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6 December 2010

Dear Katie

**Re: Invitation to review factsheet(s) that support the NSW Health Framework for Promotion of Mental Health and Prevention of Mental Ill-Health**

Carers NSW welcomes the opportunity to provide feedback on the factsheet 'Family and carers of people with mental illness.'

**About Carers NSW**

Carers NSW is the peak organisation for carers in NSW. It is a member of the national Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- Be the voice for carers in NSW
- Undertake research, policy development and advocacy
- Provide carer services and programs
- Provide education and training for carers and services providers
- Build capacity in the sector.

Carers NSW vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments.

The goal of all of the work Carers NSW undertakes is for carers in NSW to have improved opportunities and access to services that meet their needs regardless of their age, gender, circumstances, location or cultural and linguistic backgrounds.

**Who Carers NSW represents**

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful.

Across NSW there is an estimated 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

## **Feedback on Fact Sheet 2: Family and carers of people with mental illness**

Carers NSW is pleased to see the progression of the *NSW Health Framework for Promotion of Mental Health and Prevention of Mental Ill-Health*, particularly the elements relating to the family and carers of people with mental illness. As stated in our feedback to the draft Framework, it is gratifying to see the inclusion of carers in the Framework as a target group.

Carers NSW will provide responses to some of the questions provided in the feedback form.

### **1. Is the explanation of the status and main findings of the evidence base accurate?**

**If not, could you please highlight the main areas of disparity or refer us to additional literature that would provide a broader review. Is there additional material which should be referred to?**

Whilst the status and main findings of the evidence base are accurate, the factsheet is silent on some of the most significant issues and frustrations experienced by carers of people with mental illness.

Carers NSW recommends that the findings of *Adversity to Advocacy: The Lives and Hopes of Mental Health Carers*<sup>i</sup> be included in the factsheet. *Adversity to Advocacy* reports on the first ever national survey of carers of people with mental illness in Australia, conducted in 2009 with over 1500 participants. It provides an invaluable and comprehensive insight into the needs and experiences of carers of people with mental illness in Australia, which would assist mental health services staff to better understand the nature and impact of caring for somebody with a mental illness, and why these carers are at risk of poor mental health.

*Adversity to Advocacy* identifies 15 key issues faced by carers, many of which relate to the way in which mental health services are provided. While the initiatives, interventions and partnerships which are listed in the factsheet are certainly worthwhile, carers would also be much better supported, and enjoy better mental health, if mental health services staff were aware of and addressed the issues listed in this report. Examples of the needs identified include: listen to and respect carers, integrated recovery-based care for the consumer, more and better trained staff at all levels, knowledge and information for carers, carer and consumer education for all professional groups and agencies, support systems, services and processes established for carers, stigma, discrimination and isolation for carers and consumers.

The *Mental Health Carers Survey 2010*,<sup>ii</sup> also released by the Mental Health Council of Australia, provides further confirmation of the findings of *Adversity to Advocacy*, and should also be referenced in the fact sheet.

Many carers of people with mental illness have had repeated negative experiences with mental health services and with mental health staff, have been excluded from treatment, have not received help when they have asked, and have had to step in when mental health services have let their loved one down. It is important that mental health staff are aware of and have empathy with these experiences, and with this history of neglect. If staff and management have greater empathy with and understanding of carers, the gulf that persists between mental health policy and practice may be bridged.

**2. Are there any other relevant readings that cover the main issues discussed in the factsheet, or which would provide additional information for those interested in a broader understanding?**

Carers NSW recommends that references be provided to additional information from the following sources, which provide significant and comprehensive information about the experience of caring in the Australian and New South Wales context. For example:

- Groom G, Hickie I & Davenport T, *Out of Hospital, Out of Mind! A report detailing mental health services in Australia in 2002 and community priorities for national mental health policy for 2003-2008*, Canberra, 2003
- 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
- Mental Health Council of Australia, *Not For Service: Experiences of Injustice and Despair in Mental Health Care in Australia*, Canberra, 2005
- Mental Health Council of Australia, *Mental Health Carers Survey 2010*, Canberra, 2010
- NSW Legislative Council Select Committee on Mental Health, *Final Report Mental Health Services In New South Wales*, 2002
- NSW Mental Health Sentinel Events Review Committee, *Tracking Tragedy*, Fourth Report of the Committee, Sydney, 2008.
- Standing Committee on Family, Community, Housing and Youth, *Who Cares ...? Report on the Inquiry into better support for carers*, Canberra, 2009.

The NSW Mental Health Act 2007 and its provisions for carers should also be included as additional information, or within the factsheet. Although this legislation has been in place for several years, carers still report low levels of understanding and compliance by mental health services.

## **Conclusion**

Carers NSW is pleased to provide feedback on this factsheet. If you would like more information about our response, please contact Alison Parkinson on 02 9280 4744 or [alisonp@carersnsw.asn.au](mailto:alisonp@carersnsw.asn.au).

Yours sincerely,



Elena Katrakis  
CEO  
Carers NSW

## **Endnotes**

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<sup>i</sup> Mental Health Council of Australia, *Adversity to Advocacy: The Lives and Hopes of Mental Health Carers*, Canberra, 2009.

<sup>ii</sup> Mental Health Council of Australia, *Mental Health Carers Survey 2010*, Canberra, 2010.