



Mental Health Fifth Plan - Feedback – Carers Tasmania

Purpose:

Carers Tasmania is grateful to be given the opportunity to provide carer-focused feedback on the draft Fifth National Mental Health Plan (the Plan) to the Department of Health. Carers Tasmania is the only organisation completely dedicated to supporting the needs and representing the views of Carers throughout Tasmania.

Introduction/ Summary:

Carers Tasmania believes that the draft shows a commitment to supporting consumers and carers but that it could give more explicit information regarding how this commitment will translate into actions. A plan, as opposed to a strategy, will ordinarily provide “next level detail” particularly around responsibilities and timing. Whilst it is acknowledged that there may need to be budget considerations and submissions for implementation of the Plan, at a time of distinct uncertainty for the social services sector, further detail in this Plan might be warranted.

Carers Tasmania in general feels that the Plan needs to:

- Actively promote access mental health care, in particular to those who experience barriers to mental health services, including consumers and carers from culturally and linguistically diverse backgrounds and people who identify as LGBTI.
- Ensure a co-ordinated approach for those who will not be eligible for NDIS and their carers.

Feedback:

Carers Tasmania is pleased to see the plan acknowledge the need for consumers and carers to be at the centre of the way in which services are planned and delivered, but it is important that the plan acknowledges that the needs of consumers and carers are often quite different, and that they are addressed separately.

The separate needs of carers are often discussed in Carers Tasmania’s Mental Health Carers Reference Group.

Carers often note they understand and respect that the person they care for is entitled to privacy and confidentiality, and they want them to be empowered and in control of their own recovery. However, as people often intensely involved in the lives of those they care for, carers hold a wealth of information that is useful to clinicians. This could be the degree of symptoms or side effects they are experiencing, or how the person is faring in their every day lives. Carers report that the consumer often doesn’t share this information with their

clinician due to fear of what might happen if they do, issues of trust, or of a lack of continuity of case managers, and the challenge of therefore building rapport. Carers often indicate they would like to have input so that the knowledge they hold can be considered in treatment. Given carers are likely to be involved in supporting the consumer long after they have left the hospital setting, and between appointments in the community this also seems a sensible approach.

While the person with the mental illness may be quite accepting of the degree of care they receive from services, and are not comfortable to advocate for their own needs, a carer will often passionately push for the needs of the person they care for to be met.

However, and further to this, the carer has their own need for information, advice and support in their role alongside the person they care for.

The Carer Recognition Act 2010 is Commonwealth legislation which aims to increase recognition and awareness of the roles carers play in providing daily care and support to people with disability, medical conditions, mental illness or who are frail aged.¹ The Act includes the following principles which directly apply to this plan:

- Carers should be acknowledged as individuals with their own needs within and beyond the caring role;
- The relationship between carers and the persons for whom they care should be recognised and respected;
- Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

The development of the Mental Health Plan should take account of the above points enshrined in law.

It is also interesting to note that the significant lost productivity due to lost capacity to participate in the workforce referred to in the Plan, is often doubled, when a carer is unable to work, or reduces their hours in supporting the person they care for. Therefore supporting the consumer and the carer both individually and as a team could result in great economic benefits to the community.

Priority Area 1:

The Plan could extend the concepts of integrated care to involve carer inclusion, and draw on work that has already occurred to ensure that carer recognition is incorporated into the plan in an explicit way.

¹ Carer Recognition Act <https://www.legislation.gov.au>

The Practical Guide for Working with Carers of People with a Mental Illness is an example of such work.² It was developed by Minds Australia and Helping Minds in 2016 and states that “recovery orientated practice and service delivery recognises the unique role of personal and family relationships in promoting wellbeing, providing care, and fostering recovery across the life span, and recognises the needs of families and support givers themselves”. This suggests that carers play a significant role in the recovery of a person with a mental illness, and as such, the Plan need to reflect this.

While there is a distinct need to consider and respect the privacy of the individual, there are times when a person with a mental illness lacks capacity to make decisions about the involvement of their family in their care. Carers have reported to Carers Tasmania that there is often no opportunity for this to be discussed when the consumer is well, as at that time, they have limited contact with clinicians, and often their file is closed. If the Plan began from a position of the inclusion of carers as its default position, carers could be more routinely involved.

Such models of carer inclusion have been developed and implemented in other parts of the world. The ‘Triangle of Care’ originally developed by the UK Carers Trust is one example.³ This model was designed for inpatient services and has now been revised to meet the needs of all mental health services. Over 50 mental health providers in England are now involved in the project, and it has now been included as a clear action in ‘Closing the Gap 2014’, the government’s mental health action plan.

An integrated approach as mentioned in Priority Area one, could also acknowledge the impact of caring for someone with a mental illness and offer support to the carer in their own right. A 2007 study completed by Sane Australia found that 56% of people caring for a person with a mental illness reported that their physical and mental health had suffered as a result of their caring role.⁴ Sane Australia also found “the majority of families struggle alone without help from any carer support organisation, and that an even greater proportion – almost three quarters have never received any education or training on how to care for someone affected by mental illness. Based on this it is clear that a great deal more needs to be provide to Carers for them to be really integrated included in they way they need to be”.

A further area for inclusion in priority area could be further development of the peer work force in mental health services (both consumer and carers) as this seems a very logical step in the integration of consumers and carers into the mental health system, and a logical step in changing culture and creating a sense of inclusion.

² Mind Australia and Helping Minds (2016) A Practical Guide For Working With Carers of People With a Mental Illness

³ Worthington, A., Rooney, P., Hannan, R. (2013)The Triangle of Care - Carers Included: A Guide to Best Practice in Mental Health Carer in England Second Edition

⁴ Sane Australia (2007) Family carers and mental illness

Priority Area 2:

Carers usually have the main responsibility for care when service providers are not there. The degree of responsibility and work and the consequences for them is not to be underestimated. Creating a sustainable service system would therefore involve carers in decision making and treatment, ensure they are informed and skilled in the support they provide, respect their needs and experience, their knowledge of the needs of the person they care for, and provide support to them as carer and family member.

A number of carers from Carers Tasmania's Mental Health Carers Reference Group describe caring for people who are very unwell, have challenging behaviour and are very difficult to engage with. Often the person has no other supports than the family member in place, and this relationship is strained, with the carer feeling overwhelmed and sometimes scared. These carers have often expressed the wish for there to be services available that had a model of more assertive follow up, and acceptance of the complexity of the person, including their challenging behaviour, as they currently describe the person they care for as "falling through the cracks", and say that negotiating "the system" is impossible or so difficult that they would prefer to try and manage the situation themselves, or simply accept that the situation is out of their control. This group of carers are under enormous strain, and more than anything, need a service that meets their needs. Often this group of carers decline the offer of counselling from Carers Tasmania as they feel that it will not change the very real fact that the person they care for is not getting the treatment they need, and this is their reality. Feedback from one carer who reviewed the plan was that there needs to be support provided to this group of people, citing the fact that more than 40% of people in Australian prisons have had a mental health disorder at some time, over 30% have been referred to prison mental health services, and almost 20% were taking medication for a mental health related condition at the time they entered prison.⁵

Carers also often feel disillusioned by the gap between what Government commits to doing, and their every day experience.

Priority Area 3:

It is noted that Carers and family members require support and follow up following a suicide attempt, along side the person who has made the attempt. This should be included as a consideration in the Plan. Of course, support is also critical for the carer if an attempt at suicide is successful because exposure to suicide is a risk factor for subsequent suicide as stated in the Plan.

It is highly possible that the carer has been the first person to notice signs that the person was at risk of suicide. They often find themselves on "suicide watch," and describe having

⁵ Australian Institute of Health and Welfare (2009) *The health of Australia's prisoners*

to forgo their responsibilities to themselves, and the people around them to keep the person/s they care for alive when services are out of reach or unavailable.

As a result of this and the natural feelings involved in having someone close to you have a suicide attempt, the carer will have their own experience and response to the attempt and their own need for support.

Given the impact of caring on the wellbeing of Carers it must be also noted that Carers are often an at risk group in their own right. For example in recent QLD research, 26% of Carers with of a person with Dementia had contemplated suicide more than once in the previous year and 30% said that they were likely to attempt suicide in the future⁶. It would make sense in terms of early intervention, a key focus of the Plan, that increasing the support to carers would also reduce the incidence of mental health within this large demographic. Ensuring that Carers are supporting along side the person living with mental illness, is therefore critical. It should also be noted that there are many circumstances where two consumers provide support and care for each other, and are therefore in both carer and consumer roles. When this occurs there is a need for the caring role to be acknowledged and support provided alongside routine mental health support.

Priority Area 4:

Culturally competent care for the Aboriginal and Torres Strait Islander community requires acknowledgement of the carer, as the need to include ‘family’ and significant-others is enshrined in cultural expectations. Aboriginal peoples and Torres Strait Islanders are more likely to be carers. 12.4% of the Aboriginal and Torres Strait Islander population are carers, compared to 10.5 % of the non – Indigenous population.⁷ It must also be noted that there is likely to be an under reporting of the caring role amongst aboriginal community. SDAC also acknowledges that carers from the Aboriginal community are more likely to be younger, are more likely to be women, and to need assistance for their own care needs. Therefore there is a great need to support family carers from Indigenous communities.

Priority Area 5:

The incidence of physical illness in those people with a mental illness increases the complexity of the burden on the carer of someone with a mental illness.⁸ People with a persistent mental illness can sometimes suffer delayed diagnosis, non existence or inadequate preventative screening and deferred commencement of treatment of many avoidable disorders and treatment. Part of this issue may be that a person with a mental illness does not always have awareness or capacity to follow up or advocate for their physical health needs. Based on this, if there is a family member involved, it is again

⁶ Dementia Collaborative Research Centre – Carers and Consumers and Griffith University (2013) Suicidal Ideation in family carers of people with dementia: a pilot study

⁷ Australian Bureau of Statistics (2009) Ageing and Carers, Australia: Summary of Findings

⁸ National Mental Health Consumer and Carer Forum (2016) Physical Health Impacts of Mental Illness and its Treatments

imperative that they be involved in treatment and decisions, as a holder of very important information.

Priority Area 6:

Family members of someone with a mental illness also experience stigma, and often speak about feeling that their peers, colleagues, friends and even their extended families do not understand and are unable to therefore provide adequate emotional support and understanding. They speak of the loss of friends and family, who they think feel unable to deal with the complex issues they are experiencing. Carers also describe feeling labelled and responded to as difficult or over involved parents if they take on the role of advocating on behalf of the person they care for. The carer may also be unwilling to access services, in conjunction with or for the consumer, or even identify themselves as a carer due to being worried that they and the person they care for may be a target of discrimination. The Plan therefore needs to reflect the impact of stigma too, not just on the recipient, but also the carer.

Priority Area 6:

Privacy and consent are major issues for carers providing care for their family member or friend in the community. While a person may not have capacity to give consent to a carer, there may be issues of safety and risk for either or both the person with the mental illness and their carer, and this information is therefore imperative for treatment and prevention of risk.

It is interesting to see that government wishes to develop additional performance measures in response to consumer, carer and community priorities, and more information regarding these would be beneficial.

Conclusion:

The latest edition of *What Makes Us Happy*, the report on the Australian Unity Wellbeing Index, has re-iterated previous disturbing findings that carers have the lowest wellbeing of any group, including the unemployed and homeless.⁹

We can speculate that with adequate support for those with a mental illness across all areas of their lives, recognition of carers and their role and needs as separate from the person they care for, adequate support for the carer themselves, and their inclusion as partners in care, we may see this wellbeing improve.

The inclusion of carers as a separate group within the Fifth National Mental Health Plan, with explicit actions based on their needs, are some steps that could be taken in this direction.

⁹ Cummins, R. (2015) *What Makes Us Happy*: Third Edition, Australian Unity.