

CarersACT

MENTAL HEALTH
carers
voice



SUBMISSION ON THE DRAFT STIGMA AND DISCRIMINATION REDUCTION STRATEGY

January 2023

ABOUT CARERS ACT

Carers ACT is the leading body for carers in the ACT. We work to ensure that carers enjoy improved outcomes in health, wellbeing, resilience and financial security. We also work to ensure that caring is acknowledged and recognised as a shared responsibility of family, community and government.

Our purpose is to support, connect and empower carers to maintain their caring role and personal wellbeing. The Carers Recognition Act 2021 recognises the value of carers and the care relationship and defines carers in the following way:

“A person is in a care relationship with another person if the first person (the carer) provides care to the other person for 1 or more of the following reasons:

- (a) the other person has a disability;
- (b) the other person has a mental disorder or mental illness;
- (c) the other person has an ongoing medical condition;
- (d) the other person is aged and frail;
- (e) the other person is a child or young person, and the carer is a kinship carer or a foster carer for the child or young person.”

Carers include family members, friends, relatives, siblings, or neighbours. In the ACT more than 50,000 people provide care. Carers provide an important role in the family and in the broader community, supporting the quality of life of the person they care for. A carer’s role can include help with daily living activities such as housework, transport, health care, shopping, and meals, reading and writing, emotional and mental support and personal care.

ABOUT MENTAL HEALTH CARERS VOICE (MHCV)

MHCV is the Peak Body for mental health carers to inform service delivery and policy development in the ACT. The program is funded by the ACT Government and is coordinated by Carers ACT. We work with carers to effect change for a better system of support for families caring for someone with a mental illness.

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SCOPE

This submission will have particular regard to the following question:

Are there any critical issues or actions to address stigma and discrimination that are not referenced or sufficiently prioritised in the Draft Strategy?

Introduction

Carers ACT and Mental Health Carers Voice (MHCV) thanks the National Mental Health Commission ('the Commission') for the invitation to provide feedback on the National Stigma and Discrimination Reduction Strategy ('Draft Strategy'). We support and closely align our organisation's objectives with the long-term vision of "an Australian community where everyone has equal dignity, respect and value and is able to live a life of meaning and purpose free from mental health related stigma and discrimination."¹ Most notably, we are aware of the important role carers play in the lives of those experiencing mental illness – whether it be by assisting in daily tasks, providing emotional support, or guiding recovery journeys. We appreciate that the Commission has referenced families, carers, and support people throughout the Draft Strategy.

Nonetheless, we continue to be significantly concerned by the level of stigma and discrimination that mental health carers face both in the community and across the mental health sector. In the MHCV's biannual survey conducted in 2021 it was found that over a third of mental health carers in the ACT experience discrimination, a figure which has not improved since previous survey results.² Similarly, general levels of understanding of carers amongst both the community and medical professionals remained low to average.³ Carers have expressed to us that they are often blamed for the mental ill-health of their care recipient, thereby increasing their own distress and self-stigma while limiting access to supports. As such, carers are also a cohort more prone to experiences of mental ill health. Whereas 25.0% of adult Australians had moderate to high levels of psychological distress at the end of 2020, 48.1% of carers reported experiencing these levels of distress in 2022.⁴ This submission therefore highlights that the Draft Strategy should more overtly include and prioritise carers; as both a term normalised within the language of the mental health space, and as a cohort in need of specialised supports.

¹ Commonwealth of Australia (National Mental Health Commission) (2022), *National Stigma and Discrimination Reduction Strategy – Draft for Consultation*, 7.

² Mental Health Carers Voice (2022), *Filling the Cup Back Up – 2022 ACT Mental Health Carers Survey Report*, 5, [2022-MHCV-Survey-Report.pdf](#).

³ Ibid, 6.

⁴ Carers Australia (2022), *Caring for Others and Yourself – The 2021 Carer Wellbeing Survey*, 7-8, https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey_Final.pdf.

Missing Elements

Language matters

MHCV acknowledges that finding common language in the mental health space can be challenging given that people have varying preferences for how they would like their experiences described. Moreover, we appreciate that the Commission has consulted people with lived experience when choosing the language in the draft. However, MHCV would like to stress the importance of including the term ‘carers’ alongside ‘families and support people’ throughout the Draft Strategy (i.e., changing the common term used to ‘**families, carers, and support people**’). We note that across the document ‘families’, ‘friends’, ‘carers’/‘unpaid carers’ and ‘support people’, or any combination of the terms, are used inconsistently. Prima facie, while this addition may seem excessive, it is principally motivated by two reasons.

Firstly, if the Strategy seeks to work in tandem with, and improve, existing beneficial social welfare and human rights frameworks it should seek to clarify the term ‘carer’ and alleviate the stigma around the caring role. Existing beneficial frameworks include, but are not limited to, those under the federal *Carer Recognition Act 2010* and the various recognition Acts across the states and territories which aim to increase awareness and impose obligations on service providers.⁵ In addition, financial assistance provided by the ‘Carer Payment’ requires that an applicant providing care falls within the legislatively defined scope of a ‘carer’.⁶ At present, identification – both self-identification and identification by health professionals – is one of the primary obstacles to carers receiving proper support. Self-identification can be particularly problematic because many carers view their relationship with the person they care for as that of a parent, child, neighbour, friend, or partner, rather than that of a ‘carer’. In the absence of self-identification, service providers, health professionals, and the community more broadly must identify carers to provide them the most appropriate support.

Secondly, even in instances where carers are identified, they are often excluded. We appreciate that leaving out explicit reference to families, carers, and support people in many of the action items is based on the understanding that an inclusive approach will be taken regardless. Nonetheless, current carer experience indicates that this inclusive approach has not been ingrained across the board. The Draft Strategy should include further reference to carers, ensuring a uniform change occurs in the incorporation of family and carer lived experience by health professionals and service providers. It is thus crucial that the Draft Strategy include the term ‘carer’ in order to ensure that carers are considered in conversations and are able to access the support and benefits to which they are entitled.

⁵ See e.g. *Carer Recognition Act 2010* (Cth); *Carers Recognition Act 2021* (ACT).

⁶ Commonwealth of Australia (Department of Social Services), “1.2.5.20 Carer payment (CP) - description”, Guides to Social Policy Law – Social Security Guide Version 1.302, last modified January 3, 2023, [1.2.5.20 Carer payment \(CP\) - description | Social Security Guide \(dss.gov.au\)](https://www.dss.gov.au/guides-to-social-policy-law-social-security-guide-version-1.302/1.2.5.20-carer-payment-cp-description).

Understanding stigma and discrimination

There is a need to include the cohort of individuals and their families, carers and support people who have had contact with the justice system due to their mental-ill health. Studies have indicated that compared to non-forensic carers, forensic carers face more stress, burdens, and dissatisfaction with communication and interactions between service providers.⁷

The stigma around this particular cohort has recently been a matter of concern in the ACT, with the 2022 review into Dhulwa (the territory's secure mental health unit) noting that "...the stigma attached to the unit...may also have had adverse consequences for Dhulwa consumers seeking to transition to less restrictive environments or to the community."⁸ Notably, carers in the ACT have vocalised their concerns over the media's highly stigmatised reporting of those with serious mental ill-health in Dhulwa.⁹ Continued stigmatisation in the media over the years has worn down advocates and created further barriers in help-seeking for both carers and consumers. We appreciate that decreasing stigma in the media is a priority area elsewhere in the Draft, but we nonetheless take this opportunity to stress how important it is to ensure the media is educated on responsible reporting and use of language when discussing mental ill-health.

2.6 Build and supportive pathways into and within employment

MHCV notes that whilst the pursuit of employment equity for carers is mentioned briefly in one sentence, the proposed actions under this section do not overtly include or consider families, carers, and support people. Unpaid carers often assist with the day-to-day functioning of people with lived experience with mental illness at the expense of their own employment opportunities. Carers in Australia experience considerably poorer employment outcomes, with a 52.2% employment to population ratio compared with 75.9% for people without caring responsibilities.¹⁰ The actions under 2.6 should therefore expand their scope to include mental health carers, seeking to remove barriers for people with lived experience and those that care for them.

2.7 Improve mental health capabilities and supports in education and training settings

Likewise, no mention is made of carers of people living with mental illness in educational settings, particularly young carers. The education prospects for Australia's 235,000 young carers are also poor where more than 60% of young carers have not studied beyond high school.¹¹ Moreover, young carers face a complex level of stigma surrounding their own mental illness and that of their care recipients (often their parents) which

⁷ See e.g. M. Ferriter and N. Huband (2003) "Experiences of parents with a son or daughter suffering from schizophrenia" *Journal of Psychiatric and Mental Health Nursing*, 10(5), 552–560.

⁸ Barbara Deegan (2022), *Final report – Inquiry into the Legislative, Workplace Governance and Clinical Frameworks of Dhulwa Secure Mental Health Unit*, 48, [Final report Inquiry into the Legislative, Workplace Governance and Clinical Frameworks of Dhulwa Secure Mental Health Unit, 11 November 2022](#).

⁹ See Lucy Bladen, "Dhulwa Mental Health Unit inquiry finds 'poor standards of care'," *The Canberra Times*, December 1, 2022, [Dhulwa Mental Health Unit inquiry finds 'poor standards of care' | The Canberra Times | Canberra, ACT](#).

¹⁰ Carers Australia (2022), *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers – a report for Carers Australia*, 6-7, https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Caring-Costs-Us_Summary-of-Findings_FINAL_070422.pdf.

¹¹ Ibid.

prevents help-seeking behaviour. Many young carers do not disclose their own distress for fear of being removed from their families. As such, although appreciating the broad applicability of action item 2.7c, the Draft Strategy must prioritise carers, particularly young carers, in education and training settings.

3.1 Build a social movement to catalyse community action to reduce stigma and discrimination

This submission appreciates that families, carers, and support people are a targeted cohort for tailored contact-based training initiatives to provide further information about mental-ill health and reduce stigma (action 3.1c). Beyond being a target group, the Draft Strategy should also include families and carers as a subject of these initiatives under action items 3.1a and 3.1b. Professionals in the various settings mentioned in both action items are often unaware of the caring role and carers in general. Appropriate training would not only decrease the stigma around mental health caring, but also assist in embedding a carer-inclusive culture across the board.

Conclusion

The formulation of Draft Strategy is a potentially community changing piece of work that will impact the lives of all Australians. Our submission advocates for a more concrete inclusion of carers in the conversation about stigma and discrimination reduction. We hope to see the embedding of above missing elements in the finished product. We also look forward to the development of the National Stigma and Discrimination Reduction Strategy and seeing it's implementation in action.



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