NATIONAL MENTAL HEALTH
CONSUMER & CARER FORUM

MENTAL
HEALTH
COUNCIL OF
AUSTRALIA

Submission to the Australian Government discussion paper on the National Carer Strategy

January 2011

The National Mental Health Consumer and Carer Forum (NMHCCF) is the combined national voice for consumers and carers participating in the development of mental health policy and sector development in Australia. Its membership includes one consumer and one carer representative from each state and territory as well as one representative from each of a range of national consumer and carer peak organisations. Through its membership, the NMHCCF gives mental health consumers and carers the opportunity to meet, form partnerships and be involved in the development and implementation of mental health reform.

The Mental Health Council of Australia (MHCA) is the peak, national non-government organisation representing and promoting the interests of the Australian mental health sector, committed to achieving better mental health for all Australians. The membership of the MHCA includes national organisations of mental health service consumers, carers, special needs groups, clinical service providers, community and private mental health service providers, national research institutions and state/territory peak bodies. The MHCA also auspices the NMHCCF.

Both the NMHCCF and the MHCA have a strong interest in identifying and addressing issues affecting mental health carers. This submission is a joint response from the NMHCCF and the MHCA.

Mental health carers' issues

Mental health carers are family members or friends who provide care and emotional and practical support for a person with mental illness.

There are significant differences between mental health carers and other carers due to the episodic nature of mental illness, the behaviours that can be associated with mental illness, and the lack of community recovery based services and supports for people with mental illness. The mental health carer's role often becomes carer and case manager as well as friend, housemate and advocate for the person they care for.

The availability of appropriate accommodation for people with a mental illness has a significant impact on carers. In the Mental Health Carers Report 2010[1] over 60% of mental health carers reported that the person they cared for lived with them. Anecdotal evidence from carers indicates that in many cases this is due to a lack of appropriate accommodation alternatives. [2]

Mental health carers (and consumers) often feel alienated in the workplace, in social gatherings and in the community because of the stigma and discrimination around

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[1] Mental Health Council of Australia (2010). *Mental Health Carers Report 2010*. Canberra: MHCA.
[2] Mental Health Council of Australia (2009). *Adversity to Advocacy: The lives and hopes of mental health carers*. Canberra: MHCA.

mental illness. Many mental health carers do not identify themselves as carers to avoid social stigma and discrimination.[3]

Mental health professionals and community workers have varying levels of understanding about mental health carers' involvement in the lives of the people they care for. Mental health carers report that there is a lack respect for, and recognition of, their caring role and that clinicians, mental health professionals and others have been unwilling to listen to their concerns, frequently excluding carers from treatment planning.[4]

Caring for someone with a mental illness can have a significant financial impact. Carers who have access to Centrelink benefits (Carer Payment and/or Carer Allowance) have reported that the benefits are insufficient to cover the costs associated with caring for someone with a mental illness. There are a great number of mental health carers who report difficulties accessing Centrelink benefits. The questions on Centrelink application forms currently emphasise physical disability and are not applicable to caring for someone with a mental illness.[5]

People with other disabilities often have coexisting mental health problems, such as depression and anxiety. Given the high occurrence of mental illness across the disability sector, significant input from mental health carers and the broader mental health sector would improve the validity of the National Carer Strategy.

The National Carer Strategy discussion paper

The NMHCCF and the MHCA strongly support the development and implementation of a National Carer Strategy that delivers practical benefits to carers. The discussion paper is a significant start to this process. Broad comments about the paper are below.

The paper does not currently define the term "carer". We support the use of a nationally agreed definition, such as the one proposed in the Commonwealth's Carer Recognition Bill 2010. Noting that care is rarely provided by only one person, we suggest that the definition also include other family members, including young carers, and wider networks of friends.

The paper should also consider issues for specific groups. We particularly encourage discussion and actions in the Strategy about mental health carers, as their needs and issues are quite distinct from other carers.

We also encourage discussion in the Strategy about key issues for mental health carers such as lack of staff training and understanding of the effects of psychosocial disability, and systemic issues, for example, inappropriate procedures and forms from government agencies.

Accessing the discussion paper and consultation sessions

We have some concerns about carers' ability to access to the discussion paper and consultation sessions.

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[3] House of Representatives Standing Committee on Family, Community, Housing and Youth (2009). *Who Cares...? Report on the* inquiry into better support for carers. Canberra: The Parliament of the Commonwealth of Australia.

[4] Mental Health Council of Australia (2009). Op. cit.; Mental Health Council of Australia (2010). Op. cit.

[5] Mental Health Council of Australia (2009). Op. cit.

Carers with low incomes may not have internet access and rural and remote carers may only have dial up internet connections, which would have made it difficult for them to download the discussion paper.

Exclusively using Carers Australia to host carer consultation sessions would have limited the number of carers involved to those who belong to, or are in contact with, Carers Australia. The use of a consortium or a wider range of organisations would have provided a more complete picture.

We encourage future consideration of strategies for more accessible and inclusive consultations on the Strategy.

Actions following the discussion paper consultation

Carers comment regularly that while they are often consulted, very little comes of that consultation in terms of feedback or any real and discernible change to their circumstances.

To address this issue, the National Carer Strategy must be appropriately funded, with funding tied to Strategy goals and specific outcomes. The Strategy should be linked to a comprehensive implementation plan and accountability measures.

We suggest that there should also be a national publicity campaign that highlights the goals and actions of the Strategy and raises awareness about carers and caring and the services and supports available to carers.

Specific comments about the discussion paper goals and dot points

Goal 1 – Better recognition for carers

We suggest the goal be changed to "Goal 1 – Better recognition and inclusion of carers"

Suggested inclusions and changes to the dot points are noted below in italics.

Dot point 2: Carers being actively consulted and their needs*, and the needs of the person they care for,* be considered in the development and implementation of policies and services affecting them *and the person they care for*.

Dot point 3: Carers being recognised by health and community care professionals as being *an integral part of the care team*.

Dot point 4 (new): *All professionals involved with people with a mental illness (e.g. police, court officials, Centrelink workers, housing officials, school teachers) should receive education about mental health and carers.*

Goal 2 – Better support to help carers work

We suggest the goal be changed to "Goal 2 – Better support to help carers train and continue in education and work"

This change would make this goal more inclusive of carers who are under 18; it also encourages the support of carers in learning, training, education and work throughout their lifespan.

Dot point 1: Carers being supported to balance caring, *education, training* and work responsibilities at all stage of *the carer's life*.

Dot point 3 (new): *Revision of, or a separate form for, mental health carers to access Centrelink benefits.*

Dot point 4 (new): *Increase mental health awareness in workplaces and schools to reduce stigma and discrimination.*

Dot point 5 (new): *Provide appropriate accessible services for the person being cared for to enable carers' continued involvement in work and education.*

Also include Dot point 1 from Goal 4.

Goal 3 – Better information and support for carers

Include Dot point 2 from Goal 4.

Goal 4 – Better education and training for carers

We have suggested that dot points from this goal be included in Goal 2 and Goal 3, making this goal obsolete.

Goal 5 – Better health and wellbeing for carers

Dot point (new): *Review of Centrelink and tax laws to remove penalties applied to carers who provide independent accommodation support for the person they care for.*

Goal (new) – Individual service and system wide accountability

Dot point 1 – *Improved data collection and research on carers' needs to support service improvement and development.*

Dot point 2 – *Individual service and service wide independent accountability systems in place to inform policy, procedures and service provision.*

Data collection

In terms of data collection for analysis of responses (**Other Information** section in the discussion paper), we suggest that location data be standardised in future to allow comparison with other collections of carer data.

Instead of using the self description choices of "metro / rural / regional / remote" we encourage you to consider using the ABS Accessibility Remoteness Index of Australia Plus (ARIA+) to clearly define the locations of carers, as identified by their postcodes. ARIA+ is a commonly used, nationally consistent measure of geographic remoteness.[6]

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[6] Information about ARIA+ can be found at: http://www.abs.gov.au/websitedbs/D3310114.nsf/home/remoteness+structure

The NMHCCF and MHCA are pleased to have contributed to this important consultation and we encourage the Departments of Health and Ageing and Families, Housing, Community Services and Indigenous Affairs to further engage with the mental health sector during the Strategy's development.

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