageing and Carers*, Canberra.

⁸ Australian Government, 2007, *Intergenerational Report*, p. 17.

⁹ Deloitte Access Economics (2012) *Increasing participation among older workers: the grey army advances*, Report prepared for the Australian Human Rights Commission, pg i.

¹⁰ ¹⁰ Carers Australia, (2011), *Young Carers in Education – supporting rural and remote young carers*. Pg 13.

¹¹ ACOSS. 2012. *Poverty in Australia: ACOSS Paper 194*. ACOSS, Canberra.

¹² Edwards et al, op. cit.

¹³ ABS (2012). 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2012. Commonwealth of Australia, Canberra.

¹⁴ Australian Government, 2007, *Intergenerational Report*, p. 17.

¹⁵ ABS (2009). *Disability, Ageing and Carers, Australia: State Tables for Western Australia*. Commonwealth of Australia, Canberra.

¹⁶ Cumins, R., J. Hughes, A. Tomy, A. Gibson, J. Woerner and L. Lai. 2007. *The Wellbeing of Australians – Carer Health and Wellbeing*. Report 17.1. Deakin University, Melbourne.

Priority areas to support carers in Western Australia

Carers WA have identified four key priority areas that would significantly support carers in Western Australia. These themes build upon the work currently being undertaken by the Western Australian government through the development of the WA Carers Strategy. The themes also note other areas that could compliment the Strategy and similarly assist in the development of its aims and implementation.

The four key priority areas identified are:

1. Implementation of the WA Carers Strategy
2. Working Carers
3. Hard-to-Reach Carers
4. Empowering Carers

IMPLEMENTATION OF THE WA CARERS STRATEGY

The Department of Local Government and Communities (DLGC), with support from the Carers Advisory Council and Carers WA, are developing a consultation document which will form the basis of developing a WA Carers Strategy. This document is undergoing a process of consultation at the time of the publication of this submission. It is envisaged that the Strategy will aim to identify existing services and supports available to carers in Western Australia and identify further priorities and initiatives across Government. The key focus areas of the work currently being explored include carer awareness, recognition, empowerment, participation and inclusion.

Carer Awareness and Identification

Carers are often 'hidden' and commonly do not identify themselves as carers. Carers are often isolated due to their role, and put the care needs of the individual before their own health, wellbeing and life aspirations. Due to the lack of awareness about caring within the broader community carers are commonly unable to meet their own personal needs and goals. This is because carers are not recognised and therefore available services to support them are not identified and accessed. In many cases this leads to significantly poor health and mental health outcomes amongst carers. It is important to raise awareness amongst the community of the role and value of carers, and the supports and services that are available to them. An essential part of this process is that services across government, non-government and the private sector assist in identifying people who are caring for family members so that they can support them to access services for their own wellbeing.

A whole of government approach to awareness raising and identification would greatly benefit the community as well as those carers that are hidden and have not yet recognised their role. The term 'carer' is often confused with a paid employee working in direct care within health, disability and community services. This can negatively impact carer identification. Improving tertiary education to include carer issues, needs and rights into the curriculum of those training for careers in the health, disability, social, community service and education is an opportune means to raise awareness and counter such confusion. This approach is both systemic and long lasting as new graduate cohorts will enter the workplace with a full understanding of carers and carer related issues which will ensure that families are better supported and recognised during the service delivery process.

Support to Implement the WA Carers Strategy

Currently the Carer Recognition Act (2004) applies specifically to health and disability. Whilst there is still work to be done in these areas the implementation of a WA Carers Strategy will seek to expand carer recognition across a wider range of government agencies. This process will require up-skilling of staff to improve and/or develop knowledge and understanding across Government. The plans, policies and modes of service delivery of those agencies also require adjustment to ensure carers are supported. Cultural change will only be achieved through educating and gaining the commitment and support of staff at all levels.

Departments and agencies will require assistance, advice and support to effect cultural change. Dedicated resources will be required to support departments and agencies to implement the principles within the WA Carer Strategy. Enabling carers to contribute to those networks and committees responsible for developing policies and delivering services that impact those in a caring role could also assist this process on an ongoing basis. Assistance will be particularly important to ensure those agencies which have not previously had carer issues as a focus (e.g. housing, transport) are able to understand and grasp carer issues and the importance and operational benefits that can be derived from a “carer friendly” approach.

The place of Local Government to support carers

Local governments are in an ideal position to provide supports to carers through their community development work. Some local governments are working well to support carers where as others may benefit from guidance and assistance in how they can work to assist carers and their families. Supporting Local Government Authorities (LGAs) in regional and remote Western Australia may be of particular benefit to carers. This is due to services being more scarce in these areas, and the community having greater engagement with and reliance on their local government.

System navigation issues and duplication

Carers commonly note difficulties when engaging with multiple government departments and agencies and report differing levels of support, understanding and recognition. Families commonly have to repeatedly retell their story to different government representatives as well as differing service providers. This causes carers considerable stress as it is both frustrating and time consuming. This is also particularly problematic for carers as they tend to be time poor. From an administrative perspective such duplication is inefficient and is not cost effective for government agencies. Carers report that staff can fail to link them in with available services or may provide inaccurate information which results in unnecessary repeated efforts on behalf of both the carer and the government when trying to address issues. The provision of services to support carers and families to navigate the services sector across government may help to mitigate such issues and reduce government costs. Such services may also act to ensure that carers and the people they support are made aware of and linked in with all available supports. This may result in positive impacts on carer wellbeing, independence and health, in turn improving outcomes for both carers and the people they support.

RECOMMENDATIONS:

1. Establish a dedicated team of three staff within DLGC to drive the implementation of the WA Carers Strategy. The function of the team is to assist Government agencies who have signed up to the WA Carers Strategy to develop a program of information and training in relation to carer issues. The departmental programs will seek to enhance carer awareness and identification and seek changes in Departmental Strategies, Service Plans and Policies to ensure that carers are supported. The team could administer and drive an inter-agency task force to develop and share good practice.

Two members of the team would have a focus on developing training and resources (e.g. carer friendly HR policies) across State Government agencies. The third member would have a particular focus on Local Governments across the State to ensure LGA Strategies and Plans have greater focus on carer support at a local level. The team would provide specialist advice to assist the development of government wide practices consistent with the principles of the WA Carer Strategy.

2. Carers are an integral part of the support network assisting people living with a disability, or a chronic or ongoing health issue. Embedding carer awareness, issues, needs and rights into the curriculum of those professions that service such community members will result in a significant improvement of the experience of carers across the state. The introduction of a funded project to work with educational institutions to advise on, develop and enhance the curriculum should be introduced across further education facilities such as TAFE and University. The project should focus on course materials related to the areas of health, disability, aged care, social services and education.
3. Health and mental health agencies already fund carer representation programs which ensure that key policy and planning committees receive advice and input from carers. To enable the effective implementation of the WA Carers Strategy it is suggested that Carer Representation programs be developed across all agencies that come under the WA Carers Strategy. The provision of carer representation ensures that people with lived experience are provided with opportunity for input into the planning, design, delivery and evaluation of services. Carers may require training and support in order to be able to effectively participate. A number of Peak body organisations currently provide this support through government funded programs.
4. The funding of a team of three professional support officers to assist carers, where they have complex needs and/or require multiple services, which will improve system navigation and reduce duplication and inefficiencies. A pilot program adopting this concept is currently in operation in Victoria (called Services Connect). <http://www.dhs.vic.gov.au/for-service-providers/for-funded-agencies/services-connect> Carers WA has developed detailed business cases related to the above recommendations and these can be made available should the sponsoring Department seek to pursue these initiatives. If all of the above recommendations were implemented the total funding required is estimated to be \$750,000.

WORKING CARERS

In 2011, almost 1.1 million people in Australia combined paid employment with unpaid caring responsibilities, which include 99,079 employees in Western Australia¹⁷. 53.6 percent of primary carers aged 15-64 years in Australia are employed, compared to 79.4 per cent of non-carers¹⁸. The number of Australians who balance work and unpaid caring is likely to grow due to the ageing population, longer working lives and the increasing responsibility of families to care for older people¹⁹. The Australian Government 'Intergenerational Report' noted that in 2007 there were 5 people of working age in Australia to support every person 65 years and over, the report also notes that this will decrease to 2.4 by the year 2047²⁰. By supporting carers to combine employment with their caring responsibilities, carers will be enabled to gain financial security, whilst allowing them to contribute to the tax base and their own superannuation²¹. As noted in the Carers Australia report 'Combining Work and Care: the benefits to carers and the economy':

“Modelling by Deloitte Access Economics also estimates that an extra 3 percentage points of participation among workers aged 55 and over would result in a \$33 billion boost to GDP – or around 1.6 per cent of national income.”²²

Increased carer engagement in the workforce, may also increase demand and job creation in the care industry as well as the paid care sector²³.

Retaining employment is important for carers to maintain financial independence, pay for costs associated with caring and encourage a sense of identity and independence outside of the caring role²⁴. This can assist carers in maintaining self-esteem and personal satisfaction whilst enabling them to pursue their own goals. People who combine their caring role with work may experience difficulties that can impact their employment, including absences from the workforce, financial stress, and poor physical and mental health²⁵. Supporting carers in the workplace can have significant benefits for organisations such as the retention of skilled staff, corporate knowledge, increased productivity, loyalty, reduced sickness, absenteeism and turnover²⁶. Carer participation in the workforce is a concern for all employees across all sectors (public, private, NGO etc) because anyone of working age, in any profession or position can become a carer at any time. Without adequate preparation and support to assist when such circumstances arise, employers are at risk of losing

¹⁷ ABS (2011). Census Population and Housing 2011. Canberra.

¹⁸ ABS, (2012) Survey of Disability Ageing and Carers, Canberra.

¹⁹ National Seniors. (2013). A Juggling Act: Older Carers and Paid Work in Australia.

<http://nationalseniors.com.au/be-informed/research/publications/older-carers-paid-work-australia>

²⁰ Australian Government, 2007, Intergenerational Report, p. 17.

²¹ Carers Australia, (2014), Combining Work and Care: the benefits of carers and the economy, pg 5.

²² Ibid, pg 5.

²³ Carers Australia, (2014), Combining Work and Care: the benefits of carers and the economy, pg 5

²⁴ Department of Consumer and Employment Protection, (2008), Creating Carer Friendly Workplaces: Information and options for employers, West Perth.

²⁵ National Seniors, (2013), *A Juggling Act: Older Carers and Paid Work in Australia*. Australia.

²⁶ Gateshead Carers (2011). Think Carer, think working carer: An employers guide to supporting your organisation in recruiting and retaining staff. http://www.gatesheadcarers.com/wp-content/uploads/2012/05/ThinkWorkingCarer_A4.pdf

highly valued staff, incurring high absence rates and experiencing reduced workforce productivity²⁷.

Many carers would like to re-enter the work force, but find it difficult to do so due to the long periods outside the workforce and due to the demands of their caring role. Strategies to support working carers can include improving employer awareness of carer issues, promoting carer friendly work practices and providing programmes to assist carers to return to or maintain paid work. The development of carer awareness within the employment sector and flexible work arrangements will improve carer workforce participation. Initiatives such as the provision of work place awards and the promotion of carer friendly policies have been shown to be an effective means to improve carer workforce participation.

Due to the demands of their caring role, many carers may find they are limited in what jobs they can apply for. At times some carers may only be able to undertake part-time roles initially or may need to go part-time to maintain workforce participation. Equally employers would benefit from training and information on how to support and accommodate carer needs. Providing such services will improve the ability of carers to continue to maintain employment. Some carers may be out of the workforce for many years and the skill base required of the previous profession may have changed significantly. For some, particularly older carers, the way in which jobs are obtained within the contemporary context may be very different to when they have previously looked for work. Some carers, after leaving the workforce, may choose to change professions due to their caring role or changing circumstances. Carers are often overwhelmed at the prospect of re-entering the workforce and can require assistance in writing resumes, understanding and addressing selection criteria, as well as support in relation to interview preparation and advice. Carers would also benefit from assistance to gain education and training, in job seeking and employment placements.

Young carers may particularly struggle to gain employment, due to the educational disadvantages they may have experienced as well as the duties required in their caring role. Some researchers suggest that only 4% of young carers between the ages of 15 to 25 years are still in education, compared to 23% of their peers²⁸. Young carers aged 15 to 24 were found to be almost twice as likely to be unemployed than non-carers of the same age (20.0% and 11.6%, respectively)²⁹. In a 2012 report undertaken by the Australian National University on behalf of the Commonwealth Government young carers who received the Carer Payment and Carer Allowance between September 2001 and June 2006 were found to have low levels of educational and workforce participation³⁰. The study also found that these young carers "...were nine times more likely to be living in areas of high socioeconomic disadvantage, and in outer urban locations and smaller country

²⁷ Carers SA (2008). Submission to the Select Committee on Balancing Work and Life Responsibilities

²⁸ Carers Australia, (2011), Young Carers in Education – supporting rural and remote young carers. Pg 13.

²⁹ Australian Bureau of Statistics, Caring in the Community, Australia: Summary of Findings, 2012, Commonwealth of Australia.

³⁰ Bray R, J., 2012, Young carers in receipt of Carer Payment and Carer Allowance 2001 to 2006: characteristics, experiences and post-care outcomes, Social Policy, Evaluation, Analysis and Research Centre, Australian National University, Commonwealth of Australia. viii.

towns”³¹. Young carers, like all carers, should be provided with the opportunity to pursue careers in their field of choice and achieve their personal goals. At a recent International Carers Conference held in Sweden, the limitations of vocational choice young carers face due to juggling work and caring was highlighted.

RECOMMENDATIONS:

1. Undertake a program to encourage and develop carer friendly workplaces throughout WA. This project should comprise of the following elements:
 - A public campaign to raise awareness of carer issues and how employers can support their employees who have a caring role. The campaign could also focus on the business case for supporting carers.
 - Introduce a Carer Friendly Workplace Award scheme.
 - Conduct a training program with supporting resources (model HR policies, suggested carer friendly initiatives) to be delivered to organisations across all sectors.
2. Develop a Carer Return to Work Program to assist carers when re-entering the workforce. Such a program could assist carers in a number of ways including career coaching, mentoring, resume writing, developing interview skills and interview preparation. The program could establish links with training agencies and educational institutions to support the provision of training or retraining if their current skills need updating. Also the program could assist carers through an employer placement scheme.
3. Young carers have often experienced disadvantage in the education system due to their caring role and therefore require more assistance on the transition from education to work, when compared to other young people. A specialised program providing supports such as career coaching; mentoring; resume writing; developing interview skills and interview preparation would be invaluable. The development of a scheme where employers provide work experience, mentorship, apprenticeships and vocational on the job training in the young carers chosen field would be of benefit. Such a scheme would greatly assist young carers in their transition to the workplace and enhance their chances of gaining employment. It would also improve their opportunities to pursue their career of choice. A working model for this type of program can be found in the UK in Hertfordshire (refer www.carersinherts.org.uk).
4. In addition, the encouragement of employees that already have an interest in supporting disadvantaged groups could be enhanced by including young carers as a target group. The Crown Casino Perth is one employer that has recently announced an interest in assisting indigenous people at disadvantage through the federal government Employment Parity Initiative. <http://minister.indigenous.gov.au/media/2015-09-22/crown-commits-employment-parity>

³¹ Ibid

Carers WA has developed detailed business cases related to the above recommendations and these can be made available should the sponsoring Department seek to pursue these initiatives. If all of the above recommendations were implemented the total funding required is estimated to be \$600,000.

HARD-TO-REACH CARERS

Regional and remote carers

Carers have been recognised as a hard-to-reach group in the WA Health Promotion Strategic Framework 2012-2016³². It is estimated that there are 80,000 carers in the regional and remote areas of Western Australia (26% of WA's population)³³. These statistics are likely to be an understatement due to many people in these regions not identifying themselves as carers or not being identified by service providers³⁴. Carers in regional and remote areas are more likely to be isolated³⁵. Limited public transport, remote geographical location and limited opportunity for community contact intensifies social isolation for carers in these areas. Accessing services is also a significant issue due to limited choice and availability. It is notable that young carer rates are higher among young Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse (CaLD) living regionally³⁶.

Feedback we receive from both carers and service providers indicates that further work needs to be undertaken on the development of services in both regional and remote Western Australia including an assessment of respite needs and gaps in service provision and carer supports. Improving the provision of services within regional and remote Western Australia may also assist in providing employment opportunities, encourage education participation and improve health outcomes in these regions. Such initiatives can positively influence disparities relating to health, leading to long term improved impacts on both social and health outcomes in these regions³⁷.

Aboriginal Carers

It is reported that 20% of carers living in outer regional and remote areas have a profound, severe or moderate disability or long-term health condition, compared with 14.3% of carers in major cities³⁸. This can further complicate the situation of carers who have their own health issues, as they have to balance the needs of the person they care for with their own. Aboriginal communities are known to have reduced health outcomes and often face additional barriers (including language and cultural difference) which impede access to services. The 2014 'Working Together Aboriginal and Torres Strait Islander Mental Health Wellbeing and Principles and Practice' report notes that it is important that practitioners develop an understanding of these influencing factors that contribute to community and service interaction³⁹.

³² Department of Health, Western Australia. WA Health Promotion Strategic Framework 2012–2016. Perth: Chronic Disease Prevention Directorate, Department of Health, Western Australia; 2012. Pg26.

³³ ABS (2011). Survey of Disability, Ageing and Carers. Commonwealth Australia. Canberra.

³⁴ O'Connor, D. L. (2007). Self-identifying as a caregiver: Exploring the positioning process. *Journal of Ageing Studies*, 21, 165-174.

³⁵ Winterton R., Warburton, J. (2011). Models of care for socially isolated older rural carers: barriers and implications. *Rural and Remote Health*, 11, 1678.

³⁶ Carers Australia, (2011), Young Carers in Education – supporting rural and remote young carers. Pg 3.

³⁷ Dugeon, Pat., (et al), 2014, Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice. Commonwealth of Australia. Pg 85

³⁸ Hughes, J. (2009). Supporting family carers in rural and remote Australia: recent evidence. Carers Australia.

³⁹ Dugeon, Pat., (et al), 2014, Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice. Commonwealth of Australia. Pg 60

Awareness raising of the caring role is required within Aboriginal communities as caring activities are commonly seen as part of familial and kinship obligations. As mentioned in the 'Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice'

“Family and kinship systems have always been central to the functioning of traditional and contemporary Aboriginal and Torres Strait Islander societies”⁴⁰.

As such the caring role which commonly centers around familial obligation is viewed as a cultural norm, leading to a lack of identification with the term 'carer'. This, in turn, has led to a lack of understanding by the Aboriginal community of their rights, as well as the information and supports that are available to them. In addition, the Aboriginal community have a tendency to address issues as a family rather than reaching out to service providers. Initiatives that target awareness raising within community as well as improvements to service provider understanding of cultural issues that influence service access, will lead to positive improvements in aboriginal service engagement. These initiatives will also improve community engagement more generally, as well as contribute to wider reconciliation efforts.

Culturally and Linguistically Diverse (CaLD) Carers

It is estimated that between 25-30% of carers in Australia are from a CaLD background⁴¹. Of all states and territories, Western Australia has the highest proportion (27%) of its population born overseas⁴². CaLD carers can develop poor mental health and physical wellbeing if they are not able to access culturally appropriate services⁴³. CaLD carers can have difficulties expressing their needs and circumstances due to barriers such as limited English language proficiency and cross cultural issues⁴⁴. The word 'carer' is also difficult to translate in other languages with many languages not having a term for carer. This can impact the identification of carers from the CaLD community and their understanding of their rights. In addition to these issues, most information on available resources and services are communicated in English, which can impact the ability of CaLD carers to gain awareness and understanding of the services that are available to them⁴⁵. As a result, CaLD carers may be less likely to come into contact with and be identified by service providers.

⁴⁰ Dugeon, Pat., (et al), 2014, Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice. Commonwealth of Australia. Pg 59

⁴¹ Carers Australia. (2015). Culturally and Linguistically Diverse Carers. Retrieved from: <http://www.carersaustralia.com.au/about-carers/culturally-and-linguistically-diverse-carers/>

⁴² Department of Local Government WA (2012). Ageing in Culturally and Linguistically Diverse Communities: An analysis of trends and major issues in Western Australia. Retrieved from: http://www.omi.wa.gov.au/resources/publications/localgovernment/Ageing_report28NR2%29.pdf

⁴³ Cardona, B., Chalmers, S. & Neilson, B. (2006). Diverse Strategies for Diverse Carers: The Cultural Context of Family Carers in NSW. Centre for Cultural Research, University of Western Sydney. Retrieved from: http://www.uws.edu.au/data/assets/pdf_file/0005/196331/Diverse-StrategiesFINAL_REPORT_JULY.pdf

⁴⁴ Health Victoria (2010). Supporting People in Care Relationships – A Resource for Service Providers. Retrieved from: http://www.health.vic.gov.au/agedcare/downloads/pdf/supporting_people.pdf

⁴⁵ Carers Australia. (2015). Culturally and Linguistically Diverse Carers. Retrieved from: <http://www.carersaustralia.com.au/about-carers/culturally-and-linguistically-diverse-carers/>

Another barrier faced by CaLD carers are differences in cultural values related to caring and the acceptability of formal services outside the family or cultural group⁴⁶. Like Aboriginal communities, most CaLD communities and families tend to value and operate interdependently⁴⁷. In these cultures, family members tend to be considered most appropriate to provide care and they can see their caring role as a central part of their responsibilities. This may be exacerbated by language barriers and a need to make sure the person they care for is receiving culturally appropriate care and has an understanding of what is happening to them. The provision of specialist support to assist CaLD carers would greatly assist in engagement with this often hidden subgroup of carers, improving the ability of service providers to meet their needs.

RECOMMENDATIONS:

1. Develop Regional Carer Coordinator positions in selected regional areas (the South West, Wheatbelt, Goldfields, Midwest, Pilbara and the Kimberley). These positions would act to support families and service providers in developing carer supports through advice, information, education, training and awareness raising. They would also develop carer networks that will support the development of carer engagement, supports, independence and empowerment within the regions. In undertaking this work Regional Carer Coordinators would partner with local agencies in order to share resources whilst utilising existing networks. Carers WA have undertaken a successful pilot project employing a Regional Carer Co-Ordinator in the Albany area. This pilot has proven to be a cost effective way of providing support by leveraging resources and partnering with existing organisations within the area.
2. The funding of an Aboriginal Engagement Officer through Carers WA who can assist service providers in developing an understanding of aboriginal needs and circumstances in order to improve culturally appropriate services for carers. The position would also act to build awareness raising and identification of the carer role within aboriginal communities. In doing so the role would improve access and engagement with available services, whilst developing new culturally appropriate supports.
3. The funding of a CaLD Engagement Officer through Carers WA who similarly assists service providers in understanding and meeting the needs of CaLD carers. The role would also act to improve awareness and identification of the caring role within CaLD communities and the supports and services available to them. The role would help to develop culturally appropriate supports and in turn improve access and engagement with the CaLD carers and their communities.

⁴⁶ Health Victoria (2010). Supporting People in Care Relationships – A Resource for Service Providers. Retrieved from: http://www.health.vic.gov.au/agedcare/downloads/pdf/supporting_people.pdf

⁴⁷ Cardona, B., Chalmers, S. & Neilson, B. (2006). Diverse Strategies for Diverse Carers: The Cultural Context of Family Carers in NSW. Centre for Cultural Research, University of Western Sydney. Retrieved from: http://www.uws.edu.au/data/assets/pdf_file/0005/196331/Diverse-StrategiesFINAL_REPORT_JULY.pdf

Carers WA has developed detailed business cases related to the above recommendations and these can be made available should the sponsoring Department seek to pursue these initiatives. If all of the above recommendations were implemented the total funding required is estimated to be \$650,000.

EMPOWERING CARERS

Carers commonly face barriers that impact their ability to support their family members. A common barrier is the failure of service providers to recognise the caring role. This issue continues to be raised by carers across the State despite the existence of both the state Carers Recognition Act (2004) and its federal counterpart the Carer Recognition Act (2010). This lack of recognition has a significant impact on carer mental health and wellbeing. In a workshop held by Carers WA in early 2015 carers identified that improved communication with clinicians would greatly improve their stress levels, mental health and family wellbeing. This communication issue was also highlighted as one of the biggest challenges they faced in their caring role. Such support can also assist carers to fulfill their role, which will help to improve outcomes for their own well-being as well as the family and friends they support.

Many carers are socially isolated due to their caring role. As noted earlier, carers have been recognised as a hard-to-reach group in the WA Health Promotion Strategic Framework 2012-2016⁴⁸. Carers often have little time for social activities and may be housebound due to their caring responsibilities. For many, family and friend networks recede, with a reduction of the carers' ability to be socially active due to their caring role. In addition, the diagnoses of the family member can cause social barriers and stigma that arises from a lack of understanding by others of their condition. Stigma for those with mental illness and disability is well documented. Carers can also struggle to find people who are experiencing similar issues as themselves. Such isolation can leave carers vulnerable to developing mental health issues as their social and support networks may reduce and/or they may not share a common experience of the caring role. Isolation can be reduced by providing carers with support from others who have common experiences, which can enable carers to develop a sense of connection and improved wellbeing. Peer work has been recognised as a valuable means to help individuals develop a sense of normalcy relating to their experience, and has been shown to provide hope, inspiration and comfort⁴⁹.

A lack of awareness within the health and human services sector of the caring role, rights and expertise results in carers commonly being unheard and/or misunderstood. This can negatively impact engagement and experience. Social learning theory suggests⁵⁰ and evidence has shown that providing opportunities to engage with peers who have common experience may make service providers appear more credible⁵¹. Sharing experiential knowledge has been shown to promote

⁴⁸ Department of Health, Western Australia. WA Health Promotion Strategic Framework 2012–2016. Perth: Chronic Disease Prevention Directorate, Department of Health, Western Australia; 2012. Pg26.

⁴⁹ Solomon, (2004), Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal*, 27, 392-401.

⁵⁰ Solomon, (2004), Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal*, 27, 392-401.

⁵¹ Hoagwood et al., (2010), Family Support in Children's Mental Health: A Review and Synthesis. *Clinical Child and Family Psychology Review*, 13, 1-45.

improvements in the ability of the carer to cope with their situation, whilst encouraging choice, self-determination and building confidence⁵². In addition, peer work has been shown to result in: an increased sense of control; an improvement in people's ability to manage their challenges; an improved sense of self and satisfaction with their life; social support; a sense of community; as well as belonging⁵³.

In a recent carer workshop held in early 2015, carers identified the provision of formal Advocates as an effective support that provided relief and assistance and improved their mental health and family wellbeing. There is a recognised gap in formal advocacy services in the state. This is particularly true within the mental health and education sectors. The provision of additional formal advocates in the not-for-profit sector that can help to reduce carers reliance on crisis supports by reducing their stress, better enabling them to undertake care, whilst improving overall outcomes for families as a whole.

RECOMMENDATIONS:

1. Develop and implement a Self-Advocacy Training Programme to assist carers to undertake their role. Such a programme could provide training on carer rights, assertiveness, advocacy and how to work effectively with service providers including clinicians.
2. Peer led support is built on trust, understanding and sharing their own lived experience. The provision of a tiered Carer Peer Support program:
 - Implementing the volunteer carer peer package currently in development by Carers WA, an NGO would train carers with lived experience (including disability, chronic illness, mental illness and frail aged) to become Carer Volunteer Peer Mentors. A Coordinator would match trained Carer Volunteers with carers requiring support to work together to improve the carers wellbeing. This model is supported by best practice as it provides individualised, peer led support.
 - In addition, the development of two Carer Peer Support Worker roles. These Support Workers will be matched to carers who are assessed as having more acute carer issues that require a higher level of support. These carer peers will also receive additional training and support from the NGO. This role will have the knowledge to provide guided referrals and escalate the carer to other services such as advocacy and counselling but with the continued support of a peer. In addition to the direct support to carers, this role will work closely with systemic advocacy roles to improve service responsiveness to family/carer needs and facilitate peer led workshops.
3. The establishment of an Individual Advocates team comprising of two staff, to assist carers in crisis who are facing difficulties when engaging with service providers or whose immediate mental health is at risk. Individual Advocates

⁵² Solomon, (2004), Peer support/peer provided services underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal*, 27, 392-401.

⁵³ Tondora, et al., (2010), A clinical trial of peer-based culturally responsive person-centred care for psychosis for African Americans and Latinos. *Clinical Trials*, 7, 368-379.

undertake independent casework advocacy, assisting family/carers to resolve issues they have been unable to on their own. The Individual Advocate would assist carers to put in place sustainable measures which support the individual and family to move out of a crisis situation and develop greater capacity for self-advocacy.

Carers WA has developed detailed business cases related to the above recommendations and these can be made available should the sponsoring Department seek to pursue these initiatives. If all of the above recommendations were implemented the total funding required is estimated to be \$625,000.