



**Carers Australia and Network of Carers Associations
National Policy Position Statement**

Mental Health Reform

February 2012

Carers and Mental Health Reform

Carers are central to the care and support of people with a mental illness, and are the major providers of care in the community. A carer is an individual who provides unpaid personal care, support and assistance to another individual because they have a disability, medical condition or mental illness or are frail and aged. As a result of de-institutionalisation carers have had to take on an even higher share of the care of people with a mental illness, often in isolation, providing what the Burdekin report described as an 'enormous and unreasonable burden of care'.ⁱ

Caring for a person with a mental illness is often much more than a full time job, with some carers of a person with a mental illness spending as much as 100 hours per week caring.ⁱⁱ The *2010 Mental Health Carers Survey* provides some insight into the experience of caring for a person with a mental illness. The survey found that:

- 31 per cent of respondents had been caring for between 11 and 20 years
- the median length of time spent caring was 10 years, the maximum was 54 years
- 77 per cent of respondents organised the majority of care for the person they care for
- one fifth of respondents cared for more than one person with a mental illness.ⁱⁱⁱ

The role of carers of people with a mental illness is not always well understood by others. The tasks undertaken may be different to those generally understood as 'caring', such as providing personal care or cooking meals. A carer of a person with a mental illness may do those things, but other tasks might include helping the person they care for to be organised, reminding them to pay bills and attend appointments, encouraging them to seek assistance, providing emotional and social support and dealing with emergencies. When the person with a mental illness is acutely unwell there may be a risk that the person may harm him or herself or others.

One son has lived with us since he got sick and wherever we go he comes along, not that we mind as we got used to it, but at times it gets you down.

Mental Health Carers Report 2010 p 38, Mental Health Council of Australia

About this statement

Carers Australia is the national peak body representing the diversity of carers in Australia. Carers come from all walks of life, cultural and religious backgrounds, and age groups. We work in partnership with the network of state and territory carers associations, research and other relevant organisations, with the ultimate aim of improving the lives of carers. Our vision is that caring is accepted as a shared community responsibility. This statement outlines the priorities of Carers Australia and the national Network of Carers Associations in regards to carers and the current mental health reform agenda.

The need for mental health reform

In recent years there has been a growing appreciation in the community of the need for mental health reform. Arguments for reform, however, often focus solely on the needs of people with a mental illness, ignoring the knowledge, experience and needs of their carers.

The perspective of carers has been captured by the Mental Health Council of Australia's (MHCA) Carer Engagement Project, a national survey of carers of people with a mental illness, which identified 15 key issues for carers.^{iv} Carers in this survey identified as priorities the need for improved support of the people they care for, as well as for services that support the carer. This reflects the interconnectedness of the lives and needs of carers and the people they support.

Amongst the consumer issues identified were the need for increased investment in holistic recovery-based care, both clinical and non-clinical, more and better trained staff at all levels, more effective and accessible acute care, and more housing options that give consumers choice and meet individual support needs.

Identified carer issues included the desire to be listened to and respected, including by mental health professionals, the need for improved access to information about caring and carer services and supports, more flexible respite options, recognition of the effect that caring can have on physical and mental health, and greater support in meeting the costs of care and in participating in the workforce.

I had to take leave from my work place to care for my son and my work place will (not) have me return. I am currently on a carer pension and looking for work now my son is recovering. It is difficult at my age.

Mental Health Carers Report 2010 p 45, Mental Health Council of Australia

Context of mental health reform

Current reform agendas offer a rare opportunity to fundamentally reform the way in which the mental health system recognises, includes and supports carers, to embed best practice models of carer engagement within the mental health system, and to realise the principles of the Statement for Australia's Carers and the priorities of mental health carers, as identified by the Carer Engagement Project.

Broader health and social reforms currently occurring, including National Health and Hospital Reform, the enactment of the *Carer Recognition Act 2010*, the introduction of the National Carer Strategy and the Commonwealth Government's strengthening commitment to a National Disability Insurance Scheme are equally significant, and provide manifold opportunities to significantly improve the lives of people with a mental illness and their carers. These opportunities will be considered below, in addition to other key issues such as housing and income support, which are yet to receive the attention they deserve from government.

Reform within the mental health sector

Ten Year Roadmap for National Mental Health Reform

The Roadmap must address the needs of carers of people with a mental illness. Carers should have opportunities to participate in its development and implementation, as is consistent with the Carer Recognition Act 2010.

- The Roadmap should comprehensively address the 15 key issues for carers identified in the MHCA Carer Engagement Project.
- Development of the Roadmap must be informed by genuine, comprehensive and ongoing consultation with carers.
- Multiple performance indicators are needed to measure carer services and outcomes for carers, including indicators of carer health and wellbeing.
- Workforce initiatives should include training for mental health workers to better engage with, include and recognise carers, in order to overcome persistent cultural resistance to working with carers.
- The Roadmap should explicitly identify and facilitate the provision of the range of services and supports needed by carers of people with a mental illness and encourage innovative funding and delivery arrangements, for example individualised funding for respite.
- Provisions should be made for carer assessments, to ensure that carers have access to the services and supports they need and that their own physical and mental health needs are addressed.
- The Roadmap must explicitly identify population groups with significant mental health needs, including carers. Early intervention and prevention measures, including expanded carer counselling programs, should explicitly acknowledge and address the mental health needs of all carers.
- The Roadmap should recognise the importance of employment, education and social participation for the wellbeing of carers of people with a mental illness and include initiatives to improve their participation.

From a father caring for his daughter with borderline personality disorder and his wife with an Acquired Brain Injury (2010):

It needs to be understood that the whole family is on a journey with the person who is ill. It's just that the family's journey is different and their needs are different. These needs must be identified and resources allocated to meeting them.

Mental Health Commission

Carers should be systematically included in the structure and operation of the Mental Health Commission.

- Carers of people with a mental illness must be a priority focus of the Commission.
- The priorities and direction of the Commission should be informed by the 15 key issues identified by carers in the Carer Engagement Project.
- Carer participation and consultation structures need to be built into the operation and design of the Commission.
- The Commission should review the training of mental health professionals, as recommended by the MHCA,^v to promote the training of mental health professionals in family-centric approaches and the implementation of best practice information sharing models that include the carer as a partner in care.^{vi}
- Funding should be allocated to support carer (and consumer) participation, particularly for training and skills development, remuneration, reimbursement and other supports.
- The Commission should ensure that all mental health service providers report against the requirements of the National Standards for Mental Health Services, including standard seven which relates to the identification and inclusion of carers.^{vii}

From a carer whose husband is an armed forces veteran (2010):

Why does the doctor automatically include me in discussions about my husband's prostate problems but then I am excluded from discussions about his PTSD? I need to be able to care for both his mental and physical health issues.

Representation of carers

Mental health carers must have their voices heard.

- Carers must continue to be represented through the National Mental Health Consumer and Carer Forum. With the establishment of the National Mental Health Consumer Organisation it will be important that the Forum retains its standing in the policy space, and its funding levels, so that the carer perspective continues to be effectively represented.

Reform needed outside the mental health sector

The needs of people with a mental illness and their carers will not be met by the mental health sector alone. Increased investment and improvements to other key services, including disability, health and housing services, will be critical.

Housing

The availability of affordable and appropriate supported housing for people with a mental illness must be significantly improved. A lack of secure and stable housing is a significant barrier to recovery and places additional pressures on carers and the care relationship.

- Accommodation supports and services for people with a mental illness must be significantly increased.
- Increased investment and targeting of housing assistance for people with a mental illness is needed,^{viii} including social housing and the National Rental Affordability Scheme (NRAS).
- The measures recommended by the Henry Taxation Review to address financial and structural barriers to providing private rental and social housing to people on very low incomes and additional needs should be implemented.^{ix}
- Priority pathways into social housing and other accommodation services should be established for people with a mental illness supported by ageing parents. Carers should have choice in their living arrangements and caring role, and should not be obligated to provide housing support for their adult child by the absence of alternatives.

From a sister whose brother with schizophrenia could only access shared accommodation (2010):

Long term supported accommodation should be available where the family can visit and behave like a family. People need a sense of ownership of their home. They need to be able to sleep without being disturbed.

National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) must provide adequate coverage and levels of support to people with significant and enduring psychiatric disabilities, and their carers. For carers, this will require:

- A broad national mapping of existing mental health family and respite services, including eligibility policies, funding sources and levels and service delivery capacity.
- The development of a framework for the design of future mental health carer respite and support programs within or alongside an NDIS. This should consider eligibility assessment tools, access pathways and support entitlement.

Income support system

Carers and people with a mental illness could be better supported by the income support system. Inadequate financial support for people with a mental illness often has direct and significant financial impacts on their carers.

- Changes to Centrelink assessment processes for the Carer Payment and Carer Allowance are needed to better recognise the nature of the support provided to people with a mental illness. Current assessment tools are heavily biased towards physical assistance, reducing access for carers of people with a mental illness.
- Increased participation requirements for Disability Support Pension recipients which take effect from July 2012 are likely not only to prove onerous and stressful to many people with a mental illness but also to their carers who may need to provide transport and other support to ensure that the person they care for can meet their requirements. Carers' own ability to participate in paid employment could be jeopardised. An evaluation framework is needed for the new DSP rules which pays particular attention to risks posed to people with a mental illness and their carers.
- The Newstart Allowance must be substantially increased to a level commensurate to other pensions, and indexed according to the Male Total Average Weekly Earnings. The current Allowance, the single rate of which is a third lower than comparable pensions, is patently inadequate as a source of income support.

National Carer Strategy

The National Carer Strategy (the Strategy) presents the opportunity to create change for carers of people with a mental illness. The Strategy's priority areas closely align with the issues identified in the Carer Engagement Project.

- The Implementation Plan for the Strategy needs to provide detailed measures, timelines, and identified funding sources, which were largely absent from the Strategy.
- The Implementation Plan should complement other key strategy documents, including the Roadmap to Mental Health Reform and the National Health Reform Agreement.

Endnotes

ⁱ Human Rights and Equal Opportunities Commission, *Human rights and mental illness: report of the National Inquiry into the Human Rights of People with Mental Illness*, Canberra, 1993.

ⁱⁱ Mental Health Council of Australia (MHCA) and Carers Australia, *Carers of people with mental illness project report*, Canberra, 2000.

ⁱⁱⁱ MHCA, *Mental Health Carers Report 2010*, Canberra, 2010. Available at: <http://mhca.org.au/index.php/component/rsfiles/download?path=Publications/MHCA%20CarerSurv%20Layout%2015-11.pdf>

^{iv} MHCA, *Adversity to Advocacy: The Lives and Hopes of Mental Health Carers*, Canberra, 2009. Available at: <http://mhca.org.au/index.php/component/rsfiles/download?path=Publications/MHCA%20CEP%20webLR.pdf>

^v MHCA, *Consumer and carer experiences of stigma from mental health and other health professionals*, Canberra, 2011. Available at: <http://www.mhca.org.au/index.php/component/rsfiles/download?path=Publications/Consumer%20and%20Carer%20Experiences%20of%20Stigma%20from%20Mental%20Health%20and%20Other%20Health%20Professionals.pdf>

^{vi} National Mental Health Consumer and Carer Forum, *Privacy, Confidentiality and Information Sharing – Consumers, Carers and Clinicians*, Canberra, 2011. Available at: <http://www.nmhccf.org.au/documents/NMHCCF%20P&C%20ps%20&%20ip.pdf>

^{vii} Australian Government, *National standards for Mental Health Services*, Canberra, 2010.

Available at: <http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-n-servst10>

^{viii} S Tually et al, *Housing assistance, social inclusion and people living with a disability*, AHURI Final Report No.178, Canberra, 2011. Available at: <http://www.ahuri.edu.au/publications/p40585/>

^{ix} Australian Treasury, *Australia's Future Tax System*, Recommendations 102, 103 and 105, 2010. Available at: http://taxreview.treasury.gov.au/content/FinalReport.aspx?doc=html/Publications/Papers/Final_Report_Part_1/index.htm