



**Senate Community Affairs Committee Inquiry:
Commonwealth Funding and Administration
of Mental Health Services**

**CARERS WA
SUBMISSION**

August 2011

Definition of carer

The term carer is defined in both Western Australian (*Carers Recognition Act 2004*) and Commonwealth legislation (*Carer Recognition Act 2010*). A carer is a person who provides care on an unpaid basis to a family member or friend with a disability, a medical condition, chronic illness, mental illness or age related frailty. Foster parents, paid and volunteer care support staff are explicitly excluded from this definition.

About Carers WA

Carers WA is the recognised peak body for carers in Western Australia. Since 1996 Carers WA has provided systemic advocacy and grassroots support to the more than 307 000 family members and friends in WA who provide the overwhelming majority of care and support to those who need assistance to live in the community.

The key issues for carers of people who are mentally unwell

Carers nationally have identified 15 key issues that impact severely on their ability to support the person they care for who is mentally unwell¹. The following are of direct relevance to this inquiry.

Issue 1: Listen to and respect carers

Issue 2: Integrated recovery-based care for the consumer

Issue 3: More and better trained staff at all levels

Issue 4: Knowledge and information for carers

Issue 5: Carer and consumer education for all professional groups and agencies

Issue 6: Support systems, services and processes established for carers

Issue 8: Stigma, discrimination and isolation for carers and consumers

Issue 11: Physical and mental health of carers

Issue 13: Privacy and confidentiality issues

This inquiry provides a timely opportunity to identify recommendations that will explicitly address these issues.

¹ Mental Health Council of Australia (MHCA). 2009. *Adversity to Advocacy: The Lives and Hopes of Mental Health Carers*. MHCA.

Select responses to the inquiry

Services available for people with severe mental illness and the coordination of those services:

The coordination of services – the role of carers in Local Hospital Networks and Medicare Locals

Through the Our Health, Our Community project, the federal government has committed funding to the training of health consumers to participate in the Governing Councils of Local Hospital Networks and Medicare Locals². This is commendable. Similar support needs to be provided to ensure that carers are involved in, and supported to participate in the same structures. The issues that consumers and carers raise are not the same. For example, a task commonly undertaken by carers is the coordination of access to a range of services on behalf of a mentally ill person. This raises issues of information sharing protocols and confidentiality. If services do not identify and recognise the carer and put in place operational arrangements that support the carers' access to the information they need, the ability of the consumer to access services will be limited. Carers will offer useful input to the effective operations of LHNs and Medicare Locals to put these mechanisms in place. This will act to support the operations of the proposed mental health Care Facilitators.

Recommendations:

- Ensure carers are specifically represented alongside consumer and community representatives on decision making forums governing the LHNs and Medicare Locals.
- Provide training and support to carers to facilitate their role as representatives on LHN governing Bodies and the boards of Medicare Locals.
- Medicare Locals need to address issues of care coordination such as information sharing protocols that recognise carers.
- Ensure consistency between national privacy legislation and state mental health legislation on the sharing of information with carers, particularly focusing on carers under 18 who are currently excluded from the list of people with whom mental health professionals are able to share information.
- Ensure that mental health Care Facilitators are trained in carer identification and recognition, and have operational protocols in place that support a family-centric approach.

² 'To ensure the consumer voice is adequately represented as the health reforms are implemented and later health policy evolves, CHF has launched its *Our Health, Our Community* project...On 11 August 2010, the Government announced funding for CHF to train and support 120 health consumers to participate as members of Governing Councils of LHNs and Medicare Locals' <https://www.chf.org.au/our-health-our-community-survey.php#A-role-for-Consumers>

Mental health workforce issues

The skills required to identify, recognise and work with carers as partners in care
The identification of carers is an issue in itself.

'The difficulties associated with changing eight separate Mental Health Acts to obtain consistency in approach to identification and inclusion of carers is acknowledged however this is considered necessary if carers are to become true partners in the delivery of services to consumers'³.

Lack of identification and recognition impacts on all carers but particularly on young family members who are carers of parents or older siblings with mental illness.

As was clearly highlighted in *Who Cares...?*⁴, and the *The Lives and Hopes of Mental Health Carers*⁵, arguments about privacy and confidentiality are often used by mental health professionals and service providers to exclude carers from being involved in care planning for a mentally unwell person.

Training is required for mental health professionals and service providers to ensure they have the knowledge and skills to identify, recognise, respect and work with carers and other family members. This is in the best interests of the person with mental illness and the carer.

Recommendations from the House of Representatives inquiry⁶ remain pertinent to this inquiry, particularly recommendations 3, 11 and 14.

Recommendations:

- That training in carer identification and recognition, information sharing and confidentiality protocols be developed and delivered to all health professionals and service providers.
- That the curriculum of health, allied health and mental health courses include instruction on carer recognition, information sharing and confidentiality.
- 'Nationally consistent carer identification and participation policies and good practice protocols to be developed for implementation in all public and private mental health services'⁷.

³ Private Mental Health Consumer Carer Network. 2007. *Identifying the Carer Project: Final Report and Recommendations*. DOHA, Canberra, pages 39-40.

⁴ HRSCFCHY. 2009. *Who Cares ...? Report on the inquiry into better support for carers*. House of Representatives Standing Committee on Family, Community, Housing and Youth Report Commonwealth of Australia, Canberra.
<http://www.aph.gov.au/house/committee/fchy/carers/report/fullreport.pdf>

⁵ Mental Health Council of Australia (MHCA). 2009. *Adversity to Advocacy: The Lives and Hopes of Mental Health Carers*. MHCA.

⁶ HRSCFCHY. 2009. *Who Cares ...? Report on the inquiry into better support for carers*. House of Representatives Standing Committee on Family, Community, Housing and Youth Report Commonwealth of Australia, Canberra.

- Ensure consistency between national privacy legislation and state mental health legislation on the sharing of information with carers, particularly focusing on carers under 18 who are currently excluded from the list of people with whom mental health professionals are able to share information.

Any other related matter

An emerging issue - the move to self-directed funding in mental health

In Western Australia, the Mental Health Commission has made reference to the introduction of self-directed funding. The Productivity Commission also canvassed this model in the recent inquiry into the long term care needs of people with disability. This model, while welcomed by many consumers and carers, has the potential to place more financial and other decision making responsibilities on carers. This increased responsibility needs to be recognised both in terms of the requirement for appropriate education and information, but also for the possibility that it will increase the respite needs of family carers. In order for self-directed funding to achieve positive outcomes, carers and consumers will need to be able to work together. This can be a challenging process that could require support services to develop appropriate communication skills. As demonstrated by research in the UK⁸, without this support, the additional tasks of managing funds could contribute to tensions within the family and lessen the positive potential of self-directed funding.

Recommendation:

- Shifts in policy toward self-directed funding need to adopt a family centric approach and incorporate assessments of the impact on carers and other family members to identify their separate and particular needs for information, advice, skills training and respite.

⁷ Private Mental Health Consumer Carer Network. 2007. *Identifying the Carer Project: Final Report and Recommendations*. DOHA, Canberra, page 40.

⁸ Newbrunner, L., Chamberlain, R., Bosanquet, K., Bartlett, C., Sass, B. and Glendinning, C. 2011. *Keeping Personal Budgets Personal: Learning from the experiences of older people, people with mental health problems and their carers*, Adults' Services Report, 40, Social Care Institute for Excellence, London.

Interactions between the Carer Recognition Act 2010, the National Carer Strategy and the National Standards for Mental Health Services 2010

Each of these measures has significant potential to improve outcomes for carers and mental health consumers. Standard Seven of the National Standards for Mental Health Services contains 17 measures to improve the ability of services to work with carers as partners. More information is required about the reporting mechanisms that will allow measurement of the effectiveness of the standards in meeting the goals of the *Carer Recognition Act 2010* and the National Carer Strategy.

Recommendation:

- The proposed national Mental Health Commission undertake research that assesses the effectiveness of the National Standards for Mental Health Services in contributing to the goals of the *Carer Recognition Act 2010* and the National Carer Strategy.