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**Carers Queensland Inc.**

**Submission to the  
Health and Community Services Committee -  
*Queensland Mental Health Commission Bill 2012***

**January 2013**

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's mission is to improve the quality of life of all carers throughout Queensland.

Title: Submission to the Health and Community Services Committee –  
*Queensland Mental Health Bill 2012*

Date: January 2013

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## **Introduction**

As the peak representative organisation for carers we believe we are in a unique position to consult with, and advocate on behalf of, the 494,200<sup>1</sup> carers living in Queensland, many of whom who have, and continue, to play a pivotal role in the mental health care sector. 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 Queensland 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 government social policy and service delivery practices.

We take this opportunity to provide the Queensland Government with considered recommendations which, if implemented, will better support the carers who play a vital role supporting people mental health problems. Carers Queensland believes that a comprehensive system of services and programs of carer support is needed to sustain past achievements and meet the challenges of the future in the mental health and substance misuse sector. These measures complement the government's commitment to carers through the National Carer Strategy and the intentions of the Commonwealth and Queensland Compacts with the non-profit community services sector and reflect the principles in the *Carers (Recognition) Act 2008 (Qld)* and the accompanying Carers Charter.

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

## Current Carer Demographics and Context

Carers are, by and large, the main providers of care and support in the community and have been described by the National Health and Hospital Reform Commission as the 'invisible, unpaid workforce'<sup>2</sup> and a 'taken-for-granted resource', complementing and supporting formal community care<sup>3,4</sup> services. It has been estimated that carers provide 74%<sup>5</sup> of the assistance required by people with disabilities, mental health problems and the frail aged and, as such, carers can be considered an integral component of the health and community care sectors. Research conducted by the Mental Health Council of Australia indicates that 20.8% of carers of people with mental health problems care for more than one person.<sup>6</sup>

Some Queensland statistics:<sup>7</sup>

- 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.<sup>8</sup>

The 'mental health carer' role is not always well understood by others. The tasks undertaken by a carer of a person with a mental health and/or a substance misuse problems may be different to those generally understood and accepted as 'caring' such as personal care, meal preparation, domestic duties etc. A 'mental health carer' may do many of those tasks but other tasks may include reminding the person to pay bills, attend appointments, work or rehabilitation/therapy appointments, encouraging them to remain medication and treatment compliant, providing emotional, social and (often) financial support and advocating for them in times of acute illness or distress.

## **Comments**

Carers Queensland commends the Queensland Government on the commitment to establish the Queensland Mental Health Commission and the Queensland Mental Health and Drug Advisory Council and to the development and implementation of a whole-of-government strategy.

We appreciate the opportunity to provide meaningful input into the review of the draft legislation and provide the following comments for consideration.

### **1. Carer Recognition**

Carers Queensland is gladdened by the overt acknowledgement of carers and their vital role to the wellbeing and recovery of people with mental health and/or substance misuse problems in the draft legislation. We also commend the Government's commitment to ensuring carers are recognised as individuals in their own right.

### **2. Treatment Plans**

The knowledge and expertise carers can, and do, develop over the caring journey can be immense; knowledge about the efficacy of treatment regimes and support programs, skills in identifying and managing triggers to changed behaviours and expertise in implementing risk mitigation strategies etc. Having regard for this wealth of knowledge and skill base, Carers Queensland is pleased to see a commitment to the 'engagement' of carers in the 'treatment plans' (Division 1, 5 Guiding Principles, (4) (c)).

However, we are concerned that this principle has been preceded by the unqualified phrase "wherever possible". This is a rather ambiguous statement that is open to inconsistent and wide ranging interpretation by practitioners; some of whom may use it to covertly and unjustifiably discriminate against the carer and/or limit the carer's reasonable involvement in the development and implementation of appropriate and effective treatment plans.

The unjustified or indefensible exclusion of carers from the treatment planning processes has the real potential to create tensions with carers; particularly if the health and community care practitioners expect the carer to continue providing informal support. Such behaviour may result, in the longer term, with carers electing to reduce or relinquish their caring involvement to the funded health and community care sector, placing a burden on the already 'stretched' sector. High-trust relationships with practitioners are pivotal to gaining and maintaining the cooperation and respect of carers.

Notwithstanding, Carers Queensland acknowledges and accepts that there are situations where it is justifiable that carers (and others) are not participants to the treatment planning processes. In these situations, Carers Queensland recommends that clinical services and service providers develop policies and protocols for the timely and respectful communication of the situation with the carer and that these documents are prominently displayed in public areas and are routinely audited for compliance.

### **3. Evidence based policies and practices**

Carers Queensland supports the development and evaluation of evidence based policy and practices (Division 3, 7 Whole-of-Government Strategic Plan, (d)). Having regard for the expertise of carers and their contribution to the sector, we respectively recommend that wherever possible, carer representatives be included in the evaluation of policies and the associated practices.

### **4. Queensland Mental Health and Drug Advisory Council**

Carers Queensland endorses the commitment of the Queensland Government to appoint to the Council member(s) who have knowledge of the issues and concerns of carers.

Carers Queensland respectively recommends that should a dedicated 'carer representative' be appointed to the Council, it is with the following considerations. That the carer representative has:

- the lived experience of caring for a person with mental health and/or substance misuse problems
- excellent and sustainable links with carer representative (mental health and non-mental health specific) organisations
- excellent and sustainable links with service providers (mental health and non-mental health specific) who deliver carer specific support services
- existing relationships or the capability to develop sustainable relationships with other marginalised groups such as the LGBTI community, representatives of culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander communities and carers in rural and remote Queensland

- having regard for the number of young (10 to 18 years) and young adult (18 to 25 years) carers of parents or other family members with a mental health and/or substance misuse problem, Carers Queensland recommends that the carer representative has well developed links with this particularly vulnerable client group and/or their representative organisation or has knowledge of their specific issues and concerns.

## Summary

Carers Queensland commends the Government's commitment to actively engage carers as genuine partners and looks forward to working with the sector to reduce the stigmatisation and marginalisation they encounter in the clinical and community settings.

Carers Queensland welcomes any opportunity to have input into and work collaboratively with others in the development of strategies and/or programs that promote the role, expertise and knowledge of carers and as genuine partners in care.

## REFERENCES

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- <sup>3</sup> Shaver, S. & Fine, M. (1995). *Social Policy and Personal Life: Changes in state, family and community in the support of informal care*. Discussion Paper No. 65, Sydney
- <sup>4</sup> Turvey, K., & Thomson, C. (1996). *Caregiving and Employment: Who cares, what's involved? Different caregiving relationships and their impact on caregiver employment*. Paper presented at the Fifth Australian Family Research Conference Institute of Family Studies, Brisbane 27-29 November 1996. <http://www.aifs.gov.au/conferences/aifs5/turvey.html>
- <sup>5</sup> The Allen Consulting Group. (2007). *The Future of Community Care*, Report to the Community Care Coalition, Melbourne.
- <sup>6</sup> Mental Health Council of Australia. (2010). *Mental Health Carers Report*, Canberra.
- <sup>7</sup> Australian Bureau of Statistics. (2009). *Survey of Disability, Ageing and Carers: Summary of findings. Cat. No. 4430.0*. Canberra: Australian Bureau of Statistics.
- <sup>8</sup> Access Economics. (2010). *The economic value of informal care in 2010*, Report for Carers Australia, Canberra.