Carers Australia VIC

Issues paper

Recognising Carers as Service Users in Mental Health Data

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

About Carers Victoria

ABOUT CARERS VICTORIA

Carers Victoria is the state-wide peak organisation representing people who provide care. We represent more than 736,600 family carers across Victoria – people caring for someone with a disability, mental illness, chronic health issue or an age-related condition.

People receiving care could be a parent, child, spouse/partner, grandparent, other relative or friend. Carers Victoria is a member of the National Network of Carers Associations, and the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership based organisation. Our members are primarily family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

This submission was prepared by Carers Victoria’s Policy Team.

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Executive Summary

This paper elaborates on some ways to improve identification of carer needs and inform responses to those needs. The mechanisms identified in this paper to achieve this address some gaps in mental health service user experience data, outcome data, and service user documentation.

Carers Victoria believes addressing the needs of carers as mental health service users is vital, yet currently data does not capture the full breadth of carer needs and circumstances.

Carers Victoria knows carers have poorer health and wellbeing outcomes in a range of life domains. The mental health outcomes of carers are significantly lower than those of non-carers. Recent data indicates a quarter of all Australian carers experience high or very high levels of distress, indicating a likely mental disorder [1], [2], [3].

This paper identifies recommendations to improve the Carer Experience Survey (CES), the Your Experience of Service (YES) survey and other complementary service user measures and methodologies which could be adjusted to improve existing data on mental health service users.

Outcomes Carers Victoria would like to see are:

- Better recognition of carer mental health needs at a service provision level

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1 Australian Bureau of Statistics (Australian Bureau of Statistics (2012), Table 4.1 Level of psychological distress, Australian Health Survey Australia - First Results 2011-12, Canberra 2013) 2012 Survey of Disability, Ageing and Carers Australia, Cat. No. 4430.0

2Carers NSW, 2012, Biennial Carer Survey

3 Australian Bureau of Statistics (2017) Survey of Disability Ageing and Carers, Australia, 2015, Catalogue no. 4430.0, Table Builder

- Quality data on the mental health needs and outcomes of carers as service users, as well as their service experiences being captured at more points along their mental health service journey.

Carers Victoria services

Carers Victoria has 25 years’ experience providing information, referrals and education to carers across Victoria and over 15 years’ specialist expertise delivering carer counselling to individuals and groups in metropolitan, regional and rural communities.

Carers Victoria’s counselling program provides over 4,000 counselling sessions State-wide per year via face-to-face as well as by phone and video as required. Data is collected within Carers Victoria’ s regional, aged, disability and mental health programs using a Carer Wellbeing Index.

Carers Victoria’s psycho-educational and therapeutic carer support programs raise vital awareness among carer cohorts of the impacts of unsupported care roles on their health and wellbeing; and assist carers develop strategies for self-care, crisis prevention and connect them to important supports and services.

Carers Victoria’s mental health and counselling approaches and modalities were highlighted at the Carers’ Victoria inaugural National Carer Counselling Conference in 2017, which brought together counsellors, psychotherapists, health and mental health nurses and staff, and carer service providers with an interest in carer counselling and carer mental health.

Capturing carer experience and outcome data in mental health services

Carers Victoria believes carer/consumer dichotomies are useful when referring people to carer specific services; however, such dichotomies are limiting if they narrowly define perceptions of health, aged care, disability service and mental health consumers. Carers Victoria advocates for a shift in the way services identify and respond to carers when they present at key service entry points for support for themselves or the person they care for. Carers Victoria believes capturing care responsibilities and care relationships of all service users is fundamental to recognising the impacts of unsupported care relationships; and complementary to the goals of the Victorian Carer Recognition Act (2012).

Carers Victoria notes recent work undertaken by the Victorian government to incorporate results from the 'Your Experience of Service' (YES) survey into practical mental health service improvements. Results from this survey have informed 2016-2017 Victorian Mental Health Annual report data on clinical mental health services including inpatient and community services, with a total of 2,170 surveys completed in 2017. The YES survey captures information about service user experiences of care, including care planning and how services support people's ability to manage their day-to-day lives [4].

The Fifth National Mental Health Plan identified the YES to measure consumer mental health service experience, the Carer Experience Survey (CES) to measure carer experiences alongside people they support in mental health services, and the Living in the Community Questionnaire (LCQ) to measure consumer social inclusion inclusive of work, study, social activities, housing and general wellbeing.

The YES[5] survey was initiated during the development of the last two National Mental Health Plans for the 'Consumer Experience of Care Project' and funded by the Australian Government Department of Health. The YES survey is now a Victorian Department of Health and Human Services (DHHS) funded

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4 State of Victoria, Department of Health and Human Services, October 2017, Victoria's Mental Health Services Annual Report

5 https://mhsa.aihw.gov.au/committees/mhissc/YES-survey/

output. The YES survey was later followed by the Carer Experience Survey [6] (CES) to be applied in the various States and Territories.

Considerable time has passed since the Fourth National Mental Health Plan first recognised the role of carers in mental health service provision in 2009. Carers Victoria notes the National Carer Experience Survey (CES) tool has now been available for use within the mental health sector since late 2016 and its systematic roll out sits with the State jurisdictions.

Carers Victoria would like to see commitment from the Victorian Government to implement use of the CES similar to trials of the YES survey as a means of monitoring and improving carer engagement within an evidence-informed quality improvement program.

In addition, Carers Victoria wishes to highlight in this paper some fundamental issues we believe need consideration regarding both the YES survey and CES.

Closing circles of care to enable better care for carers

The CES is a useful tool to capture the specific service experiences of carers of people with mental illness. Importantly CES respondents must identify themselves as a carer, or the service user must refer to them as a carer for this survey to be undertaken. However, the CES and the YES combined do not capture the experiences of a whole cohort of mental health service users i.e. service users with care responsibilities.

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[6] http://www.amhocn.org/sites/default/files/publication_files/mh_carer_experience_survey_sample.pdf

Carers Victoria proposes an additional question is included in the YES survey to identify whether the consumer also has care responsibilities.

Collecting clinical and mental health service experience data on carers as a consumer cohort, similar to Aboriginal, LGBTIQ and ethnicity consumer data collection methods, would provide valuable information. For example, which services carers are using – or not using - and whether these services are relevant, useful and accessible to consumers with care responsibilities. As noted already, capturing consumer experiences of care planning, and how services support their ability to manage their day-to-day lives is a key goal of the YES survey. An additional question to identify care responsibilities would provide services and government with useful information to aid development of both mental health, and carer wellbeing programs.

Action 23 of the Fifth Mental Health and Suicide Plan states use of the YES survey across specialised and primary care mental health service sectors should include efforts to ensure groups who are historically poorly represented in these surveys, such as Aboriginal and Torres Strait Islander peoples, are properly represented and survey tools are suitably modified to enable this [7] .

Carers Victoria also notes State Government commitments to LGBTI and ATSI people's mental health as identified in the Ten-Year Plan [8]. The history of health and wellbeing outcomes of these populations is framed by multiple barriers to mainstream health services. This results in a reliance on informal care, compounded by a lack of identification as a 'carer'. Carers Victoria believes this reinforces the need for identifying the care relationships of

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[7] Department of Human Services, 2017, The Fifth National Mental Health and Suicide Prevention Plan p. 44

[8] State of Victoria, Department of Health and Human Services, 2015, Victoria's Ten Year Metal Health Plan.

mental health consumers among these diverse communities to more comprehensively meet the goals of these Plans.

The Living in Community Questionnaire identifies consumer care responsibilities, which is welcome, as it has some capabilities to inform service improvements[9], despite not being its key purpose. However, the application of the LCQ is limited by its use with predominantly longer-term service users [10], and is primarily about life outcomes rather than service experiences. Therefore, the YES survey data should be complemented with systematic, standardised carer identification tools such as those at intake which can capture carers who are also consumers.

Carers Victoria recommends any questions used to identify ‘carer’ status should not ask people if they are a ‘carer’ but rather focus on responsibilities and refer to definition prompts captured within the Victorian Carers Recognition Act 2012 and the Australian Carer Recognition Act 2010. For example, ‘Do you support or help a friend or family member due to a disability, who is older, has a mental illness, an ongoing medical condition or dementia?’ Due to high co-morbidity of chronic drug and alcohol misuse with a variety of mental illnesses it would be useful to also prompt any care provided due to drug and alcohol misuse.

The ongoing need for complementary and consistent data sets

The YES survey, CES and LCQ have variable criteria for participant ages. The LCQ is designed for participants over 16 years (and includes questions

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[9] Mental Health Information Strategy Standing Committee, 2016, ‘Living in the Community Questionnaire (LCQ) A measure of social participation, A guide for the use of the LCQ in clinical practice and for service development’, V1.1 p. 11

[10] Mental Health Information Strategy Standing Committee, 2016, ‘Living in the Community Questionnaire (LCQ) A measure of social participation, A guide for the use of the LCQ in clinical practice and for service development’, V 1.1 p. 8

on care responsibilities)[11] and the CES is designed for participants over 18 years but open to participants of all ages if a service sees it as suitable [12], as is the YES survey[13].

Carers Victoria would like to see improved linkage between the data sets and an understanding of a broader range of service experiences in the YES survey and the CES.

In particular, better data collection is required on young and older mental health consumers with care responsibilities. This requires a multi-pronged approach and refinement of service experience tools within more service settings, including youth and family mental health programs. This should occur alongside ‘carer awareness and carer identification’ training for workers in the mental health and community support sectors in addition to the work undertaken by peer workers.

Including a question identifying care responsibilities within the YES survey would assist in capturing carers 16 year of age and up. Furthermore, identifying care responsibilities during intake and assessments within youth mental health settings could assist in capturing the needs of young people in care relationships seeking support. This is particularly important as young carers are often classified as dependents in medical and mental health settings, which leaves their care relationships invisible to providers.

Carers Victoria believes initiation of State-wide consistently designed registration and documentation suites for mental health services in Victoria would be useful in aiding the closure of exiting gaps.

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11 Mental Health Information Strategy Standing Committee, 2016, ‘Living in the Community Questionnaire (LCQ) A measure of social participation, A guide for the use of the LCQ in clinical practice and for service development’ V 1.1, p. 13

12 Mental Health Information Strategy Standing Committee, 2016, ‘Carer Experience Survey Guide to the technical specifications of the Carer Experience Survey for licensed organisations and organisations seeking a licence to use the instrument’ V. 1

13 Mental Health Information Strategy Standing Committee, 2015 Australia’s National Mental Health Consumer Experience of Care Survey Guide for licensed organisations and organisations seeking a licence to use the instrument, V 1.1 p. 27

For example, in NSW there is a standardised suite of mental health clinical documentation modules designed for all NSW mental health services to document episodes of care from triage through to transfer or discharge.

Notably the NSW Assessment module contains screening questions regarding ‘Parental Status and/or Other Carer Responsibilities’. In the instance of parental/carer status for a child/young person 18 years or under being determined when undertaking the core Assessment module, clinicians then complete an additional Family Focused Assessment module. This facilitates gathering of information regarding this issue and determines a response and identifies matters of urgency. The completion of Family Focused Assessment module needs to be documented within the Assessment to highlight links between the two modules [14]. These ‘additional’ modules are available for use at points of care other than assessment, such as review and transfer/discharge. Furthermore, the core modules of the NSW documentation suite can be applied across child, youth, adult and aged mental health services therefore providing a whole of life lens to service delivery.

Finally, the Mental Health National Outcomes and Casemix Collection (NOCC) assists consumers to consider care options and treatment as well as support therapeutic relationships between clinicians and consumers. This could be another space to consider consumer carer service needs more holistically, the impacts of people’s wellbeing on care relationships, and vice versa.

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14 Mental Health and Drug and Alcohol Office Mental Health Clinical Documentation Guidelines space Document Number GL2014_002 Publication date 31-Jan-2014 Functional Sub group Clinical/Patient Services - Mental Health Clinical/ Patient Services – Records p. 6

Carers Victoria believes this could be a useful consideration in any further review and adjustment of the NOCC instruments.

Creating an ecosystem of carer identification

Data is required on service experience, service needs and outcome measurements for all carers including those who are also consumers. A significant shift in the culture of service environments is required. Carers Victoria recognises stigma as an issue for the way carers are viewed in health or mental health settings. We note perceptions of carers who seek information, can be labelled as 'angry', 'over-involved' or 'difficult' [15]. Such reactions and experiences may impact a carer seeking help for their own mental health due to prior experiences in health and mental health settings.

Some excellent recent work encourages health and mental health professionals to work in partnership with carers and identify them as partners in care [16] [17]. Indeed, some initiatives to include carers and increase awareness, such as the use of generic information in service waiting areas to increase carer self-identification, will also increase self-help seeking among consumers with a care role. Similarly, when carers are identified it is considered best practice to refer carers to support or family services. The need to apply Standards of Practice when working with families of people with a mental illness in the mental health sector has been well articulated [18].

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15 A practical guide for working with carers of people with a mental illness, March 2016, Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia p. 8

[16] 16 A practical guide for working with carers of people with a mental illness, March 2016, Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia p. 10

17 Carers Identified?, Identifying the Carer Report 2010

18 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'Hanlon2 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

Similarly, standards of working with families in aged care, health and disability support need to be applied.

Carers Victoria believes mental health system data collection capability needs to reflect the complexities among service users and best practice models with carers.

Standardised, shared data collection tools, which do not solely identify carers in relationship to people they support, but also recognise their needs as consumers, will contribute to a more practical understanding of how to engage and support them. Understanding ‘carer needs’ in relation to the impacts of care relationships is important. However, understanding how a person’s wellbeing can impact their care relationships or a service’s ability to engage with them as a cohort is also vital.

This would lead to a better understanding of the impact and accessibility of clinical supports, as well as capture care responsibilities of service users reluctant to define their relationships this way.