



**Carers Victoria submission
Productivity Commission Inquiry into Mental Health
Response to Draft Report**

January 2020

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

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 policy paper was prepared by Carers Victoria's Policy Team.

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Executive Summary

Carers Victoria welcomes the opportunity to respond to the Productivity Commission's (the Commission) Inquiry into Mental Health, Draft Report (Draft Report).

Carers Victoria values a chapter dedicated to 'Carers and Families'. The chapter accurately highlights that 'many carers value their caring role'¹ at the same time recognising 'caring also has costs – it affects some people's mental and physical health, social participation, career trajectory, educational attainment and financial security.'²

Whilst one in eight Australians is an unpaid family and/or friend carer, there is still much work required to recognise the mental health of carers and the contributions carers make.

This submission builds on Carers Victoria's initial submission by considering the content within the Draft Report and the Commission's public hearings. The submission focuses on carers in mental health settings, at schools, in workplaces and the financial impacts of providing informal or unpaid care.

Carers Victoria recommends the Commission further considers the needs of carers from diverse communities; issues relating to psychosocial disability and the NDIS; and issues of affiliate stigma experienced by many carers, especially mental health carers.

¹ Productivity Commission 2019, *Mental Health*, Draft Report, Canberra, p. 463.

² Productivity Commission 2019, *Mental Health*, Draft Report, Canberra, p. 457.

Recommendations

1. The 25-hour rule be replaced with a 300-hour per 13-week block.
2. The Mental Health Carer Experience Survey must be formally adopted by all states and territories in 2020, with the goal of nationwide implementation in 2021. This will drive a coordinated approach to identify and include carers with information sharing in mental health settings across the nation.
3. All state and territory mental health services to adopt guidelines on working with families and carers as 'partners in care'. Where they don't exist already, the Victorian Chief Psychiatrist Guideline to be considered as an example. Relevant government departments to evaluate their implementation to ensure inclusion of families and carers becomes standard practice.
4. As every classroom is likely to contain two or three young carers, mandatory training is required for all teachers regarding the role played by young carers and the support they need to succeed at school.
5. The Australian Government to adopt the Productivity Commission's recommendations to extend the funding term with peak bodies and psychosocial services to a minimum of five years.
6. The Productivity Commission undertakes research into the most appropriate method of introducing a payment solution for unpaid carers within in Australia's superannuation system.
7. Establish the 'Carers Tick' – an employer accreditation program.
8. The Australian Government mandate carers leave as an additional allocation of leave to personal leave in the National Employment Standards.
9. The Australian Government to mandate 'portability' of personal leave and carers in the National Employment Standards.
10. Care coordinators should receive training on the care relationship to understand the expertise of carers, as well as the health needs of carers.
11. Care coordinators should provide information and referrals to people with care needs and carers to support the care relationship.
12. Carers Victoria supports Thorne Harbour Health's recommendation that mandatory training on working with LGBTIQ+ communities is implemented across all health services.
13. All mental health staff and teachers in educational settings be required to undertake training on the impact of culture and diversity on mental health.

14. Recommendations from Mental Health Australia's report 'National Disability Insurance Scheme: Psychosocial Disability Pathway' are implemented in the roll out of the psychosocial pathway. In particular, 'Recommendation 10: That consumers' families/carers/advocates are acknowledged and supported, including – where agreed with the consumer – involvement in all relevant meetings and discussions'³ and 'Recommendation 24c: Certain support types should be discussed in every planning conversation with NDIS participants with psychosocial disability: [including] carer support and respite.'⁴

15. The Australian Government funds research into interventions to address affiliate stigma associated with providing care to a person with mental illness and funding to implement interventions identified.

³ Mental Health Australia, 'National Disability Insurance Scheme: Psychosocial Disability Pathway', 2018, p. 31.

⁴ Mental Health Australia, 'National Disability Insurance Scheme: Psychosocial Disability Pathway', 2018, p. 33.

Draft Report - Chapter 13 – Families and Carers

Carers Victoria welcomed the Mental Health Inquiry – Draft Report, devoting the whole of Chapter 13 to ‘Carers and Families’. The chapter correctly highlights that ‘many carers value their caring role’,⁵ at the same time recognising ‘caring also has costs – it affects some people’s mental and physical health, social participation, career trajectory, educational attainment and financial security’⁶.

Carers Victoria supports draft recommendation 13.1.

- Agreement with the Commission that the Adult Disability Assessment Tool should be reviewed to better reflect the impacts of mental illness and carers should be consulted in this process.
- Agreement with the Commission that the list of persons who can complete the health professional questionnaire should include psychologists and social workers.
- Agreement with the Commission that the eligibility criteria for Carer Payment (adult) and Carers Allowance (adult) should be amended as per the points listed on page 481.

Carers Victoria has long advocated for removal of the 25-hour rule and this remains our recommendation. The recommendation to replace the 25-hour rule with a 100-hour per month restriction on work and volunteering is a welcome step. However, Carers Victoria recommends that this be expanded further to a 300 hour per 13-week period.

This would more accurately reflect the often episodic nature of providing care to people with a mental illness. Carers have advised that a three-month block would allow them greater flexibility, with scope to pick up additional contract/casual work when the person they are caring for has a period of improved mental health. This in turn would support greater availability to provide care when the person receiving care experiences a decline in their mental health.

RECOMMENDATION: The 25-hour rule be replaced with a 300-hour per 13-week block.

⁵ Productivity Commission 2019, *Mental Health*, Draft Report, Canberra, p. 463.

⁶ Productivity Commission 2019, *Mental Health*, Draft Report, Canberra, p. 457.

Supporting information sharing between services and carers

The Draft Report highlights the experience well known to carers, of being excluded from information sharing with mental health services due to 'privacy' issues. Carers Victoria agrees with the Commission that 'services need to invest in the processes and skills which enable carers to be identified and consent to share information to be recorded.'⁷ Carers have expertise from their unique knowledge of the person with mental illness and their care relationship which will assist the treating team working with the person receiving care.

As the Commission identifies, Standard Seven from the National Standards for Mental Health Services already recognises that mental health services need to identify carers and address the issue of sharing confidential information in accordance with legislation and additional guidelines.⁸ Yet carers continue to report they are routinely not recognised and face a range of barriers from mental health clinicians when supporting the person receiving care.

Lack of mandatory Standards and lack of data about carers' experiences has compounded this situation.

Carers Victoria welcomed the publication of the updated Chief Psychiatrist's Guideline 'Working Together with Families and Carers' (The Guideline) in 2018. The Guideline provides a framework for Victorian mental health services to engage with families and carers at every stage of people receiving support for mental health concerns. Feedback from carers has demonstrated mixed experiences regarding carer inclusion in mental health services. The Guideline includes a section on including families and carers in organisational governance and practice. This includes inclusion through surveys, complaints processes and service development.

RECOMMENDATION: The Mental Health Carer Experience Survey must be formally adopted by all states and territories in 2020, with the goal of nationwide implementation in 2021. This will drive a coordinated approach to identify and include carers with information sharing in mental health settings across the nation.

RECOMMENDATION: All state and territory mental health services to adopt guidelines on working with families and carers as 'partners in care'. Where they don't exist already, the Victorian Chief Psychiatrist Guideline to be considered as an example. Relevant government departments to evaluate their implementation to ensure inclusion of families and carers becomes standard practice.

⁷ Productivity Commission 2019, *Mental Health*, Draft Report, Canberra, p. 496.

⁸ Productivity Commission 2019, *Mental Health*, Draft Report, Canberra, p. 497.

Young carers

People under the age of 25 providing unpaid care to family or friends (usually parents or siblings) are referred to as young carers. One in ten carers are young carers.⁹ This means, in every Australian classroom there are likely to be two or three young carers.

The Commission has rightfully noted young carers often do not identify in school settings and that young carers require support from the education system.¹⁰ The Commission refers to Department of Social Services (DSS) Carer Gateway guidelines stating that allowing young carers to have access to their phones to fulfil their caring roles can assist young carers to balance their educational responsibilities.¹¹

The Victorian Government is rolling out a mobile phone ban in schools from Term One 2020. Carers Victoria advocated with the Minister for Education and the Department of Education for young carers to be eligible for an exemption from this ban. If other jurisdictions implement mobile phone bans in schools, they should adhere to the DSS Carer Gateway guidelines, ensuring national consistency to provide young carers with the right to apply for an exemption.

The Commission has recommended each school employs a wellbeing leader to support the mental health of students.¹² This recommendation does not go far enough. Wellbeing leaders are already present in many schools in Victoria. They perform a vital role in supporting students but are often unable to meet the demand for their services. This understandably results in the prioritisation of students in acute mental health crisis.

RECOMMENDATION: As every classroom is likely to contain two or three young carers, mandatory training is required for all teachers regarding the role played by young carers and the support they need to succeed at school.

⁹ State of Victoria, Department of Health and Human Services, *Recognising and supporting Victoria's carers: Victorian carer strategy 2018-22*, p. 10.

¹⁰ Productivity Commission 2019, *Mental Health*, Draft Report, Canberra, p. 501.

¹¹ Productivity Commission 2019, *Mental Health*, Draft Report, Canberra, p. 501.

¹² Productivity Commission 2019, *Mental Health*, Draft Report, 'Overview and Recommendations', Canberra, p. 86.

Longer term funding

Throughout the Draft Report the Commission recommends extending funding timelines. This includes 'extending the funding cycle length for peak bodies to a minimum five years to improve business planning and capability development'¹³; as well as 'streamlining psychosocial funding arrangements and extending funding cycle lengths beyond annual contracts for providers to a minimum of five years.'¹⁴

The Victorian Council of Social Service articulated the impact of short-term funding cycles on people receiving social services and the staff providing them in their 2019 Victorian state budget submission; stating:

'Workers can find themselves on a short-term contract 'merry-go-round,' moving from one contract to another, trying to secure sustainable work. This undermines both organisational capacity and worker morale. It can also disturb trusting therapeutic relationships built with vulnerable people – the foundation of quality, person-centred services.'¹⁵

For peak bodies, longer funding cycles will increase efficiency in the workplace by providing greater certainty in business and workforce planning, reducing the costs of staff turnover including the associated loss of knowledge and expertise.

Extending the funding cycles for psychosocial service providers will benefit people with psychosocial disability, as well as their carers. It will result in continuity of service, enabling people with psychosocial disability and their carers to focus on their wellbeing, without the stress of regularly having to re-navigate the service system. It will also be more efficient as people will not have to re-tell their story and establish new relationships, allowing for a more productive and meaningful engagement.

RECOMMENDATION: The Australian Government to adopt the Productivity Commission's recommendations to extend the funding term with peak bodies and psychosocial services to a minimum of five years.

¹³ Productivity Commission 2019, *Mental Health*, Draft Report, 'Overview and Recommendations', Canberra, p. 101.

¹⁴ Productivity Commission 2019, *Mental Health*, Draft Report, Canberra, p. 415.

¹⁵ Victorian Council of Social Service, 'Delivering Fairness: Victorian Budget Submission 2019-20', https://vcoss.org.au/wp-content/uploads/2019/03/DF_Online.pdf, 2019, accessed, 14.01.20.

Carers and employment

The Commission rightly acknowledges that carers face many barriers to employment and that carers have been calling for 'greater and more sustained investment in employment support'.¹⁶

One in five carers gives up work to care. This means carers tend to have lower household incomes – the weekly median income of a primary carer is \$520, which is 42 per cent lower than a non-carer. Carers who give up work can lose up to \$60,000 in superannuation for a 10 to 15-year period out of the workforce and find it difficult to find employment later in life. Carer retirement incomes suffer as a result. Female carers are more financially affected than male carers, contributing to their increased risk of homelessness in later life.

Carers Victoria is a member of the 'Caring Fairly' coalition and endorses their submission in response to the Draft Report. As the 'Caring Fairly' submission identifies, the provision of care is gendered. In Victoria, 70 per cent of carers are women. The Commission needs to recognise the negative impact of unpaid care has on women's participation in the workforce.

The Australian Human Rights Commission articulates this point well in its report 'Investing in care: Recognising and valuing those who care':

'It is important that a public debate about unpaid care asks what stops men from taking on more responsibility for unpaid care, and challenges the model of the 'ideal worker' who is unencumbered by any caring responsibilities.'¹⁷

The same report identifies that 'there are social, economic, business and human rights cases for valuing the contributions of unpaid carers'.¹⁸

The social case recognises that the provision of unpaid care itself is 'work' and that it is essential to the functioning of families and the broader community.

The economic case acknowledges that the provision of unpaid care boosts the economy. Carers make a \$60.3 billion contribution to the Australian economy each year through support provided to people with care needs.¹⁹ As stated above, carers can experience significant personal and financial costs through providing care losing thousands in lost superannuation and earning a significantly lower income.

¹⁶Productivity Commission 2019, *Mental Health*, Draft Report, Canberra, p. 501.

¹⁷ Australian Human Rights Commission, *Investing in care: Recognising and valuing those who care* • Volume 1: Research Report, 2013, p. 3.

¹⁸ Australian Human Rights Commission, *Investing in care: Recognising and valuing those who care* • Volume 1: Research Report, 2013, p. 3.

¹⁹ Deloitte Access Economics, 'The economic value of informal care in Australia in 2015', <https://www.carersaustralia.com.au/storage/access-economics-report3.pdf>, p. iii.

The gendered nature of caring needs to be recognised to ensure women's skills can be effectively utilised at work and women experience greater financial security. The business case follows on from this as it is more efficient to support carers to maintain their employment participation rather than having staff turnover.

Several countries already recognise the impact that providing unpaid care has on a person's ability to save for their retirement.²⁰ This is recognised through the provision of 'carer credits' to a bank or superannuation account. The Australian Human Rights Commission recommendations, which Carers Victoria strongly endorses, states that the Productivity Commission undertakes research into the most appropriate method of introducing a system of carer credits in Australia's superannuation system.²¹

RECOMMENDATION: The Productivity Commission undertakes research into the most appropriate method of introducing a payment solution for unpaid carers within in Australia's superannuation system.

Employer accreditation program

An employer accreditation program – and associated standards – would provide guidance and incentive for employers to be more supportive of carers.

The accreditation program could be guided by similar models already in operation:

- Carers Australia – Work and Care program which requires carer-friendly workplaces to sign a Charter, complete a Self-Assessment and implement a Carer Action Plan.
- Carers NSW – the Carers + Employers program which recognises employers actively supporting paid work for people with caring responsibilities.
- Rainbow Tick – a national, voluntary accreditation program for organisations which are committed to safe and inclusive practice and service delivery for LGBTIQ+ people. Organisations undergo accreditation against the Rainbow Tick Standards which were developed by the Victorian Government-funded organisation Rainbow Health Victoria.
- Little Dreamers – a support organisation for young carers which has a carer friendly certification program whereby businesses assess policies and set expectations on both employers and employees to make businesses carer friendly, with a view to helping young carers transition into the workforce.

²⁰ Australian Human Rights Commission, Investing in care: Recognising and valuing those who care • Volume 1: Research Report, 2013, pp. 53-54.

²¹ Australian Human Rights Commission, Investing in care: Recognising and valuing those who care • Volume 1: Research Report, 2013, p. 54.

Case Study

The caring company – Harvard Business School ‘How employers can help employees manage their caregiving responsibilities – while reducing costs and increasing productivity’.

As the global economy continues to rapidly evolve, Harvard Business School has closely examined the social and economic imperatives for businesses to develop innovative approaches which support those within their workforce who have caring responsibilities.

The study found that the impact of caregiving will become more pronounced as the economy approaches full employment. It argued that employers will need to overcome instances where employees leave the workforce as a consequence of caring obligations, as well as eliminate barriers to workforce participation and re-entry.

Key findings of the report found:

- Employers do not measure and thus do not realise the extent to which employees are impacted by providing care;
In the absence of a supportive ‘care culture,’ employees worry that admitting to caregiving responsibilities penalises their career growth;
Employers do not realise the extent to which caregiving affects employee performance;
Employers grossly underestimate the direct and indirect costs of caregiving; and
Employers underestimate the spectrum of care responsibilities affecting the different demographics in the organisation.

The full report can be found here: www.carersvic.com.au/caringcompany

Carer Associations could work with employers to develop and implement carer-friendly workplace guidelines that enable carers to continue to participate in work and promote wellbeing.

RECOMMENDATION: Establish the ‘Carers Tick’ – an employer accreditation program.

Carers Leave

The online publication, *The Conversation*, recently featured an article on carers leave.²² This article highlights the economic benefits of providing more support to carers who may need time out of the workforce. Initiatives highlighted include:

- Providing ‘carers leave’ in addition to an employee’s ‘personal leave’. This would allow carers to be able to focus on their caring responsibilities alongside their own health needs.
- Longer carer’s leave provisions based on parental leave models.
- Introduction of portable personal and carers leave. Like portable long service leave schemes, this scheme would enable employees to accumulate leave from multiple employers to optimise the care they are providing and to look after their own health.

²² Zeppel, Hofstätter, Graham and Sze, *More carers’ leave may help Australians look after elderly parents and stay in work*, *The Conversation*, <http://theconversation.com/more-carers-leave-may-help-australians-look-after-elderly-parents-and-stay-in-work-127496>, 28.11.19, accessed 17.12.19.

Furthermore, in addition to expanding funding cycles for peaks and psychosocial services discussed earlier, Carers Victoria urges the government to extend the length of funding cycles more broadly. This would provide greater certainty for carers, as well as people receiving care. Short-term contracts make it difficult for carers to accumulate enough leave to support the person they are caring for, as well as the carer's own health needs.

RECOMMENDATION: The Australian Government mandate carers leave as an additional allocation of leave to personal leave in the National Employment Standards.

RECOMMENDATION: The Australian Government to mandate 'portability' of personal leave and carers in the National Employment Standards.

Care Coordination

Carers Victoria supports recommendation 10.4 which states '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'.²³ We appreciate that the Commission recognises the scale of this need by stating that 460,000 people with complex mental health concerns would benefit from care coordination.²⁴ Furthermore, we welcome the Commission's description of these roles:

Care coordinators would work directly with the consumers, their carers, clinicians (or clinical coordinator) and providers from other sectors, to establish the types of services needed and provide access to those services.²⁵

A holistic approach would go a long way to spare carers the stress of having to navigate a range of services and systems for the person they are caring for. Carers would welcome the opportunity to work as partners in care with a professional dedicated to the individuals needs and circumstances of each care relationship.

RECOMMENDATION: Care coordinators should receive training on the care relationship to understand the expertise of carers, as well as the health needs of carers.

RECOMMENDATION: Care coordinators should provide information and referrals to people with care needs and carers to support the care relationship.

²³ Productivity Commission 2019, Mental Health, Draft Report, 'Overview and Recommendations', Canberra, p. 68.

²⁴ Productivity Commission 2019, Mental Health, Draft Report, 'Overview and Recommendations', Canberra, p. 27.

²⁵ Productivity Commission 2019, Mental Health, Draft Report, 'Overview and Recommendations', Canberra, p. 27.

LGBTIQA+ Carers

As discussed in our initial submission, carers who identify as LGBTIQA+ can experience additional difficulties in the healthcare system, as many carers have reported that staff do not recognise or support their relationship.

RECOMMENDATION: Carers Victoria supports Thorne Harbour Health's recommendation that mandatory training on working with LGBTIQA+ communities is implemented across all health services.

Aboriginal and Torres Strait Islander Carers and Carers from Culturally and Linguistically Diverse Backgrounds

A carer's cultural background has significant impact on their beliefs about mental health and how they perceive the caring roll.²⁶

The Commission succinctly articulates the impact past actions and discrimination has had on Aboriginal and Torres Strait Islander communities.²⁷

Whilst the Commission recognises that services need to be delivered in culturally appropriate ways and that staff delivering services in mental health²⁸ and educational contexts²⁹ need training on the impact of culture, the Draft Report does not go far enough.

RECOMMENDATION: All mental health staff and teachers in educational settings be required to undertake training on the impact of culture and diversity on mental health.

²⁶ Carers Victoria, 'For love, for faith, for duty, for deed: Beliefs and values about caring in Anglo-Celtic, Greek, Italian, Polish, Turkish and Vietnamese communities in Victoria', 2003.

²⁷ Productivity Commission 2019, Mental Health, Draft Report, 'Overview and Recommendations', Canberra, p. 96.

²⁸ Productivity Commission 2019, Mental Health, Draft Report, 'Overview and Recommendations', Canberra, p. 14

²⁹ Productivity Commission 2019, Mental Health, Draft Report, 'Overview and Recommendations', Canberra, p. 84.

Psychosocial disability and the NDIS

The Commission identifies that less than one in 10 people with a severe mental illness will be eligible for psychosocial supports under the NDIS.³⁰ It is still very difficult for people experiencing psychosocial disability to access the NDIS.

Like the Commission, Carers Victoria also welcomed the introduction of a 'Psychosocial stream' by the NDIA. Carers Victoria supports Recommendation 12.4 to fully roll out this stream by the end of 2020 across all NDIS sites.³¹ This stream was developed with guidance from Mental Health Australia.

Mental Health Australia's report 'National Disability Insurance Scheme: Psychosocial Disability Pathway' articulates numerous 'pain points' people with psychosocial disability experience with the NDIS. Carer specific points include:

Pain Point IV: Families, carers and advocates are critical to successful outcomes for many people experiencing psychosocial disability. Failure to engage and support them can lead to applicants being denied access to the Scheme or receiving insufficient plans.

Pain Point V: Carers (formal and informal) can also experience significant stress and fatigue through the NDIS process, placing at risk their own mental health and capacity to undertake their crucial role.³²

The following case study demonstrates:

- the importance of carers in the lives of people with psychosocial disability and the experience of the above 'pain points';
- the need for which that can work with carers *and* people receiving care; and
- the preparatory work often required to engage people with psychosocial disability to access the NDIS. Mental Health Australia articulates this as 'phase zero'.³³

³⁰ Productivity Commission 2019, Mental Health, Draft Report, 'Overview and Recommendations', Canberra, p. 31. The Commission states there are 690,000 people who have a severe mental illness, 21,700 people currently access the NDIS and a further 42,300 people are expected to access the NDIS.

³¹ Productivity Commission 2019, Mental Health, Draft Report, Canberra, p. 453.

³² Mental Health Australia, 'National Disability Insurance Scheme: Psychosocial Disability Pathway', 2018, p. 31.

³³ Mental Health Australia, 'National Disability Insurance Scheme: Psychosocial Disability Pathway', 2018, p. 30.

Case Study

Joan³⁴ contacted Carers Victoria's NDIS Carer Advisor Team as she was having difficulty encouraging her son Tim³⁵ to access the NDIS.

Tim has a psychosocial disability and was on a defined program. The NDIA had been attempting to contact Tim, but because of his disability, Tim was reluctant to engage with the NDIA. The NDIS Carer Advisor (advisor) recognised that both Joan and Tim needed support.

Tim agreed to meet with the advisor to discuss what the NDIS is and the types of areas the NDIS could potentially support him with. This was framed as not another service that was going to tell him what he had to do and when, but more about him having a choice in who supported him to work on goals of his choice that were important to him.

Tim was focused on "I am not sick and don't need help". The advisor spoke about applying for NDIS as not about him being "sick" but more about setting himself up with supports while he is traveling well, in case he may have a time when he isn't traveling so well. The advisor talked about the things he is not happy with in his life, like housing, work, social interaction etc and explained how which the NDIS could support him with these things, which in turn also helps with mental wellbeing. At the end of this visit Tim had a completely different perception and was starting to talk positively about his life and future.

The NDIS Carer Advisor recognised the stress that Joan was experiencing in encouraging Tim to apply for the NDIS. The advisor provided emotional support to Joan and supported Joan to complete the pre-planning forms on Tim's behalf.

The advisor worked with Tim and Joan to prepare for the planning meeting with the NDIA. While Tim was initially reluctant for Joan to be present, he recognised that Joan knows him well, his goals and where he requires additional supports.

The meeting went well, Tim was happy with the plan he received. Tim's confidence grew and he described feeling more hopeful through having an NDIS plan. Joan also felt more positive about her future, knowing Tim would receive the supports he had identified.

This case study is a 'lived experience' demonstration of what can be achieved if the recommendations from Mental Health Australia are fully implemented.

RECOMMENDATION: Recommendations from Mental Health Australia's report 'National Disability Insurance Scheme: Psychosocial Disability Pathway' are implemented in the roll out of the psychosocial pathway. In particular, 'Recommendation 10: That consumers' families/carers/advocates are acknowledged and supported, including – where agreed with the consumer – involvement in all relevant meetings and discussions'³⁶ and 'Recommendation 24c: Certain support types should be discussed in every planning conversation with NDIS participants with psychosocial disability: [including] carer support and respite.'³⁷

³⁴ Pseudonym

³⁵ Pseudonym

³⁶ Mental Health Australia, 'National Disability Insurance Scheme: Psychosocial Disability Pathway', 2018, p. 31.

³⁷ Mental Health Australia, 'National Disability Insurance Scheme: Psychosocial Disability Pathway', 2018, p. 33.

As stated previously in this submission, Carers Victoria welcomes the Commission's Recommendation 12.1 that 'Australian, State and Territory Governments should extend the funding cycle length for psychosocial supports from a one-year term to a minimum of five years.'³⁸ This will result in improved service delivery with an increased rate of staff retention.

Carers Victoria endorses the Commission's recommendation 12.2 'Guarantee of continuity of psychosocial supports.'³⁹ Implementation of this recommendation would ensure psychosocial support is available to people requiring psychosocial support whether they are eligible for the NDIS or not, and/or whether they test their eligibility or not.

Carers Victoria reinforces and strongly supports the closing remarks of the Draft Report's chapter on psychosocial disability: 'in future, it is important that the Australian mental health system reaches a stage where regardless of their NDIS status, people are able to access the supports they need.'⁴⁰

Stigma

At the Commission's public hearing on Monday 18 November 2019, Commissioners identified the need for additional information regarding mental health stigma.

Carers experience 'affiliate stigma' associated with providing care to a person with a mental illness. A systematic review and meta-analysis of affiliate stigma was completed in 2018.⁴¹ This review demonstrates that further research is needed to understand affiliate stigma and the best ways to address it. However, researchers have identified that the mental health of carers is key to their experience of affiliate stigma.

Researchers identified that support groups can help carers to share their experiences and reduce isolation, as well as the importance of psychoeducation to assist carers to understand their conceptions of mental health.

Researchers recognise the existence of affiliate stigma, particularly in carers of people with a mental illness; however, it appears that systematic interventions have yet to be developed to address it.^{42 43}

³⁸ Productivity Commission 2019, Mental Health, Draft Report, 'Overview and Recommendations', Canberra, p. 68.

³⁹ Productivity Commission 2019, Mental Health, Draft Report, Canberra, p. 439

⁴⁰ Productivity Commission 2019, Mental Health, Draft Report, Canberra, p. 456.

⁴¹ Shi, Y, Shao, Y, Li, H, et al. Correlates of affiliate stigma among family caregivers of people with mental illness: A systematic review and meta-analysis. *Journal of Psychiatric and Mental Health Nursing*, 2019; 26: 49– 61. <https://doi.org/10.1111/jpm.12505>

⁴² Yunjue Zhang , Mythily Subramaniam, Siau Pheng Lee, Edimansyah Abidin, Vathsala Sagayadevan, Anitha Jeyagurunathan, Sherilyn Chang, Saleha Binte Shafie, Restria Fauziana Abdul Rahman, Janhavi Ajit Vaingankar, Siow Ann Chong, 'Affiliate stigma and its association with quality of life among caregivers of relatives with mental illness in Singapore', *Psychiatry Research*, Volume 265, July 2018, Pages 55-61, <https://doi.org/10.1016/j.psychres.2018.04.044>, accessed 08.01.2020.

⁴³ Mak, Winnie W; S; Cheung, Rebecca Y; M., Psychological Distress and Subjective Burden of Caregivers of People with Mental Illness: The Role of Affiliate Stigma and Face Concern, *Community Mental Health Journal*; New York Vol. 48, Iss. 3, (Jun 2012): 270-4. DOI:10.1007/s10597-011-9422-9, accessed 08.01.2020.

RECOMMENDATION: The Australian Government funds research into interventions to address affiliate stigma associated with providing care to a person with mental illness and funding to implement interventions identified.