



Assessment, identification and response to mental health carers and families

Background

Mental Health carers and families¹ play a major role in providing support and care to people with mental illness. Their caring role is critical to client support and recovery, with an estimated (2015) 240,000 Australians providing informal care to an adult with mental illness. Of these 54,000 were primary carers (1).

However, despite this significant contribution too frequently carers are not respected, acknowledged or included in a variety of health, mental health and other service settings. This is despite the introduction of the Victorian Carers Recognition Act 2012 (2) which was created with the objective to officially recognise care relationships and the role of carers in our community.

Carers legislation is not consistently enacted

The Victorian Carers Recognition Act 2012 complements the Commonwealth Carer Recognition Act 2010 (3) and includes a set of principles regarding the import of care relationships, as well as stipulates obligations for state government agencies, local councils, and other organisations that interact with people in care relationships. These principles apply to any work with people (including those under 18 years of age) who are providing informal unpaid care to an older person/s, a person/s with a disability, a mental illness or an ongoing medical condition.

Mental health interventions that lack acknowledgement of families or don't include them as part of therapeutic and recovery processes can have significant consequences on the effectiveness of treatment and support outcomes for individuals, children/young people and adults. Many current clinical interventions do not place a high enough value on family/carer involvement, focussing primarily on the individual client or service user. This in turn can isolate or remove clients from their natural, safe or preferred social supports while impeding their

recovery and increasing their shame, stigma and fear.

Interventions focused only on individuals frequently miss critical opportunities to strengthen supportive and caring relationships. Limiting understanding to individual outcomes prevents a wider exploration of the effects (both positive or negative) of mental illness on families (4) and how families can support recovery that occurs in-between counselling rooms and hospital wards.

From an ethical standpoint, family/carer-centred models must consider family/carer resources, competing demands, and should protect people from caring responsibilities which negatively impact or overwhelm them. Issues to consider regarding family/carer involvement in supporting loved ones are; loss of economic participation in other livelihood activities, interference with domestic duties, secondary stigmatisation and the loss of a family or carer's social supports/connection.

Carers also need their own emotional and mental health support. For example, an

¹ The use of the terms 'family/families' throughout this document refers to biological families *and* 'families of choice'.

estimated 56% of carers experience (at minimum) moderate depression, and one fifth experience severe depression in addition to high levels of anxiety, psychological distress as well as lower perceptions of self-worth and personal well-being overall ⁽⁵⁾. Stigma for carers in mental health settings, negative or dismissive perceptions of their caring role, as well as guilt or shame can also hinder their own help-seeking.

Increasing supports to mental health carers

Recent submissions to the Royal Commission into Victoria's Mental Health System have outlined the many negative experiences of families and carers within clinical settings and a lack of inclusion ⁽⁶⁾. The application of Standards of Practice when working with families of people with a mental illness has also been well articulated ⁽⁷⁾.

Interventions aimed at increasing family/carer knowledge and capabilities are noted to be among the most helpful and effective. These include interventions that reduce feelings of 'burden', distress, and provide psychological/emotional support; or those which increase coping/crisis management skills, improve quality of life and raise self-esteem ⁽⁸⁾. When offered early, these types of interventions help both carers and those receiving care to improve the quality of their relationships, overall family functioning and promote recovery from symptoms of poor mental health.

Data collection on carer service use is vital

drummond street/queerspace believes mental health system data collection capability needs to reflect the complex circumstances of consumers. This can build the knowledge needed to apply best whole of family and carer practice models.

Standardised, shared data collection tools, which do not only identify carers in relationship to service users they support, but rather also recognise carers as service users, will build better understandings of how to support them. drummond street/queerspace concur with Carers Victoria's position on the need to create 'an ecosystem of carer identification' and assessment; and, to expand service scope to 'enable better care for carers' and client's families ⁽⁹⁾.

Adequate services for carers supports their mental health and wellbeing

Mental health consumers may also have their own care responsibilities, including for people with complex needs or comorbidities (such as an intellectual disability or chronic physical illness alongside a mental illness). Consumers should be routinely screened at mental health services to determine any care responsibilities (at intake, assessment, review and discharge).

We refer to Carers Victoria's submission to the Royal Commission into Victoria's Mental Health System and support the following two recommendations:

That Government provide "access to carer needs assessment within mental health services and/or screening to identify and refer carers to appropriate carer support services.

That Government provide "access to evidence-based early intervention programs for carers starting out in the carer role to mitigate some of the negative mental health impacts of caring" ⁽¹⁰⁾.

Likewise, drummond street/queerspace refer to Tandem's recommendations to the same Royal Commission demanding Government invest in "services that support family with the maintenance of their own emotional and physical wellbeing. These include respite, peer support, psychosocial education, assessment, planning and direct service to assist carers in identifying their own support needs, particularly mutual support and self-help services" ⁽¹¹⁾.

Finally, drummond street/queerspace note Priority 5 of the Victorian Carers Strategy, that Carers should be 'recognised, acknowledged and respected' and that diverse carers such as Aboriginal, culturally diverse, LGBTI, older and younger carers should be identified and targeted in community campaigns. We would like to see better understandings of how to prevent and intervene early so as to minimise poor carer/family outcomes and respond to the high rates of unsupported care relationships in these communities.



Recommendation for Early Intervention and Response: Victorian Government improve access to mental health and wellbeing services, and family/carer supports as per the recommendations identified in this paper by Carers Victoria and Tandem in their submissions to the Royal Commission inquiry into Victoria's Mental Health System.

Recommendation for Early Intervention and Response: Victorian Government include carer targets and measures as part of the Victorian Public Health and Wellbeing Plan Outcomes Framework and complementary targets and initiatives across a range of health and human services.

Recommendation for Prevention: As part of the Victorian Government response to Priority 5 of the Victorian Carers Strategy, 'Carers are recognised, acknowledged and respected' Government support further research which explores carer/family needs and the unique risks to the wellbeing of marginalised carer cohorts as well as the most effective service responses for these cohorts.

1 Diminic, S., Hielscher, E., Lee, Y., Harris, M., Schess, J., Kealton, J. and Whiteford, H. 2017, The Economic Value of Informal Mental Health Caring in Australia: Summary Report, Mind Australia, Melbourne (p. xiii).

2 Carer Recognition Act 2010, No. 123, 2010, An Act to provide for the recognition of carers, and for related purposes

3 Carers Recognition Act 2012, No. 10 of 2012

4 Ladson Hinton, Brandon A Kohrt, Arthur Kleinman, Department of Psychiatry and Behavioural Sciences, University of California Davis, 2230 Stockton Blvd, Sacramento, CA, USA (LH); Department of Psychiatry and Behavioural Sciences, George Washington University, Washington, DC, USA (BAK); and Department of Global Health & Social Medicine, Harvard Medical School, Boston, MA, USA (AK) (p.366).

5 Carers Victoria (2019) 'Initial Submission Royal Commission into Victoria's Mental Health System July 2019', Melbourne, p. 4

6 Tandem (2019) Royal Commission into Victoria's Mental Health System p. 12

7 Standards of practice for the adult mental health workforce: Meeting the needs of families where a parent has a mental illness Melinda Goodyear, 1, 2 Terri-Lee Hill, 3 Becca Allchin, 4 Francis McCormick, 5 Rochelle Hine, 6 Rose Cuff 2 and Brendan O'Hanlon 2 1 School of Rural Health, Monash University, Moe, 2 The Bouverie Centre, La Trobe University, 3 Latrobe Regional Hospital Mental Health Services, Traralgon, 4 Eastern Health Adult Mental Health Program, Melbourne, 5 Psychiatric Services, Bendigo Health, Bendigo, 6 Mental Health Services, Southwest Healthcare, Warrnambool, Victoria, Australia

8 Schumacher, K., Beck, C. A., & Marren, J. M, 2006, FAMILY CAREGIVERS: caring for older adults, working with their families. AJN The American Journal of Nursing, 106(8), 40-49

9 Issues paper Recognising Carers as Service Users in Mental Health Data, 2018, Carers Victoria, Melbourne Australia

10 Carers Victoria (2019) 'Initial Submission Royal Commission into Victoria's Mental Health System July 2019', Melbourne, p. 5

11 Tandem (2019) Royal Commission into Victoria's Mental Health System p. 12