



**Carers NSW submission in response
to the Productivity Commission
Mental Health Draft Report**

23 January 2020

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

1. INTRODUCTION

Mental health carers: experiences and mental health

According to the Australian Bureau of Statistics 2018 Survey of Disability, Ageing and Carers (SDAC), there are approximately 2.65 million carers in Australia¹, of whom 976,000 are mental health carers.² Carers play a significant role in the support and recovery of many people living with mental illness. Despite this, there has historically been limited focus on the needs and experiences of mental health carers. Carers NSW commends the Productivity Commission for their recognition of mental health carers and the valuable contribution they make to those living with mental illness in Australia.

It is well known that mental health carers often experience reduced mental health themselves as a result of the challenges of their caring role. National data 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.³ A further quarter of all carers experience moderate levels of distress⁴; 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.⁵ Supporting someone who is living with mental illness can be episodic, 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 planning of the person they care for due to privacy and confidentiality concerns often exacerbates existing challenges.⁶

Information sharing and decision making

The Statement for Australia's Carers⁷ stipulates that carers are partners in care and that their unique knowledge and experience should be acknowledged. The importance of carers is also recognised in some national and state or territory mental health legislation, such as the NSW *Mental Health Act 2007*.⁸ Many carers accessing services in a variety of sectors, including the mental health sector, experience inadequate information sharing by professionals, which can increase the risks of harm to themselves and the person they care for.

The 2019 Royal Commission into Victoria's Mental Health System identified that the confidentiality rights of individuals can be overly emphasised to the detriment of providing critical information to carers who are expected to provide care integral to mental health recovery. All people, including all care recipients, should maintain their human right to privacy, which must be upheld by professionals in all sectors, including in the health and mental health systems. Care recipient privacy however, must be balanced with a carer's right to receive information relevant to their caring role which safeguards both the carer and their care recipient.

¹ Australian Bureau of Statistics. (2019). *Survey of Ageing, Disability and Carers 2018*. TableBuilder Dataset. Canberra: Australian Government. Online available under: www.abs.gov.au.

² Productivity Commission (2019), *Mental Health, draft report, Productivity Commission*, Canberra.

³ Australian Bureau of Statistics. (2019). *Survey of Ageing, Disability and Carers 2018*. TableBuilder Dataset. Canberra: Australian Government. Online available under: www.abs.gov.au.

⁴ Ibid.

⁵ Ibid.

⁶ Carers NSW, (2019). *Productivity Commission Inquiry into the Social and Economic Benefits of Improving Mental Health*. Sydney.

⁷ *Carer Recognition Act 2010* (Cwth).

⁸ In Section 68, 'Principles for care and treatment', the Act stipulates that: (j) the role of carers for people with a mental illness or mental disorder and their rights under this Act to be kept informed, to be involved and to have information provided by them considered, should be given effect⁸.

Withholding information from carers that has direct application to their caring role may negatively impact on the quality and sustainability of care provided, increasing the patient's risk of complication or readmission. A lack of appropriate and ethical information sharing may also have a detrimental impact on care recipient outcomes, particularly with regards to physical and mental health, safety in the community, medication compliance, behaviour needs and potential relapse, and may result in serious safeguarding risk.

The current service environment relies on individuals and families maintaining their own care and support structures to support people living with mental illness in the community and following an admission, but the effectiveness of these structures can be undermined by a lack of information and transparency.

Laura was not informed by the treating team that her son, Max*, was discharged from a mental health facility, despite the fact it was expected that Max would live with Laura, and receive her support in recovery. Max was discharged into homelessness whilst still being unwell, and was subsequently reported missing for a period of time. The implications of this included a lack of psychosocial stability, limited access to mental health treatment and further negative effect on mental health outcomes.*

The 2007-08 National Mental Health Consumer and Carer Forum⁹ has highlighted that there are multiple barriers to appropriate information sharing, including provider concerns about losing consumer trust, fear of legal consequences, insufficient training opportunities, and a general lack of knowledge with regards to privacy law and subsequent impacts on consumer recovery and carer support. Given the complexity in relation to information sharing, and the ethical implications of decision making with regards to privacy and confidentiality, there is an identified need for improved training and practical support for professionals to promote compliance under current legislation and ensure best outcomes for both consumers and carers.

New Zealand's mental health legislation¹⁰ requires mandatory consultation with family and carers unless there is evidence to suggest that such consultation is not in the best interests of the consumer. This requirement reflects recognition of the role of family and carers on the basis that they are likely already involved and are often a strong support network. Carers NSW recommends investment in education and training for providers to better understand information sharing as a best interest decision, meaningful consultation and disclosure, and disclosure as a means to mitigate risk. It is also recommended that information pathways be clear for consumers, families, carers and sector providers.

Another considerable challenge faced by carers is their lack of recognition and right as the result of inconsistent legislation, particularly with regards to decision making. The inconsistent protections within State and Commonwealth legislation, as well as between the private and public sectors, creates confusion and ambiguity for consumers, carers and professionals alike. Further inconsistency is noted between the mandate that family participate in supporting care recipients, and the lack of clarity with regards to those same carers' rights to participate in decision making and receive adequate information relevant to their caring role and individual wellbeing.

Legislative consistency and recognition within State and Commonwealth legislation is required in relation to the guidelines and principles relating to decision making. This is particularly the case when consumers access multiple service systems e.g. mental health and aged care, within a context where current Commonwealth legislation does not always align with State and Territory laws. Carers NSW

⁹ National Mental Health Consumer & Carer Forum (2011) *Privacy, Confidentiality and Information Sharing- Consumers, Carers and Clinicians*. Canberra: NMHCCF.

¹⁰ *Mental Health (Compulsory Assessment and Treatment) Act 1992* (Cwth).

also recommends that substitute, supported and co-decision making be viewed as part of a spectrum in order to recognise and respond to the complexity of capacity and decision making. Further consideration should also be given to establishing consistent and timely support for decision makers to promote individual wellbeing and ensure protection of consumers.

Carers NSW strongly recommends a whole of government approach whereby legislation is consistent across jurisdictions in promoting individual protections for both consumers and their formal/informal supported decision makers. Legal recognition is a means to achieving protection of both care recipients and their carers. In addition to consistency across jurisdictions, clear and enforceable guidelines on the hierarchy of conflicting decision making arrangements should be available to carers and recognised by agencies and services.

Regional and remote mental health carers

Approximately 41% of mental health carers live outside of metropolitan areas, 12% of whom are aged 15-24.¹¹ Regional, rural and remote communities face a range of challenges due to their distance from key services and employment opportunities. Mental health carers living in these areas can experience additional barriers to participation and support as a result of their caring responsibilities. They also experience disability and chronic health conditions at higher rates compared to carers living in metropolitan areas.¹² The poorer health and wellbeing of non-metropolitan carers is often attributed to the lack of services such as respite, increased isolation, and the tendency for such carers to have fewer informal networks to provide additional support.¹³

Despite proportionately higher rates of disability and chronic health conditions in rural and remote areas, health and mental health care services are not distributed accordingly. Many services are centralised in regional centres and major cities and inadequate or inaccessible public transport infrastructure often requires carers to drive vast distances to access the services they and the person they care for require.¹⁴ Not only is this time-consuming, but carers in non-metropolitan areas are more likely than those in metropolitan areas to find transport costs to be an added financial burden.¹⁵ While there are schemes available to cover travel costs for specialist appointments, anecdotal evidence indicates that such programs are not being adequately promoted to carers. Furthermore, such schemes have strict eligibility criteria and often do not adequately cover the out-of-pocket costs associated with such travel. Carers NSW recommends that significant investment in adequate transport infrastructure and financial compensation for travel costs incurred is considered a priority for all carers living in regional and remote locations.

Under the Commonwealth *Carer Recognition Act 2010*, public sector agencies are required to consider carers' needs in line with the Statement for Australia's Carers when designing and delivering services that affect carers, and the Statement specifically identifies the need for tailored support for young carers and in regional and remote communities.¹⁶ While supports reaching young people generally are likely to benefit many young carers, targeting support to young carers and their families increases their likelihood of feeling included and supported by services, and therefore of seeking support. Carers NSW therefore recommends that established youth focused initiatives in regional and remote areas prioritise

¹¹ Productivity Commission (2019), *Mental Health, draft report*, Productivity Commission, Canberra.

¹² Edwards, B., Gray, M., Baxter, J. and Hunter, B. (2009), *The tyranny of distance? Carers in regional and remote areas of Australia*, Prepared for Carers Australia by the Australian Institute of Family Studies.

¹³ Winterton, R. and Warburton, J. (2011), 'Models of care for socially isolated older rural carers: barriers and implications', *Rural and Remote Health* (online) vol. 11, no. 1678.

¹⁴ Peel, N., Westmoreland, J. and Steinberg, M. (2002) 'Transport safety for older people: A study of their experiences, perceptions and management needs', *Injury Control and Safety Promotion*, vol. 9, no. 1, pp. 19-24.

¹⁵ Dew, A., Bulkeley, K., Veitch, C., Bundy, A., Gallego, G., Lincoln, M., Brentnall, J. and Griffiths, S. (2013) 'Addressing the barriers to accessing therapy services in rural and remote areas', *Disability and Rehabilitation*, vol. 35, no. 18, pp. 1564-1570; Carers NSW (2014) *Carers Survey: Main Report*, Sydney; Schirmer (2017).

¹⁶ *Carer Recognition Act 2010* (Cwth).

young carer outreach and support, including assisting young carers to identify and connect with other young carers in their area.

Collaboration with mental health carers

Mental health carers will be best supported through collaboration and coordination using a whole of government approach. Carers NSW advocates that opportunities for co-design with mental health carers be pursued when designing and delivering services and supports. The subsequent sections of this submission will focus in more detail on the specific recommendations outlined in the Productivity Commissions' report.

2. MENTAL HEALTH CARER SUPPORTS

Carers NSW acknowledges and supports the Commission's draft report findings that mental health carers have a unique experience and as such may have differing needs than other carers. However, Carers NSW believes that the recommendation to separate mental health carer supports from the new national carer support services delivered under the Carer Gateway (formerly referred to as the ICSS)¹⁷ would be detrimental to the support and wellbeing outcomes for mental health carers and create a fragmented approach to carer support.

As highlighted in the Draft Report, the Mental Health Carers: Respite Service (MHC:RS) has been earmarked to transition to the NDIS and Carer Gateway services in ongoing disability and carer support reforms. Additionally, it has been reported that some states and territories have also transitioned their mental health carer support funding to the NDIS.¹⁸ However, in cases where a care recipient is deemed ineligible for the NDIS, is over the age of 65 or actively chooses not to engage with the service system due to the nature of their condition, carers will be unable to access direct or indirect carer supports through the NDIS. Where care recipients are receiving supports through the NDIS, funded supports are centred on participant needs, meaning that their carer's needs still may not be considered or addressed directly or indirectly by funding allocated in the participants NDIS plan.

In response to the increasing unmet demand for mental health carer supports due to these funding changes, the Commission has recommended (Draft Recommendation 23.2) that mental health carer supports be separated from the newly established Carer Gateway services, with funding provided by the Australian Government to State and Territory Governments to commission mental health carer support services outside of the service offerings available through NDIS and Carer Gateway.

Carers NSW fundamentally disagrees with this proposal. The Carer Gateway aims to move away from cohort specific carer supports which were fragmented, inconsistent and dependent on care recipient health conditions or disability. Instead, the Carer Gateway aims to provide holistic and person centred carer supports that focus on carer health and wellbeing, having the flexibility to meet each individual carers needs based on an independent carer-focused assessment.

A range of inclusive services will be available to all carers under the Carer Gateway, including online peer support, self-guided coaching and telephone counselling, as well as a range of in-person supports: counselling, coaching, peer support, emergency respite and a limited number of financial packages. The separation of mental health carers and their proposed exclusion from the newly established carer support services would disadvantage them by excluding them from these services and channelling them into a support stream that would likely be more restrictive due to addressing anticipated needs of mental health carers as a cohort rather than treating carers as diverse individuals with a range of needs.

¹⁷ Integrated Carer Support Services (ICSS) are now referred to as Carer Gateway services.

¹⁸ Productivity Commission (2019), *Mental Health, draft report*, Productivity Commission, Canberra.

Additionally, approximately one in five carers is caring for two or more people¹⁹ and many people with psychosocial disability or mental ill health report comorbid disability or long term health conditions. As such, carers would be required to navigate and access multiple services systems, impacting on the distribution and allocation of resources, and jeopardising equitable achievement of adequate support across mental health and other carers. This is more likely to result in the provision of overlapping services or the creation of service gaps.

The Carer Gateway aims to streamline access to carer support services nationally, with one single entry point, catering services to the needs of each carer based on their own individual circumstances. Not only will this encourage a more holistic approach to carer supports, it will also enable the collection of a national data set for carers. The collection of increased, accurate carer data will allow for a better understanding of carers numbers and the demand for services, as well as help Carer Gateway Service Providers identify, monitor and address the needs of specific groups (e.g. mental health carers) in their region, enabling carer support services to be more targeted and responsive to community need. Segregation of mental health carers from the Carer Gateway would likely impact on data collection and analysis.

Carers NSW recommends that any additional supports for mental health carers, that are state or territory based, should be complementary to the supports available to carers through the Carer Gateway and aim to address identified service gaps, avoid duplication and make services more streamlined and cost effective.

3. PREVENTATIVE SUPPORT

According to the 2018 Survey of Ageing, Disability and Carers, there are approximately 83,000 young carers in NSW who are aged 25 years and under.²⁰ Young carers provide a variety of practical, specialist and emotional assistance which often exceed community expectations of what a child or young person can and should be responsible for. The tasks undertaken by young carers can range from domestic duties such as meal preparation and cleaning, to personal care such as showering, to supervising siblings and providing emotional support.²¹

While young carers often gain important skills from their caring role as well as a sense of pride, satisfaction and a strong bond with the person they care for, young carers are more likely to experience a number of vulnerabilities when it comes to their own health and wellbeing, social participation, education and employment.

Carers NSW commends the Productivity Commission for identifying the role schools should play in identifying and supporting young carers so they can remain engaged and succeed in education. Young carers are often at risk of experiencing mental ill-health and other challenges as a result of their caring role, and often do not come forward for support. The situation is further complicated in that many young carers do not identify as young carers, either because they or the people around them do not know what a young carer is, or because they are afraid of the implications of disclosing their family situation, which may lead to stigma, bullying or raise questions of child protection.²² Failing to identify can prevent young carers from accessing support at school or university, in the workplace, in the community and

¹⁹ Department of Social Services (2016), *Designing the new integrated carer support service: A draft Service Concept for the delivery of interventions to improve outcomes for carers*, Australian Government, Canberra.

²⁰ Australian Bureau of Statistics (2019) *Survey of Disability, Ageing and Carers*, 2018, TableBuilder.

²¹ Moore, T. and McAArthur, M. (2007), 'We're all in it together: supporting young carers and their families in Australia', *Health and Social Care in the Community*, 15(6):561–568; Cass, B. et al. (2009), *Young carers in Australia: understanding the advantages and disadvantages of their care giving*, Social Policy Research Paper No. 38, Social Policy Research Centre; Cass, B. et al. (2011) *Young carers: Social policy impacts of the caring responsibilities of children and young adults*, Social Policy Research Centre.

²² Cass, B, Brennan, D, Thomson, C, Hill, T, Purcal, C, Hamilton, M, and Adamson, E (2011) *Young carers: Social policy impacts of the caring responsibilities of children and young adults*, Report prepared for ARC Linkage Partners, October 2011.

within service systems. The effects of this can be long lasting, as young carers have lower levels of educational attainment and workforce participation²³ compared to their non-caring peers. Further, as identified in the Draft Report, while there may be programs to support young carers in school settings access to these programs are not consistent across the country.²⁴

Engaging disengaged students through identification and support of young carers

A young carer's capacity to complete education and participate in paid work is significantly affected by the intensity of their caring role, including the number of hours they care, the tasks they perform and their access to alternative support.²⁵ Recent research has also indicated that certain types of caring roles are linked to lower school engagement and performance.²⁶ As a result, young carers, especially those with intensive caring roles, are at risk of long term disadvantage.²⁷

The Draft Report identifies how the wellbeing of students can be significantly impacted by disengagement, highlighting the necessity of providing adequate support to students who may be at a higher risk of disengaging from their education. Many young carers have trouble balancing school work with their caring role and research indicates that young carers have higher rates of absenteeism and may have difficulties in completing assignments or homework due to their caring responsibilities.²⁸ Furthermore, young carers are less likely to finish year 12 and have a post-secondary education than non-carers of the same age.²⁹ Without adequate support, such issues can affect students' long term educational achievement and employment prospects.³⁰ Unfortunately schools often fail to recognise young carers and address their needs.

"If someone had picked up in high school that I was a young carer and helped me to receive services earlier, I think it would have made a real difference to me maybe finding things to help me go to university while looking after Mum and also to help me when I was doing my HSC."

- Young carer

Wellbeing Leaders

Carers NSW welcomes the Productivity Commission's recommendation to introduce Wellbeing Leaders into schools to ensure students and their wellbeing is better recognised and supported. While the Draft Report identifies how the role of Wellbeing Leaders should include providing support to schools to identify and support young carers, Carers NSW was disappointed to not see this suggestion as an explicit recommendation. As previously identified, young carers remain largely hidden even while at school. It is therefore important to embed young carer directed supports within policy and practice to ensure that young carers are adequately recognised and supported.

Carers NSW has previously recommended that the NSW Department of Education promote increased engagement among schools in carer identification and education and to integrate young carer outreach and support into its mainstream initiatives supporting staff and students around mental health, health

²³ Hill, T et al. (2011), 'Young Carers: Location, Education and Employment Disadvantage', *Australian Journal of Labour Economics*, vol. 14, issue 2, pp. 173-198.

²⁴ Productivity Commission 2019, *Mental Health*, Draft Report, Canberra

²⁵ Carers NSW (2017). *Young Carers, Barriers to Accessing Employment*.

²⁶ Hamilton, M. and Redmond, G. (2019) *Young carers' futures look bleak without flexible school support*, UNSW Newsroom, 28 May 2019.

²⁷ Cass et al, 2009, 2011; Lloyd, K. (2013) Happiness and Well-Being of Young Carers: Extent, Nature and Correlates of Caring among 10 and 11 Year Old School Children. *Journal of Happiness Studies*, 14(1), 67-80. The Children's Society. (2013) *Hidden from View: The Experiences of Young Carers in England*. London: The Children's Society.

²⁸ Carers NSW (2017) *Young Carer Policy Statement*.

²⁹ Hill, T et al. (2011), 'Young Carers: Location, Education and Employment Disadvantage', *Australian Journal of Labour Economics*, vol. 14, issue 2, pp. 173-198.

³⁰ Moore and McAArthur (2007); Bray, R. (2012) *Young carers in receipt of Carer Payment and Carer Allowance 2001 to 2006: characteristics, experiences and post-care outcomes*, Occasional Paper No. 47, Social Policy Evaluation, Analysis and Research Centre, Australian National University.

and wellbeing.³¹ Training and resources regarding young carers should also be made mandatory among school counsellors, student support officers and Wellbeing Leaders in order to raise awareness, increase engagement and reduce stigma. Carers NSW has previously suggested building on existing resources such as the School Refusal – Every School Day Counts³² resource developed by South-Western Sydney Local Health District (SWSLHD). The resource provides guidance on how to engage with students, including young carers, who may have difficulty in meeting school attendance requirements. While this resource does mention the possibility of care interrupting a student's education, a young carer specific resource would be more effective in building the capacity of wellbeing leaders, school counsellors, teachers and other staff members, as caring roles can differ significantly based on the level of intensity of the caring role or the nature of the care provided, affecting each young carer differently, and recent research indicates that particular kinds of caring roles are simultaneously more likely to remain hidden and more likely to impact school engagement.³³

Supporting young carers to remain in school

Another way young carers can be supported to remain in school is to ensure new and existing policies and programs have flexibility and inclusion in-built to better support young carers in their caring role while at school. In 2018 the NSW Department of Education announced a state-wide mobile phone ban of primary schools. Carers NSW strongly advocated on behalf of young carers, asserting that while remote supervision and monitoring by a child may not result in the best educational outcomes, in some families this is necessary with many young carers using their mobile phone to monitor or maintain their caring role. Many young carers commonly report feeling anxious or worried while away from the person they care for.³⁴ To alleviate this stress and anxiety, access to mobile phones means that young carers can be contacted in the event of an emergency or can contact the person they care for to check in with them at appropriate times throughout the day.³⁵ As well as flexibility, policies like the mobile phone ban also provide a potential opportunity for young carers to self-identify and be referred to support. If an exemption is implemented, a supportive approach should be taken in making this known and in ensuring that the disclosure of a caring role results in subsequent support from the school.

4. GAPS AND OPPORTUNITIES

Addressing gaps in NDIS and mental health supports

The Department of Health estimates that there are 775,000 people living with severe mental illness, and 684,000 people living with severe or moderate mental illness that require psychosocial support.³⁶ Many Commonwealth, State and Territory psychosocial support programs including Personal Helpers and Mentors Service (PHaMS), Partners in Recovery (PiR) and Day to Day Living (D2DL) are earmarked to be transitioned to the NDIS. However, as highlighted by the Draft Report, it is estimated that only 64,000, or 9% of people with severe mental illness, or moderate illness who are likely to require psychosocial support, will be eligible for support through the NDIS. The most recent NDIS quarterly report indicates that only 9% of participants or 27,900 people with psychosocial disability, are engaged and accessing the NDIS, less than half originally estimated.³⁷

³¹ Carers NSW (2019). *Keeping carers at the centre*, Carers NSW Pre-Budget Submission 2020-21.

³² South Western Sydney PHN (SESPHN) (2017). *Every School Day Counts: An approach to school refusal*. Available online at: <https://www.swsld.health.nsw.gov.au/services/ICAMHS/pdf/School-Refusal.pdf>, viewed 22 January 2020.

³³ Hamilton, M. and Redmond, G. (2019) *Young carers' futures look bleak without flexible school support*, UNSW Newsroom, 28 May 2019.

³⁴ Cass et al, 2009.

³⁵ Moore et al. (2006), *Reading, writing and responsibility: Young Carers and Education*, Institute of Child Protection Studies, Dickson.

³⁶ Productivity Commission (2019), *Mental Health, draft report*, Productivity Commission, Canberra.

³⁷ National Disability Insurance Agency (NDIA) (2019), *COAG Disability Reform Council Quarterly report, 30 September 2019*, NDIA, Canberra.

A recent report on the transition of people from PIR, PHaMs and D2DL to the NDIS identified that over a quarter of people with psychosocial disability who had applied were assessed as ineligible.³⁸ Carers NSW has previously raised concerns regarding access and eligibility of people living with mental illness and the implications if they are unable to receive necessary and appropriate support. If these former recipients of government funded disability support, who often belong to vulnerable population groups and have complex needs associated with episodic or chronic health conditions, are not adequately supported, they risk ending up in inappropriate care situations, such as lengthy hospital stays or within unsustainable informal care arrangements, affecting carer health and wellbeing.

Carers NSW recognises and supports the Government's extension of the Continuity of Supports (CoS), National Psychosocial Support Transition (NPS-T) and National Psychosocial Support Measure (NPS-M) programs to support the NDIS as it continues its transition. However, Carers NSW has concerns that there is no long-term plan for mainstream or residual psychosocial support services. The implications of this are far-reaching as people with psychosocial disability and their carers are left with uncertainty, resulting in high levels of psychological distress and inability to plan for the future. Carers NSW supports the recommendations in 22.2, however believes that recommendations should be extended to require governments to clarify long term funding arrangements for psychosocial supports in the community.

Carers NSW recognises that people living with mental illness or psychosocial disability face additional challenges once deemed eligible for the NDIS including inadequate funding for supports, higher levels of plan underutilisation and inability to access funded supports due to thin markets. However, Carers NSW acknowledges the NDIA's actions in addressing inequities faced by participants or potential participants living with mental illness or psychosocial disability and supports the Draft Report's recommendation that the NDIA should continue to evaluate and improve its approach to people with psychosocial disability. As the NDIS is not within scope for this review, Carers NSW will focus on the service gaps that have emerged or increased with the transition to the NDIS.

The interface between mental health and the NDIS

Many people living with mental illness or psychosocial disability who are able to access NDIS may still face significant costs or service gaps due to the complex interface between the NDIS, publically available mental health services or treatment, private health cover and other insurance claims. Carers have reported that unclear and confusing treatment and billing pathways have resulted in significant gaps in services and funding. Carers have reported that many health professionals are also unclear about the appropriate processes and procedures to enact when supporting people with mental illness or psychosocial disability who are participants of the NDIS. In some cases, this has inhibited care recipient's access to services when treating professionals were not sure which service system they should be providing treatment under.

"Financial hardship due to all the appointments that are in different towns... psychologist every 3 weeks is \$220, receive back \$86, no NDIS cover on this. Paediatrician every 3 months \$254 travel 4 hours each way. No NDIS cover..."

Carer Survey 2018
Respondent

Furthermore, carers have reported that where the participant's primary condition is psychosocial disability, they have still had significant costs to access mental health treatment. Where care recipients are not able to meet the costs of this care, carers often provide financial support to enable access to treatment and supports that facilitate recovery. However, many carers also face financial hardship due to the nature of the

³⁸ Hancock, N., Gye, B., Digolis, C., Smith-Merry, J., Borilovic, J. & De Vries, J. (2019). *Commonwealth Mental Health Programs Monitoring Project: Tracking transitions of people from PIR, PHaMs and D2DL into the NDIS. Final report.* The University of Sydney & Community Mental Health Australia, Sydney.

caring role. Significant treatment costs resulting from the Medicare gap or unclear funding responsibilities between the mental health and disability sectors place further financial strain on carers.

Carers NSW recommends ongoing review of the interface between disability and mental health services to ensure clear funding arrangements for psychological treatment and to ensure that mental health treatment is adequately funded in NDIS packages where appropriate. Additionally, Carers NSW recommends that the NDIS provides clear information for participants, their carers and health professionals regarding the appropriate pathway for accessing psychological therapies for NDIS participants.

Service navigation

People living with mental illness often face significant challenges navigating and coordinating services due to the nature of their condition and the complexity of service interfaces between siloed sectors such as disability, housing, health, justice or education. It is estimated that up to 460,000 people require care coordination for seamless and effective implementation of their care plan.³⁹ As noted in the Draft Report, inadequate care coordination can result in gaps in supports that may lead to deterioration in mental health and unnecessary hospitalisations. Where formal services are not available to provide coordination of care, additional strain is also placed on carers to fill administrative gaps or to provide care at a higher level of intensity.

It is important to note that people accessing the NDIS and living with mental illness may not be able to access adequate care coordination through the NDIS. While Support Coordination is a support type funded under the NDIS, carers have reported that funding for support coordination has been inconsistent and often inadequate. Additionally, support coordinators are limited in their role, generally assisting with understanding an NDIS plan, linking participants to services and assisting in the negotiation of service agreements as opposed to directing or coordinating supports. While specialist support coordination is also available under the NDIS for people with more complex support needs, it is intended to be time limited, as opposed to long term specialist care coordination. Further, the threshold of complexity that enables a participant to qualify for this support type is unclear.

The National Disability Services (NDS) *State of the Disability Sector Report 2019*,⁴⁰ stated that 75% of providers who responded (n=667) agreed that helping people to navigate the scheme is taking away from service provision. Similarly, the Carers NSW 2018 Carer Survey found that 61% of respondents caring for a person with disability (n=713) were spending more time organising supports for the person they care for since the roll out of the NDIS in 2016.⁴¹ These findings suggest that there are not adequate care coordination supports within the NDIS and alternative care coordination may be required.

Carers NSW supports the Draft Report's recommendation the development of a single, holistic care plan for people with moderate or severe mental illness, developed in consultation with the person living with mental illness and their carers, to facilitate improved service navigation and the collaboration of treating professionals and supports. Additionally, Carers NSW supports the Draft Report's recommendation that all people with severe and persistent mental illness who require care coordination services due to their complex health and social needs should be receiving them, regardless of their NDIS eligibility or access. However, Carers NSW feels that access to care coordination should be extended to people living with mild or moderate mental illness who have complex health and social needs to minimise the likelihood of further deterioration and ensure no additional strain is placed on carers to facilitate access to available supports. Carers NSW believes that care coordination services

³⁹ Productivity Commission (2019), *Mental Health, draft report*, Productivity Commission, Canberra.

⁴⁰ National Disability Services (2018), *State of the Disability Sector Report 2019*. Available online at: <https://www.nds.org.au/pdf-file/d3f2aa1f-52e9-e811-80cf-005056ac7853>, viewed 22 January 2020.

⁴¹ Carers NSW (2018), *Carers NSW 2018 Carer Survey: Summary report*. Available online at: <http://www.carersnsw.org.au/research/survey>, viewed 12 September 2019.

should be funded for a minimum funding cycle of five years to enable services to build strong networks and trust in the community.

Housing

Affordable, secure tenancy is fundamental to the recovery and wellbeing of people with mental illness or psychosocial disability. It is also vital for the health and wellbeing of carers, many of whom face housing insecurity and associated psychological distress due to the financial implications of their caring role. Approximately 70% of mental health carers live with their care recipient.⁴² In many cases, the housing security of carers and their care recipients is intrinsically linked, with the lease held by either the carer, care recipient or both.

The 2018 SDAC,⁴³ indicated that approximately 36,000 carers live in State managed housing in NSW, with estimates drawing on administrative data from social housing being considerably higher.⁴⁴ Carers are more likely than non-carers to live in low income households and are more likely to be out of the workforce and reliant on Commonwealth income support, leading many to apply for social housing. However, less social housing overall and low levels of affordable housing stock, has seen an increase in low-income earners in the rental market, increasing competition for the limited, affordable rental properties available. Research indicates that 26% of carers living in the private rental market are in housing stress, spending more than 30% of their income on housing costs.⁴⁵

Carers NSW supports the Draft Report's recommendation (15.1) that social housing workers should receive training in understanding and supporting people with mental health. Carers NSW recommends that this should be extended to include carer awareness training, such as the Carers NSW *Carers in Social Housing*⁴⁶ e-learning module, to support carers of people living with mental illness who are accessing accommodation support. Additionally, Carers NSW recommends the embedding of carer support officers within public housing agencies to assist carers with complex housing issues resulting from the nature of their care recipients' condition.

Carers NSW also supports the recommendation to review social housing policies that aim to reduce the risk of eviction, and recommends that this review is extended to include the consideration of protections for carers of people with mental illness who may be at risk of eviction due to behaviours associated with their care recipient's mental illness.

Justice

As identified in the Draft Report, there is an over-representation of people living with mental illness in the criminal justice system. Carers of people living with mental illness in contact with the justice system, or forensic carers, are often hidden due to lack of identification with the caring role, lack of recognition by services and health professionals, stigma associated with mental illness or the justice system, or due to the complexity of their circumstances. Forensic carers play a significant role in supporting their care recipient or filling service gaps throughout interactions with the justice system.

As noted in the PC draft report, evidence suggests that periods of incarceration can exacerbate poor physical and mental health leading to worse outcomes in the community. Lack of identification of mental illness and limited access to mental health services within and following contact with the criminal justice system further disadvantage people living with mental illness. Release from custody can be a highly

⁴² Productivity Commission (2019), *Mental Health, draft report*, Productivity Commission, Canberra.

⁴³ Australian Bureau of Statistics. (2019). *Survey of Ageing, Disability and Carers 2018*. TableBuilder Dataset. Canberra: Australian Government. Online available under: www.abs.gov.au.

⁴⁴ Carers NSW (2017), *Recognition as a tenant policy: Implications for carers*, Carers NSW, unpublished.

⁴⁵ Beer, A. and Faulkner, D. (2009), *The housing careers of people with a disability and carers of people with a disability*, Australian Housing and Urban Research Institute, Southern Research Centre; *ibid*.

⁴⁶ Carers NSW (2017), *Carers in social housing*, available online at: <http://ngolearning.com.au/files/Online-Classroom/Hidden%20Carers%202017/Module%203>, viewed 22 January 2020.

distressing period of readjustment and vulnerability that can exacerbate an individual's mental illness, leading to a higher risk of psychiatric hospitalisation or dying by suicide. Where adequate mental health services and supports are not available in the community following contact with the criminal justice system, significant levels of pressure are placed on carers to provide high intensity care.

Carers NSW supports the Commission's recommendation to improve mental health screening within the justice system to better identify and support people living with mental illness. Carers NSW also recommends that policies be reviewed to ensure that where people living with identified mental illness come in contact with the criminal justice system, carers be notified, included as partners in care in the development of care planning where appropriate and supported in their caring role. Inclusion of carers in justice system processes is likely to result in reduced psychological distress of carers and improved outcomes for people living with mental illness.

Lack of mental health support in aged care settings

The Draft Report has indicated that due to the current ongoing royal commission into Aged Care Quality and Safety, they have chosen not to examine the interface between mental health and the aged care system. Carers NSW believes that in the same way that the Productivity Commission (The Commission) has examined the interface between mental health and the NDIS, housing and justice, the Commission should examine the interface between mental health and the aged care system to identify and address any barriers or challenges to accessing mental health services and supports. Additionally, many of those who are ageing and frail and their carers may not be accessing supports through the aged care system, therefore it is imperative that the Commission identifies and addresses any concerns regarding equity and adequacy of access to mental health services and supports that meet the needs of those who are ageing or frail and their carers.

Mental health or psychological wellbeing are often overlooked in the aged care sector.⁴⁷ In many cases, changes in mood or cognition are perceived to be part of the ageing process. However, increasing evidence suggests that mental illness is inadequately identified and addressed in people who are ageing or frail due to under-identification by health professionals and ongoing stigma regarding mental illness.⁴⁸

The World Health Organisation (WHO) estimated that approximately 15% of those aged 60 or over are living with mental illness. For those in residential aged care, this is even more apparent, where a period of adjustment and loss often heightens psychological symptoms. As of 30 June 2018, 86% of people living in permanent residential aged care in Australia were diagnosed with at least one mental health or behavioural condition, with almost half (49%) of all residents diagnosed with depression.⁴⁹ In Australia, men over the age of 85 and over have had the highest age-specific suicide rate from 2011-2018.⁵⁰

Older people experiencing symptoms of depression have been found to have lower levels of function than those with chronic medical conditions such as lung disease, hypertension or diabetes.⁵¹ Symptoms of depression can also increase perceptions of poor health, resulting in higher utilisation of support services and higher associated costs.⁵² Carers may also be required to provide a higher intensity of care for longer periods due to their care recipients reduced functioning associated with their mental illness.

⁴⁷ World Health Organisation (WHO) (2017), *Mental Health of older adults*, available online at: <https://www.who.int/news-room/fact-sheets/detail/mental-health-of-older-adults>, viewed 16 January 2020.

⁴⁸ Ibid.

⁴⁹ GEN Aged Care Data (2019), *People's care needs in aged care*, available online at: <https://www.gen-agedcaredata.gov.au/Topics/Care-needs-in-aged-care>, viewed 17 January 2020.

⁵⁰ Life in Mind (2019), *Suicide facts and stats*, available online at: <https://www.lifeinmindaustralia.com.au/about-suicide/suicide-data/suicide-facts-and-stats>, viewed 16 January 2020.

⁵¹ WHO (2017).

⁵² Ibid.

The Mental Health Commission of NSW reports that there is a paradoxical divide between mental health care and aged care.⁵³ As opposed to seamless supports that address mental health and physical care needs holistically, systems create competing priorities that result in significant barriers to accessing mental health supports for people who are ageing or frail.

Carers NSW recommends that the Commission explores the significant mental health gaps for those who are ageing or frail and their carers due to the complex interface between the aged care, disability, health and mental health sectors for inclusion in the final report. Additionally, the Commission should examine the adequacy and availability of current mental health services and supports for people who are ageing and frail and their carers to identify opportunities to improve service provision and subsequently reduce strain on carers.

5. MENTAL HEALTH AND PAID EMPLOYMENT

Access to income support for mental health carers

Carers NSW commends the Draft Report in advocating for mental health carers to have improved access to various levels of income support, particularly the Carer Payment. Carers NSW has previously raised similar concerns, highlighting that mental health carers were less likely to receive the Carer Allowance and Payment⁵⁴ due to restrictive policy around the level and frequency of care provided. Carers NSW supports the recommendations suggested in the Draft Report to review the Adult Disability Assessment Tool which has long been considered to be inadequate when assessing the level of care provided by carers for someone living with mental illness.⁵⁵ Carers NSW supports amending the eligibility criteria for the Carer Payment and Allowance to reduce the barriers to accessing income support for mental health carers.

Young carer support to overcome barriers to employment

Analysis of data from the Carers NSW 2016 Carer Survey, indicated that the participation of young carers in paid employment was significantly affected by their caring role, with many indicating that they had stopped work or changed their work hours to accommodate caring responsibilities, while others were in a job below their skillset or were reluctant to take on work entirely.⁵⁶

Carers NSW has previously advocated for the NSW Government to consider explicitly including young carers in eligibility criteria for relevant youth focused vocational training initiatives similar to the free traineeships for young job seekers announced in 2019 and the Smart and Skilled program. Furthermore, quarantining a portion of these apprenticeships for young carers (such as the Carer Achievement Pathway project, delivered by Carers NSW and the Young Carer Bursary, managed by Carers Australia) would allow young carers to receive more holistic support, assisting them to overcome some of the many barriers they face in pursuing further education and employment.⁵⁷

⁵³ Mental Health Commission of New South Wales (2017), *Older People*, available online at: <https://nswmentalhealthcommission.com.au/mental-health-and/older-people>, viewed 16 January 2020.

⁵⁴ Carers NSW (2019) Mental health carers fact sheet. Online available at: <http://www.carersnsw.org.au/research/survey>

⁵⁵ Carers Victoria (2013). *Invisible Care: Access to carer payment and carer allowance by Victorian carers of a person with a mental illness*.

⁵⁶ Carers NSW (2017). *Young Carers, Barriers to Accessing Employment*.

⁵⁷ *Ibid*

Mentally healthy workplaces and flexible working arrangements

Carers NSW welcomes the Draft Report's position on mentally healthy workplaces and its view that all employees should be better supported by their workplace if they experience or live with mental illness. To ensure policy and practice is fully inclusive, it is necessary to ensure policy review is carer friendly and ensures greater recognition and support of carers, their health and wellbeing. Carers NSW has previously advocated for mental health carers and carers generally, highlighting the necessity to actively include carers in the development and implementation of policy and practice for mentally health workplaces.

It is important to recognise that approximately two thirds of the 2.65 million carers across Australia are of working age. More than one in four (29%) are not in the labour force, compared to one in five (19%) non-carers,⁵⁸ and carers commonly report having exited the workforce or reduce their engagement with paid work in order to attend caring responsibilities.⁵⁹ As a result, a larger proportion of carers than non-carers rely on an income support payment as their main source of income.⁶⁰

For carers who wish to maintain, increase or re-enter paid employment for financial or other reasons, significant barriers persist. These include limited workplace flexibility, stigma and discrimination within the workforce, inadequate 'replacement care' to enable carers to work, financial and policy barriers to upskilling, and limited tailored support to remain competitive in the job market. Additionally, Carers NSW has heard from carers that they have been discriminated against whilst job-seeking due to appearing unreliable based on their need for flexibility, and/or the potential for mental health issues experienced by the care recipient to extend to the carer, and have implications for their work performance. For carers who are unable to work or would prefer to focus on the caring role for personal, familial or cultural reasons, policy restrictions and budget constraints also reduce carers' social and economic participation.

Greater awareness and inclusion of carers by employers is required in order to implement the kind of flexibility that will enable many employees with caring responsibilities to maintain both roles effectively. This includes developing workplace policies that actively include and support carers to maintain their caring roles as well as employment but to also ensure their health and wellbeing is adequately supported. Some industries and roles are more amenable to flexibility than others (hence the higher concentration of carers within certain industries),⁶¹ and specific types of employers (such as large corporate and government agencies) are more likely to invest proactively and innovatively in flexibility and inclusion due to existing incentives and regulation.

"Childcare is generally well accepted. Other care types (mental illness, aged care, terminal care) I feel are not completely understood and supported by management."

Carer Survey 2016
Respondent

Initiatives such as the Carers + Employers program⁶² support employers of all sizes and sectors to improve their support, retention and recruitment of carers in line with a strong business case. Further, an increasing focus on both workplace diversity and flexibility, in relation to a range of employee cohorts, holds broader benefits for working carers. Proponents of 'flexibility by design' suggest that it prevents the need to accommodate individual scenarios and

⁵⁸ Australian Bureau of Statistics. (2019). *Survey of Ageing, Disability and Carers 2018*. TableBuilder Dataset. Canberra: Australian Government. Online available under: www.abs.gov.au.

⁵⁹ Carers NSW (2018).

⁶⁰ ABS (2016).

⁶¹ Carers NSW (2018); Skinner, N., Pocock, B. (2014), *The Persistent Challenge: Living, Working and Caring in Australia in 2014. The Australian Work and Life Index 2014*. Centre for Work and Life, University of South Australia: Adelaide, p. 38.

⁶² Carers + Employers (2019), *Carers + Employers*, available at: <https://carersandemployers.org.au/>, last viewed 2 December 2019.

instead recognises that all employees are likely to have some form of caring commitment outside of work at some stage.⁶³

Conclusion

Carers NSW commends the Productivity Commission as they work to improve the experiences of people living with mental illness, their families and their carers. The Draft Report presents a valuable opportunity for significant and meaningful reform across a number of services and systems that, if implemented correctly, would allow for a more holistic approach to mental healthcare including effective early-intervention and prevention. As identified throughout this submission, Carers NSW has highlighted the significant role carers play in the support and recovery of people living with mental illness, and urges the Productivity Commission to ensure that the unique experiences and needs of carers are appropriately recognised and represented.

⁶³ Russell, G., O'Leary, J., Tilly, J., Brown, C. (2016), *Future-Flex: Mainstreaming Flexibility by Design: Redesigning work to make flexibility standard business practice in Australian retail workplaces*, Synopsis Report, Diversity Council Australia, available online at: <https://www.dca.org.au/files/file/Research/DCA%20Future%20Flex%20Synopsis%20Online%20Accessible.pdf>; viewed 17 October 2016.