

Unit 2, 11 McKay Lane Turner, 2612
<a href="mailto:ceo@carersaustralia.com.au">ceo@carersaustralia.com.au</a>
P 02 6122 9901
<a href="mailto:www.carersaustralia.com.au">www.carersaustralia.com.au</a>

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The Australian Commission on Safety and Quality in Health Care

Via email: mentalhealth@safetyandquality.gov.au

To whom it may concern

## RE: Draft National Safety and Quality Health Service (NSQHS) Standards user guide for acute and community mental health services.

Carers Australia welcomes the opportunity to comment on the draft NSQHS Standards 'user guide for acute and community mental health services' (Guide). Broadly, we agree that each element of the continuum of care is important to the needs of the community when responding to mental illness. We support the need to have relevant systems in place to ensure expected standards of safety and quality are met, irrespective of whether the service is a local health network specialist community mental health service or an acute psychiatric intensive care unit.

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged. In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Carers Australia welcomes the inclusion of carers as a 'spotlight issue' by the Australian Commission on Safety and Quality in Health Care (ACSQHC). It is clear the voice of carers has been incorporated in development of the Guide, as well as recognising the diversity among carers of people with mental illness. It is also welcome to see that the Guide includes a clear definition of who a 'carer' is that is separate from 'family or friends' and that the definition aligns with the *Carer Recognition Act 2010*<sup>1</sup> (Commonwealth).

Carers Australia are strong advocates for carer inclusion in services delivered to people they care for — whether these be clinical services or other types of support services. This is at the heart of the concept of "partners in care" which is a central principle of the *Carer Recognition Act*, and it is with this in mind that Carers Australia request the following information to be included in the Guide, to support improvement in the safety and quality of mental health services.

As is the case for all carers, care is often provided at considerable cost to their own wellbeing, including their own health, financial security and opportunities to pursue education, employment and interests. However, carers of people with a mental illness often don't have the same visibility as carers of people in other circumstances, and this can be an additional obstacle to accessing recognition and support. While the Guide states that "Carers may have their own needs, and mental health services should ensure they are linked with support" (p.43) it is also essential to emphasise that carers may also be a consumer of mental health services and consumers of mental health services may also have care responsibilities. All consumers need to be asked about their care responsibilities, and how this impacts on their mental health.

<sup>&</sup>lt;sup>1</sup> Australian Government, *Carer Recognition Act 2010*, No.123,2010 [accessed online]



While the Guide acknowledges that "carers also have extensive knowledge of treatment effectiveness and the operation of mental health systems, developed from lived experience of another's illness, can benefit the service and the consumer" (p.43), there is lack of clarity as to whether the 'peer workforce' and mentoring programs and opportunities relate to both consumers and carers. Carers Australia request that the carers lived experience as a 'peer' is made clearer in the Guide, and a definition of 'peer worker' be included. As an example, the following definition is used by Primary Health Networks, with the document referenced also containing a number of useful resources:

"In this document, any reference to the mental health peer workforce or peer workers refers to both consumer peer workers and carer peer workers. Consumer peer workers apply their personal lived experience of mental illness and recovery in supporting consumers. Carer peer workers apply their experience from caring and supporting family or friends with mental illness in supporting other carers and family members<sup>2</sup>."

There are approximately 235,000 'young carers' aged 11-25 years in Australia. All young carers are at increased risk of mental health issues, regardless of whether the person they are caring for has a mental illness or another care requirement. Many young carers report that due to their care responsibilities they experience lack of sleep, ongoing stress and mental health issues which then affects their engagement with school or education. They also experience a restriction in achieving their potential, or ability to build a sense of belonging, and are unable to socialise with friends or participate in extracurricular activities<sup>3</sup>. Young carers face a particular lack of recognition of their caring role and its impact and are often not being identified by services. Given that about 12% of mental health carers in Australia are aged between 15 and 25 years.4 Carers Australia request the Guide is reviewed for where young carers can be incorporated and supported through the Standards.

A distressed or exhausted carer is not well-placed to support the person they are caring for. Often carers have their own care needs - they may be in multiple care relationships and be balancing their caring role with employment and/or education commitments. Due to the fluctuating nature of mental illness, mental health carers manage a high level of unpredictability in their caring role in addition to a high level of emotional support, planning and behaviour management. For this reason, respite services are critical to many carers' own health and wellbeing. In many cases access to respite can mean the difference between a carer being able to provide care and support or having no alternative but to seek other accommodation options; cease employment; or risk further strain on the carer and wider family. The Guide does not mention respite. Because of the importance and need for increased availability of respite within acute and community mental health services, it is requested that the Guide be reviewed for where specific reference to respite could occur, including in the Standards.

Awareness of, investment in, and increasing access to appropriate community-based respite care for mental health carers is a critical gap within the recommendations. Carers Australia note the cessation of funding for previous programs such as Mental Health Carer Respite Services, the difficulty accessing respite through the Carer Gateway, and very limited access to carer respite via the NDIS for people with a mental illness. Carers Australia recently welcomed the House of Representatives Select Committee on

<sup>&</sup>lt;sup>2</sup> Australian Government, Department of Health, 'Peer workforce role in mental health and suicide prevention' [accessed online]

<sup>&</sup>lt;sup>3</sup> 'No space in my brain to learn - Young carers and their engagement with education: an analysis of applications to the Carers Australia bursary program 2017-2018'. University of South Australia for Carers Australia [accessed online]

<sup>4</sup> Australian Government, Productivity Commission, 'Mental Health Inquiry Final Report' 2020 (p.257, Volume 2) [accessed online]



Mental Health and Suicide Prevention recommendation to implement a fit-for-purpose respite care program that is flexible and includes access to educational components, counselling services and other supports to boost resilience.<sup>5</sup>

In relation to resources targeted to specific groups, we request inclusion of the Carers Australia website; Young Carers Network; and the Australian Government's Carer Gateway. The Carers Australia website can provide carers with access to a range of information and linkages to support the caring role broadly, including the National Carer Network. The Young Carers Network<sup>6</sup> is a nationally coordinated resource to raise young carer awareness, provide information, and direct young carers to appropriate pathways for support. The Carer Gateway enables carers to access a range of tailored supports and services to help them manage their daily challenges, reduce stress and plan for the future. The services focus on providing carers with access to early-intervention, preventative and skill building supports, to improve well-being and long-term outcomes<sup>7</sup>.

Carers Australia support the addition of the issues identified by the ACSQHC for inclusion in the Guide:

- That mental health services should have clear documented policies on accepted legislative and national policy commitments, such as the rights of carers, both when the consumer wishes their involvement and when they don't, and supporting the self-determination and autonomy of consumers and carers;
- To protect consumers and carers from abuse and exploitation, and actively encourage consumers and carers to report potential or actual risks- as well as support patients, carers and families to communicate concerns or incidents;
- To use validated survey instruments such as the Carer's Experience of Care Survey and support active engagement of consumers and carers in care planning meetings;
- To include recording of carer's contact details, noting that the nominated carer may not be the person's next of kin, within healthcare record; and
- Having processes in place for carers to directly escalate care when they are concerned about deterioration in a person's mental state.

We are looking forward to engaging more with the ACQSHC in work towards a safe, high-quality and sustainable health system.

**Yours Sincerely** 

Liz Callaghan

Chief Executive Officer

<sup>&</sup>lt;sup>5</sup> Parliament of the Commonwealth of Australia, House of Representatives Select Committee on Mental Health and Suicide Prevention 'Mental Health and Suicide Prevention - Final Report' [accessed online]

<sup>&</sup>lt;sup>6</sup> Young Carers Network [accessed online]

<sup>&</sup>lt;sup>7</sup> Australian Government, Carer Gateway [accessed online]