

5 April 2019

Productivity Commission
GPO Box 1428
Canberra City, ACT 2601

Productivity Commission Inquiry into the Social and Economic Benefits of Improving Mental Health

Carers NSW welcomes the opportunity to respond to the Productivity Commission Inquiry into the Social and Economic Benefits of Improving Mental Health. This submission addresses the unique needs and experiences of mental health carers, the necessity for flexible workplaces for all carers, and the need to ensure that mental health carers receive appropriate financial support. It draws on feedback from mental health carers provided to Carers NSW through the Carers NSW 2018 Carer Survey and our experience delivering services to carers, including carers of people living with mental illness.

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

Thank you for accepting our submission. For further information regarding this submission, please contact Grace Cherrington, Policy Officer

Yours sincerely

Elena Katrakis
CEO
Carers NSW



Carers NSW submission:

Friday, 5 April 2019

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

Mental health carers and their needs

According to the Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers (SDAC), there are approximately 904,400 carers in New South Wales, of whom 240,000 are mental health carers.¹ Carers play a significant role in the support and recovery of many people living with mental illness. Despite this, there remains limited focus on the needs and experiences of mental health carers.

It is well known that mental health carers experience reduced mental health themselves as a result of this supportive role. National data from the SDAC indicates that a quarter of all carers experience high or very high levels of distress, and are therefore highly likely to have a moderate to severe mental disorder.² A further quarter of all carers experience moderate levels of distress.³ These figures are significantly higher than the general population.

There is also evidence that carers of people living with mental illness are at greater risk of poor mental health outcomes than other carers.⁴ Supporting someone with a mental illness can be sporadic, uncertain, and unpredictable. Like all carers, mental health carers may experience financial stress, strained relationships, and emotional distress, but are likely to also experience exacerbated challenges specific to their caring situation, including social stigma. Managing symptomatic behaviour can be very challenging for carers and being excluded from treatment of the person they care for due to privacy and confidentiality concern is another major stressor.

Workplace flexibility

Caring for a family member or friend can impact a carer's ability to participate in paid employment. SDAC data shows that working carers aged 15 to 64 are less likely to be employed (66.0%) compared to non-carers (77.2%).⁵ Additionally, carers who provide more hours of care are less likely to participate in the labour force.⁶ Less than half (45.6%) of primary carers who spend 20 to 39 hours per week caring are employed.⁷

While the amount of hours spent caring can affect carers' ability to participate in the labour force, carers have also cited lack of employer flexibility and lack of understanding of their caring role as a barrier to employment. This is particularly the case for mental health carers who regularly encounter stigma or lack of awareness regarding mental illness.

Sue* is a carer for her mother who lives with mental illness and has found it very difficult to find paid employment. Despite having relevant qualifications, Sue feels that being a carer prevents her from being considered by potential employers, especially in the private sector. Sue has expressed her frustration in trying to negotiate flexible working hours so she can continue to care for her mother. She would like employers to have a greater understanding of carers and recognise the work they do.

**Name changed*

¹ Australian Bureau of Statistics (2016) Survey of Disability, Ageing and Carers 2015, TableBuilder.

² Australian Bureau of Statistics (2016) Survey of Disability, Ageing and Carers 2015, TableBuilder.

³ Australian Bureau of Statistics (2016) Survey of Disability, Ageing and Carers 2015, TableBuilder.

⁴ Broady, T. & Simpson, C. (2016) Living With Mental Illness: Focusing On Carers, presentation to the Australian Institute of Family Studies Conference 6-8 July 2016, available at: <http://www.carersnsw.org.au/policy/changing-systems>

⁵ Australian Bureau of Statistics (2016) Survey of Disability, Ageing and Carers 2015, TableBuilder

⁶ the Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers

⁷ the Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers

Sue's experience in navigating workplace flexibility and recognition for her caring role is not unique. According to the Carers NSW 2018 Carer Survey, mental health carers are less likely to feel their caring is recognised by others (48.0%), and experienced higher levels of psychological distress. Further, survey data indicated that only 1 in 2 mental health carers had used carers leave and flexible start and/or finish times⁸ and less than 1 in 3 had worked from home and other types of flexible work arrangements. More than 1 in 6 had never used any form of flexible work arrangements.⁹This is because carers often feel that their employers or colleagues do not understand or are even aware of their caring situation and so do not feel as though they comfortably navigate flexible work arrangements. Feeling as though their caring role is not understood can be felt more acutely by mental health carers due to stigma around mental health and the sporadic and uncertain nature of their caring role.

Carers NSW is pleased to observe that the Productivity Commission understands the necessity for mentally healthy workplaces as well as providing suggested actions that workplaces could take to improve mental health of employees (p28). However, Carers NSW would like to see greater recognition of mental health carers in these recommended actions, particularly in regards to workplace flexibility and awareness around mental health carers.

Carers NSW welcomes the Productivity Commission's invitation to provide advice on how to better support informal carers, particularly with regards to participation and productivity. Carers NSW has recently developed the Carers + Employers Network, an initiative designed to better support carers in the workplace through a three-part accreditation process. The Carers + Employers Network emphasises the importance of flexible and supportive workplaces and seeks to build the capacity of workplaces through best practice approaches, in order to support mental health carers and carers more broadly. By creating workplaces that recognise and understand the role of carers, reduces the barriers felt by carers trying to enter the workforce. It is recommended that the Australian Government looks to endorse and implement this framework, to create carer-friendly workplaces.

Income support

Carers NSW welcomes the opportunity to comment on the level of income support that is available to mental health carers and whether these pensions and payments sufficiently provide support to carers. According to data from the Department of Social Services in December 2018, approximately 100,000 carers 803,666 carers¹⁰ in NSW were receiving the Carer Payment, while 210,000 people in NSW were receiving the Carer Allowance.¹¹

The Carers NSW 2018 Carer Survey identified that compared to all carers, mental health carers had comparatively lower household incomes and experienced greater difficulty meeting living expenses. Mental health carers were also less like to report receiving the Carer Allowance, which is reflective of anecdotal evidence from carers highlighting the challenges associated in claiming such payments. In particular, mental health carers often report that the Adult Medical Report Form which is required to be completed to be eligible for the Carer Payment or Carer Allowance does not appropriately accommodate the care needs of people with mental illness. This is due to the Adult Disability Assessment Tool which focusing on physical function as opposed to the psychosocial impact that is

⁸ Carers NSW (2018) *Carers NSW 2018 Carer Survey*, unpublished data.

⁹ Carers NSW (2018) *Carers NSW 2018 Carer Survey*, unpublished data.

¹⁰ Department of Social Services (2018), *DSS Demographics December 2018*, Australian Government, available online at: <https://data.gov.au/data/dataset/cff2ae8a-55e4-47db-a66d-e177fe0ac6a0>

¹¹ Department of Social Services (2018), *DSS Demographics December 2018*, Australian Government, available online at: <https://data.gov.au/data/dataset/cff2ae8a-55e4-47db-a66d-e177fe0ac6a0>

often experienced by people living with mental illness. In addition, there is a discrepancy between the Child Medical Report Form which enables a psychiatrist or psychologist to complete the form, whereas the Adult Medical Report Form does not.

Mental health carers are also more likely to encounter debt or pay fines that have been incurred from the person they care for, adding to their difficulty in meeting living expenses and potentially leading carers to apply for financial hardship support. Anecdotal evidence from carers highlights the additional or hidden costs of mental health carers, as well as the common experience of mental health carers paying bills or debts on behalf of the person they care for due to mental illness.

“I was hit with the harsh fact I had to quit my job to nurse my child around the clock, while accumulating regular considerable medical expenses, losses, and property damage repairs.”

- Mental health carer.

Conclusion

As mental health carers often experience lower mental health, carer wellbeing should be a key area of focus for the Productivity Commission’s final report. Carers NSW recommends that carers be recognised not only as a significant stakeholder but as a client group with their own needs.

Carers should be included in consultations to ensure that they are appropriately supported through workplace flexibility and receive adequate income support payments to maintain the sustainability of caring roles whilst participating in the workforce.