

**Carers Queensland Inc.**



**Submission to the Productivity  
Commission, draft report – *Caring  
for Older Australians.***

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## **Productivity Commission Hearing into Caring for Older Australians**

### **Carers Queensland**

Carers Queensland is the peak body that represents the diverse needs and interests of carers in Queensland and is dedicated to advancing the recognition of the carers role. We promote the rights and needs of carers and a greater community understanding of the role of a carer. We also provide direct service provision through programs such as counselling, advocacy, no interest loan scheme, carer support groups & retreats, information and guided referral. Carers Queensland also has specific programs for young carers, culturally & linguistically diverse carers and care recipients, and as a registered training organisation, provides both accredited and non accredited training specifically targeted to the learning needs of carers.

#### **1. Carers – A snapshot**

- In 2010, over 1 in 8 Australians (2.6 million people) are estimated to be providing informal care to a person who needs assistance due to disability, chronic illness or old age. This represents 13.1% of Australia's population. Of these, 770,000 are estimated to be primary carers.
- In 2010, unpaid family carers provided 1.32 billion hours of care to people with a disability, mental illness or disorder, chronic condition, terminal illness or who was frail aged.

1. Over 90% of primary carers in Australia are close family members of the person for whom they care —41% are a spouse or partner, 26% are a son or daughter and 23% are a parent. Almost half of all primary carers are providing support to a person aged 65 years and over.

#### **2. Demographic trends and their implications for unpaid care**

The projected ageing of the Australian population suggests a subsequent increase in rates of disability and a concomitant increase in the need for care. This is occurring in the context of government policies and societal preferences that increasingly favour community care to enable older people and people with disabilities to remain living in the community. Taken in conjunction, these trends can logically be expected, over the coming years, to culminate in an increase in demand for unpaid care and a considerable reliance on the unpaid care that family and friends provide.

Government and policy makers are well aware of the demographic trends predicting the ageing of the population; including the demographic changes that will have implications for the availability and willingness of unpaid carers to provide support to the ageing population such as:

- Changes in the labour force, most notably, the increased participation of women who traditionally constitute the majority of primary carers

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<sup>1</sup> Australian Institute of Health & Welfare. Nov 2009

- The changing nature, structure and function of family (i.e. increases in single person households, increased rates of divorce and separation, lower fertility rate, delay of childbearing and expected dual responsibilities as parents and unpaid carers of parents, etc), and
- Geographic mobility and other factors that contribute to more mobile lifestyles.

These trends suggest the possibility of a scarcity of unpaid carers to support the ageing population in the future.

### **3. Care for the ageing population – Who's responsibility?**

Australia has moved, for both philosophical and fiscal reasons, from an institutional based system for the aged towards a community care system. The success of the governments' community care policy relies, to a great extent, on the ability of the family and the community to provide care for the ageing population.

Carers' willingness to provide support will, in turn, be influenced by the relative costs (including opportunity costs) and benefits experienced as a consequence of the caring role. The role of government in this respect is to promote caring responsibilities through policy and legislative responses. It is necessary that the State provide an effective regulatory framework to support citizens to undertake unpaid care in the community.

Carers' lives are affected not only by the direct demands of the caring role but also by the extent to which caring impacts on other aspects of life. Carers have historically experienced a lack of choice and opportunity as a direct consequence of their caring role, usually in relation to their employment and education prospects, their financial position, their health and wellbeing and their ability to participate in social and community life. This is associated with poorer health, social and economic outcomes.

### **4. Queensland Perspective**

- In June 2009 Queensland's population reached 4,407,000. 536,000 people are carers with an estimated 110,175 being primary carers.
- The replacement value of Queensland carers is an estimated \$6.1 billion dollars per year

### **5. Indigenous carers**

According to Australian Bureau of Statistics (ABS) adjusted data from the 2006 Census, Indigenous peoples number 517,200 or 2.3 per cent of the population. The State with the largest number of Indigenous people is NSW with 28.7 per cent of the total Indigenous population. Queensland is not far behind with 146,400 Indigenous people or 28.3 per cent of the Indigenous population.

Indigenous carers are likely to be caring for more than one person.

Little consistent information about the number of Indigenous carers in Australia exists. This may reflect that the construct of caring in Indigenous communities is one that includes caring for somebody with a disability, chronic condition, mental illness or who is frail as a community responsibility, and that programs are delivered to communities rather than services or programs to individual Indigenous carers. The ABS 2006 Census adjusted data indicates that there were 517,200 Indigenous people in Australia (ABS 2006). Using the current carer ratio (1 carer:8 people) results in 65,650 Indigenous carers in Queensland, with approximately half likely to be living in rural and remote areas.

Carers Queensland welcomes the reports recommendations relating to the needs of Aboriginal and Torres Strait Islander people and specifically emphasises the need for assessment and services to be provided locally.

Carers Queensland participated in the development of the Carers Australia submission on behalf of the network and supports all of the recommendations in that submission.

This submission provides the Queensland perspective and address two areas that Carers Queensland see as inter-related, in the Productivity Commissions Draft Report – *Caring for Older Australians* – being Carers Assessments and Carer Support Centres.

## **6. Assessment**

### **6.1 Carer inclusion in assessment of care recipient**

Carer's knowledge of the care recipient is rarely taken into account during the assessment process, particularly by medical and mental health services. This is despite the fact that carers possess extensive knowledge and unique skills and expertise relating to the care recipient. Due to the carer's central role in providing care, carers are often the best source of information on the history, needs, and resources of the care recipient. As such, the valuable knowledge possessed by the carer should be utilised during the assessment process.

It is also necessary that, following assessment, the results and outcomes of the assessment are provided to carers (with the care recipient's consent) so that carers receive an understanding of the care recipient's condition and are aware of how best to provide care; ensuring carers are seen as a partner in the care continuum of the person they are caring for.

A study commissioned by Carers Queensland in 2007 demonstrated the need for assessment and support pre-discharge. Common experiences identified were:

- Disagreements about discharge options, with the carer being treated poorly as a result
- Premature releases from hospital resulting in negative outcomes for the carer and care recipient
- Discharge being conducted in a cavalier and ad hoc manner, without follow through on discharge plans, at a time inconvenient to the carer and in some cases without the carer being informed

- Unrecognised impacts on the caring role

Many carers complained that patient confidentiality and privacy issues were used to frustrate their attempts to participate fully as part of the management team of their loved one.

## **6.2 Carers' Assessment**

Carers Queensland supports the inclusion of a comprehensive, holistic and nationally consistent assessment of carers needs.

It is acknowledge that assessment of the carer is necessary to accurately determine whether the carer has the physical, psychological, emotional and financial capacity to effectively undertake the expected care functions (such as medicating, providing physiotherapy, bathing, feeding and transporting their care recipient). This assessment will be able to inform what services may be required to ensure that the carer is properly supported in their role and that the care recipient receives appropriate care. Carer assessments need to address what the carer is willing to do, and for how long they are willing to do it; and the system needs to have the capacity to undertake regular re-assessment of the carers role, ability and willingness.

However, an effective assessment of the care situation should not only be exclusively for the purpose of assessing the carer's capacity to provide care.

Carers have needs in their own right such as (but not limited to):

Respite: Respite that provides a break from caring, is recognised as one of the most valuable services for carers, and particularly when dealing with aged care recipients with dementia related illness.

Education and Training: This includes education and training that assists the carer to undertake their role, but also accredited and unaccredited training to assist carers to return to the workforce on a part time or full time basis, if they so wish, when the care recipient is placed in an aged care facility.

Counselling: Support to address the responsibilities and difficulties sometimes associated with carers such as making difficult decisions about a loved one going into care; struggling to come to terms with a loved ones long term or sudden illness or disability; adjusting to the care situation; nursing home placement and grief and loss. The reported benefits of counselling include increased self-worth and confidence; a reduction in feelings of guilt; increased feelings of control; and an understanding of the importance of having time to look after themselves.

Advocacy: Many carers speak on the exhaustion that they feel in continuing to have to battle the aged care system to ensure the best possible services are provided to the care recipient and often need support in advocating on their own and their loved one's behalf.

It is unclear in the draft report whether carer assessment is contingent on the care recipient undergone assessment and / or the result of that assessment. Carers needs can be related or separate to those of the care recipient, and their access to services and support must not depend on the willingness of the care recipient to have contact with the aged care system. Nor should it depend on the eligibility for the care recipient for services in the aged care system.

Carers Queensland supports the following recommendations:

- a) Individuals who are assessed as being able to care will not be obligated to do so
- b) Carers access to assessment, services and support is not contingent on the care recipient
- c) Carer assessment can and will occur when required, for example pre-discharge
- d) Carer assessment will consider the capacity of carers across the life course

## **7. Carer Support Centres**

Support for carers and carer recipients must be timely, responsive, appropriate and accessible.

Carers Queensland welcomes the Productivity Commission's recommendations regarding the development of Carer Support Centres and notes that the Productivity Commissions report into Disability Services supports a similar service development.

Carers Queensland believes that Carers Support Centres need to:

- Provide a comprehensive carer assessment and guided referral process.
- Provide a broad range of supports including carer counselling, carer advocacy, peer groups support, educations and training, respite, in home support, and advocacy.
- Be adequately resourced to provide ongoing preventative support and assistance to carers, particularly during times of intensive caring situations, rather than the current practice of focusing solely on the relief of stress and burden (i.e. Carers talk about the need to tell Commonwealth Respite and Carelink Centres that they are DESPERATE and at wits end, in order to get a respite service, and bemoan the fact that they cannot access pre-planned respite.)
- Provide support to carers regardless of whether the carer recipient receives aged care services or is eligible for aged care services.
- Be effectively linked with Medicare Locals, Local Health Networks, mental health services and other community and service providers.
- Demonstrate experience to deliver quality services and meet established service standards.
- Demonstrate capacity to meet contractual obligations in regard to finance and performance reporting.
- Have the capacity and infrastructure to assess and deliver services in both metropolitan and rural and remote areas; and in a culturally responsive way.

The final dot point is specifically relevant to a State the size of Queensland, and impacts directly on the needs of Aboriginal and Torres Strait Islander communities. Carers Queensland has deliberately decentralised its service provision and currently

operates 12 regional offices in Queensland as well as an administrative support site at Camp Hill (Brisbane). Regional offices are located in Cairns, Townsville, Mackay, Rockhampton, Hervey Bay, Maroochydore, Stafford (Brisbane North), Mt. Gravatt (Brisbane South), Gold Coast, Ipswich, Toowoomba and Roma.

Local knowledge has been developed over a long period of time and responses are provided to meet the varied needs of our clients, which currently include carers and care recipients (particularly through our large culturally and linguistically diverse program.)

Regional staff have a broad range of experience in working with people living in geographically isolated areas. Local office linkages can be utilised to provide information and services to carers who are geographically isolated. Carers Queensland staff frequently 'take the service to the person' where required when transport and isolation are barriers to access to service.

I believe that Carers Queensland is ideally situated to provide comprehensive services as a Carer Support Centre. Carers Queensland recommends that the Commission clarify its position on the ability for suitable organisations to tender for Carer Support Centres, rather than 'morphing' current Commonwealth Respite and Carelink Centres into Carer Support Centres.

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