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Carers Queensland Inc.

**Submission to the
Health and Community Services Committee -
Disability Services (Your Life Your Choice)
*Amendment Bill 2012***

October 2012

Family carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic medical condition, terminal illness or are frail aged.

The activity and impact of providing care is best understood in terms of its context; as a relationship between two or more individuals, rooted in family, friendship or community. Caring is a role rarely chosen by most, nor does it discriminate. Children and young people, people of working age and older people, people with a disability, people who identify as culturally and linguistically diverse, indigenous Australians and those living in rural and remote Queensland provide care to a family member or friends on a daily basis. For some caring is a short term commitment whilst for others, it is a role that literally lasts a lifetime.

Carers Queensland Inc. is the peak body representing the diverse concerns, needs and interests of carers in Queensland. Carers Queensland believes that all carers regardless of their age, disability, sexuality, religion, socioeconomic status, geographical location or their cultural and linguistic differences should have the same rights, choices and opportunities and be able to enjoy optimum health, social and economic wellbeing and participate in family and community life, employment and education like other citizens of the State. Carers Queensland believes that caring is a shared community responsibility.

The Carers (Recognition) Act 2008 Carers Charter includes many of the above statements in the thirteen key principles.

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Disability Services (Your Life Your Choice) Amendment Bill 2012

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Introduction

Carers Queensland commends the Queensland Government on the proposed changes to the Disability Services Act 2006 and welcomes the opportunity to provide meaningful input. We believe we are in a unique position to consult with, and advocate on behalf of, the 494,200¹ carers living in Queensland, many of whom who have, and continue, to play a pivotal role in providing carer and support to children and adults with disabilities, mental health problems, and chronic health problems.

We aspire to provide an independent platform from which to advance the issues and concerns of carers and believe our knowledge and expertise in carer issues means that we are able to provide the State Government with relevant and trusted information that will ensure that the needs of carers will be recognised, respected and acted upon. Our ambition is to ensure that carers are recognised and included as active partners in the development of State social policy and services delivery practices.

Carers Queensland believes that a comprehensive system of different models of carer support is needed to meet the needs of carer in urban, regional, rural and remote Queensland. These measures complement the government's commitment to carers through the Queensland Carer Action Plan 2011-2014 and the intentions of the Queensland Compact with the non-profit community services sector.

This submission has been informed by consultation with Queensland's carers, Australian and international research and the annual C3 (carer) Consultations.

Current Carer Demographics

Some Queensland statistics:²

- One in eight citizens identify as a carer
- One third of carers identify as a primary carer
- Two thirds of carers are women
- Carers are equally likely to live in a major city as in regional Queensland
- In 2009, there were 60,300 identified young carers between 15-24 years of age. The majority of these young carers are male

Of the 152, 800 primary carers in Queensland:

- 87.69% (134,000) co-reside with the person they care for
- 23,000 primary carers between the ages of 45 to 64 years provide 40 or more hours of care per week
- 8500 or 5.56% of all primary carers have been caring 25 years or more and of this group, 4,100 have been providing 40 or more hours of care per week
- 46.9% are a spouse or partner; 19% are a child and 23.7% are a parent

Nationally, carers provide 1.32 billion hours of care per year. Conservative national estimates suggest the replacement value of informal care is approximately \$40.9 billion per annum (equivalent to 3.2% of GDP and 60% of other formal health care). Carers provide on average 460 hours of care annually or 9 hours per week. However, the provision of care is not evenly distributed. Primary carers provide 54% or 714 million hours annually, despite representing only 19% of the citizens who identify as carers. The more severe a person's disability or illness, the greater the amount of time devoted to caring by the primary carer. Informal family care remains the lowest subsidised form of care provided in Australia.³

Research shows that many carers experience health, social, emotional, economic and employment disadvantages and are often marginalised in society^{4,5}. To address these persistent inequalities carers are included in one of six social inclusion priorities in the Commonwealth Government's Social Inclusion Statement- A Stronger, Fairer Australia⁶ and have been identified as a group at risk of long term social exclusion in the Queensland Department of Communities 2009-2013 Strategic Plan.⁷

Submission

Whilst current community care ideology acknowledges the contribution of carers and recommends the involvement of carers in service assessment, planning and delivery, anecdotal evidence from carers suggests that reality is far removed from ideology and policy.⁸ As carers have repeatedly pointed out, traditional service planning and delivery appears to be reactionary and usually in response to a crisis or imminent crisis, rather than planned with the carers and the person they are caring for. This situation is magnified in rural and remote Queensland where there are fewer service delivery options for people with disabilities and their carers.

In order to meet the future demand for disability services in a cost effective and timely manner it is vital that a range of service delivery models is available to meet the unique needs of the carers and the people they care for and support and to assist them to engage effectively, and remain engaged, with the community and workforce, irrespective of where they reside.

Restoring a carer's sense of control and an acknowledgment of their expertise is at the heart of building and maintaining resilience for carers. Research⁹ conducted in the UK has found that the payment of service delivery budgets directly to a person with a disability, their carer or a nominated guardian has, for many carers, substantially enhanced their quality of life. Many carers involved in the study spoke of improved health and wellbeing as a result of increased ability to manage services flexibly and proactively. In a recent survey of carers conducted by Carers Queensland, nearly 90% of respondents indicated that they would be interested in participating in consumer directed care.¹⁰

Recommendation:

The implementation of truly person-centred planning and flexible service delivery options will see carers as genuine partners in the delivery of disability services and will restore control with the carer and the person they care for and support.

Carers Queensland supports the proposed amendments to the Disability Services Act 2006 as specified in the Disability Services (Your Life Your Choice) Amendment Bill 2012.

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