



# Response to the Office of Multicultural Interests Strategic Plan 2014 -16 Discussion Paper



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With our thanks to the families who shared their experiences with us so that we can advocate for change on behalf of all carers.

## Introduction

Carers WA appreciates the opportunity to contribute to the Strategic Plan of the Office of Multicultural Interests.

Carers WA is the peak body representing people who provide ongoing care to a family member or friend with ongoing care needs due to disability or chronic illness, including age-related disability and mental illness.

The Carers Recognition Act 2004<sup>1</sup> is West Australian legislation that requires health, mental health and disability service providers to identify and recognise family members and friends who provide ongoing, unpaid care for a person with care needs. This legislation was reviewed in 2008. Recommendations included a strengthening of provisions to address barriers to service access identified by CaLD family members in a caring role<sup>2</sup>. The recommendations have not yet resulted in any changes to the legislation.

### What roles do family carers undertake?

Family carers provide the majority of care needs to people living with disability including young children born with life-long disability, people of any age with mental ill health, through to older family members who are ageing. Roles undertaken include:

- personal care, such as showering, wound dressings, feeding, toileting, dressing, meal preparation, feeding, peg tube feeding, exercising
- assisting with participation in educational, employment, cultural, social and sporting activities, transport and meal preparation.
- property maintenance and organising home modifications
- social and emotional support for a person with mental ill health or psychosocial disability.
- decision making on behalf of a person with significant intellectual disability or dementia
- coordinating care amongst other family members and friends/neighbours.

This can occur across many sectors including financial, housing, transport, education and employment. It may involve coordinating access to medical, mental health and other service provision.

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<sup>1</sup> Available from the State Law Publisher at [http://www.slp.wa.gov.au/pco/prod/FileStore.nsf/Documents/MRDocument:21015P/\\$FILE/CarersRecognitionAct2004-01-a0-01.pdf?OpenElement](http://www.slp.wa.gov.au/pco/prod/FileStore.nsf/Documents/MRDocument:21015P/$FILE/CarersRecognitionAct2004-01-a0-01.pdf?OpenElement)

<sup>2</sup> EDAC 2008. *Submission to the Review of the Carers Recognition Act 2004*. EDAC. <http://www.edac.org.au/pubattach/08augcarersact.pdf>

Access Economics has estimated that if the care undertaken by carers was to be replaced by formal service providers, this would cost the Australian economy \$41 billion annually<sup>3</sup>.

### **How many Western Australians are in a caring role?**

The Survey of Disability, Ageing and Carers conducted by the Australian Bureau of Statistics<sup>4</sup>, recently estimated that there are more than 251,000 people in a caring role in Western Australia. Academic researchers have argued that this is an undercount and there are more likely to be upwards of 307,000 people in Western Australia in a caring role.<sup>5</sup>

The Census conducted by the Australian Bureau of Statistics also attempts to identify carers but for various reasons achieves a much lower count. In 2011 this was 167,344<sup>6</sup>. Over 31 per cent (52,603) of carers identified in the Census were born overseas. Just over half of these carers (25,555) spoke a language other than English with over 3,000 over those carers not having English-language proficiency.

### **The social and economic impact of being in a caring role**

While many people in a caring role report benefits to themselves and their relationship with the person they provide care for, carers are unfortunately over represented amongst low income households. They experience higher than average levels of depression and disability, and lower levels of wellbeing than the general population<sup>7</sup>.

Carers are less likely to participate in paid employment. While specific data for CaLD carers is not available, Access Economics has estimated that almost 130,000 people across Australia who would like to be in paid employment are not able to do so due to their caring role.

Assumptions are sometimes made that CaLD families have access to extended networks enabling caring to be shared. This assumption overlooks the reality of the diversity of CaLD families particularly those families who have recently arrived and are not linked in with other families and formal service providers. Those migrants who were living in traumatic circumstances prior to their departure, and whose journey and arrival has also been traumatic, are likely to have increased needs for information and support both as individuals in their own right but additionally as

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<sup>3</sup> Access Economics. 2010. *The Economics Value of Informal Care in 2010*. Access Economics and Carers Australia.

<sup>4</sup> ABS. 2012. *Survey of Disability, Ageing and Carers*. Canberra.

<sup>5</sup> Edwards, B., Gray, M.C., Baxter, J. and Hunter, B.H. 2009. *The Tyranny of Distance? Carers in Regional and Remote Areas of Australia*. Commonwealth of Australia and Carers Australia, Canberra.

<sup>6</sup> ABS. Census 2011. Available <http://www.abs.gov.au/census>

<sup>7</sup> ABS. 2012. *Survey of Disability, Ageing and Carers*. Canberra; Cummins et. al. 2007. *The Wellbeing of Australians – Carer Health and Wellbeing*. Deakin University and Carers Australia. <http://www.deakin.edu.au/research/acqol/auwbi/survey-reports/survey-017-1-report.pdf>

carers of their family members who may be living with complex and interrelated physical and mental ill health.

Given that research has highlighted concerns regarding the impact of caring on the physical and mental health of carers, we recommend strategic actions at the systemic level to address these impacts. This is consistent with the recent inclusion of carers within groups identified by the WA Department of Health<sup>8</sup> as 'hard to reach' and for whom it may be necessary to 'develop unique interventions'. Carers WA argues that this is particularly important for CaLD carers.

### **'Hidden' carers are less likely to access support services**

As noted by the Department of Health and Ageing in 2012<sup>9</sup>;

CALD carers can experience greater difficulty in accessing and navigating the aged care system - many CALD carers are 'hidden' carers who are more likely to experience barriers related to differences in language and culture.

While carer support services are available, unless service providers identify the carer, or the individual self-identifies, they are less likely to utilise the supports that assist in sustaining the caring role. CaLD carers are less likely to self-identify; the word 'carer' is problematic in many cultures and languages<sup>10</sup> and, given that most information about services is available in English, CaLD carers are less likely to come into contact with and be identified by service providers. Young CaLD carers, and CaLD carers in rural and remote regions, are also at risk of being 'hidden' and therefore unlikely or unable to access services.

Reports on the delivery of Home and Community Care (HACC) service provision in WA indicates that 7 per cent of HACC service clients report their main language spoken as a language other than English<sup>11</sup>. In other service sectors, national data indicates a lower take up of disability support and disability employment services<sup>12</sup>.

The result is that these carers bear the burden of their care giving in the absence of supports to which they are entitled and which could make their care giving situation more sustainable. Better access to carer supports and services could enable the

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<sup>8</sup> Department of Health, Western Australia. 2012. *WA Health Promotion Strategic Framework 2012-2016*. Perth. Chronic Disease Prevention Directorate, Department of Health, WA.

<sup>9</sup> Department Health and Ageing. 2012. *National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse Backgrounds*. Commonwealth of Australia. Canberra.

<sup>10</sup> EDAC. 2003. *Supporting CALD Carers: The service needs of culturally and linguistically diverse carers of people with disabilities*. EDAC. <http://www.edac.org.au/carersreport.html>

<sup>11</sup> WA Department of Health. 2013. *Home and Community Care Program Minimum Data Set Report 2011-2012 Annual Report*. Available [http://www.health.wa.gov.au/hacc/docs/mds/HACC\\_Report\\_2011\\_2012.pdf](http://www.health.wa.gov.au/hacc/docs/mds/HACC_Report_2011_2012.pdf)

<sup>12</sup> National Ethnic Disability Alliance. 2013. *One Million People Fact Sheet*. <http://www.neda.org.au/index.php/reports/item/one-million-people-fact-sheet>

carer to maintain or regain their attachment to the workforce, education, social and cultural activities.

### **Literacy regarding health, community and aged care services is vital to enable self direction of service provision**

Members of CaLD communities are at risk of not receiving the full benefit of self-direction in service provision. Current moves in the provision of health, disability, mental health and aged care services towards providing consumers with greater choice can be of benefit to the individual and their family carers but it is important that people have full knowledge of the implications of their decision making. Carers are often involved in supporting their family member to make care decisions but in the absence of being able to access information in an appropriate format, the best decision for the family member or carer may be more difficult to identify.

### **The ageing population**

By 2021, more than 30 per cent of Australia's older population will have been born outside Australia<sup>13</sup>. The majority of care provided to older people in the community is provided by family members, usually the partner/spouse but also by adult children, in particular, daughters.

Cultural resistance to formal aged care services in many CALD communities means that many older people from CALD backgrounds are themselves a carer for a family member and many CALD carers face cultural and other barriers in accessing carer support services<sup>14</sup>.

### **The introduction of the National Disability Insurance Scheme (NDIS)**

Currently, data suggests that people with disability from a CaLD background are less likely to access various disability support services<sup>15</sup>. This increases the importance of the care and support provided by family carers. The NDIS will provide funding to eligible people for the provision of services above that which is considered reasonable to expect from the person's family. It is important that individuals and their family speak honestly about the amount of care required and the amount of care that can be sustainably provided within the family. It is important that service providers, when assessing a person's eligibility for formal services, be aware of the potential for people to under estimate the formal services they require as this can lead to people missing out on the services they need. It can also result in family

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<sup>13</sup> Department Health and Ageing. 2012. *National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse Backgrounds*. Commonwealth of Australia. Canberra.

<sup>14</sup> <sup>14</sup> Department Health and Ageing. 2012. *National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse Backgrounds*. Commonwealth of Australia. Canberra.

<sup>15</sup> National Ethnic Disability Alliance. 2013. *One Million People Fact Sheet*.

<http://www.neda.org.au/index.php/reports/item/one-million-people-fact-sheet>

carers being unable to engage with paid employment or education due to the extent of their caring role.

### **Safe health and hospital services**

Carers WA have been made aware of instances where hospital staff have relied on family members to translate information for the patient. This is inconsistent with WA Health's Language Services Policy which requires that a qualified interpreter be utilised to communicate clinical information to the patient or to the patient's carer<sup>16</sup>. Miscommunication between patients, their family carers and medical staff have been identified as a potential safety and quality issue, with even higher risks posed to patients who require the use of interpreters<sup>17</sup>. The incidence of misunderstanding between clinicians and patients was significantly higher when family members were used as interpreters. As seen in the comments below, the failure to utilise interpreters was also identified by FECCA in their research.

A survey respondent felt that many health professionals do not view culturally responsive care as being a part of standard care and patient-centred care approaches. He explained that he had personally observed clinicians disregarding the needs of CALD patients by failing to ensure they properly understood instructions or diagnoses<sup>18</sup>.

CaLD carers have also informed Carers WA of communication barriers in emergency settings such as when utilising ambulance services. The concerns of family carers need to be clearly understood and responded to by medical staff. The potential for the concerns of carers to be overlooked in an emergency setting when one or both parties face communication barriers is heightened and procedures or strategies for addressing this must be communicated by relevant agencies to CaLD communities.

### **Mental health reforms – the impact on CaLD carers**

The Mental Health Bill 2013 was recently presented to the WA Parliament. When operationalised it is expected to provide greater opportunities for family carers to be involved in the treatment and supports for the person they care for. It is vitally important to both the person with mental ill health and the family member providing care, that the information shared with them, and the tasks they are expected to carry out to assist with the person's recovery, are fully understood. Clinicians in

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<sup>16</sup> WA Health. 2011. Language Services Policy.

<http://www.health.wa.gov.au/CircularsNew/attachments/606.pdf>

<sup>17</sup> Iedema, R. and Manidis, M. (2013) *Patient-Clinician Communication: An Overview of Relevant Research and Policy Literatures*. Sydney: Australian Commission on Safety and Quality in Health Care and UTS Centre for Health Communication.

<sup>18</sup> FECCA. 2013. *Multicultural Access and Equity: Strengthening Connections Between Communities and Services*. FECCA, Canberra.



mental health settings must be supported with adequate training and other resources in order that they can effectively communicate both with patients, and their family/friend carers of all cultural backgrounds.

### **Concerns about service provision**

Families for whom English is not their first language have raised concerns with Carers WA about services delivered in the home both for older and younger people with care needs. Families lack confidence that the service provider has fully understood the care requirements of the individual and whether the staff members have the skills to support the individual in a culturally safe manner. When service provision falls below the standard expected by the family and the individual receiving care is adversely affected, this news is quickly shared within the community and further adds to the reluctance to make use of formal services.

### **Complaints mechanisms**

Some CaLD groups are less likely to be aware of, or to pursue, formal complaints processes<sup>19</sup>. This means that families are potentially denied access to recourse, and also that service providers do not have the opportunity to improve their service delivery as a result of responding to complaints.

The Health and Disability Services Complaints Office (HADSCO) is the Western Australian agency to whom consumers *and carers* can take complaints about their treatment by health, aged care, mental health and disability services. In 2012-13, HASDCO reported that 20 per cent of complaints received by health providers related to communication, while a further 32 per cent related to Access, Rights, respect and dignity<sup>20</sup>. From the published data, it is not apparent whether the complainants were from a CaLD background although it is possible this data may be available.

### **Ensuring the voice of CaLD carers is heard - learning from lived experience**

Carers WA encourages all government and non government agencies to involve carers in the design and planning of community and other services. The Carers Recognition Act 2004 requires health and disability service providers to include carers in the assessment, planning, delivery and review of services. People with lived experience of being a carer contribute a learned wisdom and unique perspective which should be incorporated throughout government decision making bodies.

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<sup>19</sup> Australian Human Rights Commission. 2012. Access and Equity: Inquiry into the responsiveness of Australian Government services to Australia's culturally and linguistically diverse population. AHRC. Sydney.

<sup>20</sup> Health and Disability Services Complaints Office (HaDSCO). 2013. Annual Report 2012-2013. Available <https://www.hadscow.gov.au/docs/reports/2012-13/HaDSCO-Annual-Report-print.pdf>

## **Ensuring CaLD carers can participate in social and economic activities**

The caring role can be isolating and demanding. Overall, carers are less likely to participate in paid employment and young carers are less likely to complete their education. With access to appropriate carer supports, carers will have an increased opportunity to pursue and maintain paid employment, education and training, as to retain their engagement in their community.

## **Priorities for newly arrived migrants in a caring role for their family members**

Coordinated cross sector/cross agency access to information about relevant services for the family member with disability and for the person in the caring role is required. Conversely, service providers need to be informed about the needs of newly arrived migrants and able to identify specific needs and undertake appropriate supported referrals, keeping in mind that services are available that are designed specifically to support the person in the caring role in addition to those which will support the person with care needs.



## **Recommendations:**

OMI to include data on the number of CaLD carers within its statistical fact sheets and other research and reporting in order to highlight their existence to government agencies and other service providers.

OMI to engage with the Carers Advisory Council and the Department of Local Government and Communities to ensure community awareness raising strategies designed to encourage community and self-identification of carers are appropriate to carers within CaLD communities.

OMI to provide advice to the Department of Local Government and Communities regarding amendments to the Carers Recognition Act 2004 to strengthen provisions that would assist in addressing barriers to accessing services identified by CaLD carers.

OMI to assist Medicare Locals with the provision of information regarding CaLD communities.

OMI to engage with peak bodies representing community service providers to assist them to embed culturally appropriate and safe methods of engaging with individuals and their family carers regarding decision making and assessment in service provision.

OMI to engage with relevant agencies to ensure the needs of the carers of older CaLD people are addressed in state wide strategies to support older Western Australians.

OMI to advocate for a CaLD consumer and carer representative program in order that they can participate in decision making forums on behalf of all CaLD consumers and carers and provide feedback to CaLD communities.

OMI to engage with peak bodies to ensure staff providing community aged care and working in aged care accommodation facilities are able to provide culturally appropriate services to residents and to support CaLD carers during the transition of the older person from their home in the community to supported accommodation.

OMI to engage with the Disability Services Commission and the National Disability Insurance Agency to ensure service providers are able to work in a culturally appropriate way with CaLD people with disability and, where appropriate, their family members in a caring role.

OMI to promote the availability of disability and carer services and supports to CaLD communities.

Omi to encourage participation by CaLD peak bodies and communities in consultation processes conducted by the Australian Commission on Safety and Quality in Health Care.

Omi to clarify with ambulance service providers their procedures for working with CaLD patients and their family carers.

Omi to offer any high level advice or expertise required by the Mental Health Commission and the Office of Mental Health in order to meet the standards of the WA Health Language Services Policy.

Omi to engage with HaDSCO in the promotion of HaDSCO services to CaLD communities

Omi to engage with HaDSCO to strengthen research and data collection mechanisms such that they highlight trends in complaints about health and disability services made by members of CaLD communities and to determine that mechanisms are in place at the systemic level to address these.