

# Submission to the Productivity Commission Inquiry into Mental Health

Mental Health Inquiry  
Productivity Commission  
GPO Box 1428  
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2601  
And by online submission

Tandem Inc.  
Representing Victoria's mental health carers

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## About Tandem

### Who we are

Tandem is the Victorian peak body representing carers of people living with mental health issues.

### What we do

We advocate for carer involvement in planning and care, participation in system change, and support for families and friends.

We promote and support the development of the mental health carer workforce and leadership.

We inform and empower mental health carers to access the National Disability Insurance Scheme (NDIS).

We promote and collaborate on the delivery of training on family inclusive practices for mental health professionals.

We provide information, education and training to mental health families, friends and supporters.

We support and advocate for the diverse needs of families, friends and supporters of people living with mental health issues.

We collaborate on research and policy development on matters relating to mental health carers.

We raise community awareness about the important role of families, friends and supporters in mental health recovery.

We administer the Carer Support Fund which provides financial assistance to families, friends and supporters of people registered with Area Mental Health Services in Victoria.

### Who is a carer?

A carer may be, and will continue to be, primarily the person's wife, husband, partner, son, daughter, parent, neighbour, friend, ... their child or children. It doesn't matter how many hours are spent each week providing support. Carers may live with the person they are caring for, providing assistance with daily needs, or may visit the person regularly. Carers are people who invest time, energy and support, generally in an unpaid capacity. However, some may receive Centrelink benefits to enable them to continue in their caring role. Carers are often hidden.... Children who become carers face particular difficulties in being recognised and having their needs met. In culturally diverse communities, care may involve the entire community and may provide additional challenges during the process of identifying who is a carer.

*Adapted from A Practical Guide for Working with Carers of People with a Mental Illness, p.6*

### Details

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Tandem is proud to be the trusted voice of family and friends in mental health in Victoria. As the Victorian peak body with a sole focus on the needs and interests of mental health carers, Tandem's role is to provide leadership, coordination and knowledge for the organisations and individuals who are working to improve outcomes for Victorian people living with mental health issues. Tandem is committed to ensuring that the importance of the contribution, expertise, experiences and needs of family, friends and other carers is recognised and addressed, and that they will be essential partners in treatment, service delivery, planning, research and evaluation.

Tandem would like to thank the Productivity Commission for the opportunity to provide input into the Inquiry into Mental Health. As well as this submission, we have participated in the development of the Submissions to the Inquiry from the Department of Health and Human Services in Victoria, Mental Health Victoria, Victorian Council of Social Services, Mental Health Carers Australia and the Caring Fairly Coalition.

## Background

Unpaid mental health carers in Australia play an essential role in our society. Not only do they provide ongoing emotional support, but often find themselves having no option but to also provide extensive social and practical support in the absence of support services. More than a third of mental health carers find themselves responsible for providing over 40 hours of care each week, often due to government support services being inappropriate, inaccessible, underfunded or unavailable.

Most people with mental health issues live in the community with family and friends supporting them. A major study of subjective wellbeing of family carers in Australia undertaken in 2007 showed that carers had the lowest collective wellbeing score of any group sampled utilising the wellbeing scale. 56% of carers were found to have moderate depression, and carers reported stressors in employment, with over one third being concerned about job loss as a consequence of being in a carer role.<sup>1</sup>

There is a current tendency in policy design to focus on the individual consumer without sufficient regard to the relational context of a person's life. Research has shown that there are significant benefits associated with the move to individualised funding arrangements, but the presence of supportive interpersonal relationships is critically important to ensuring that people can access these benefits<sup>2</sup>.

Mental health carers consistently tell us that their primary relationship with the mental health consumer is relational: husband, wife, friend, daughter, son, sister etc. They do not want their relationship defined by the caring role; however, commissioning and service delivery processes effectively confines them to this limiting identity.

*The economic value of informal mental health caring in Australia*<sup>3</sup> report highlights that Australia's 240,000 carers for people with mental health issues contribute informal support which would cost the government an estimated \$14.3 billion to replace per annum.

**These carers could be children and young people who experience reduced educational and employment opportunities, with 71.4% aged between 15-24 studying or in paid work, compared to 91.3% of their non-carer counterparts. Many of these carers are also parents and grandparents well into their twilight years.**

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<sup>1</sup> Cummins, R et al. Special Report 17.1. **The Wellbeing of Australians – Carer Health and Wellbeing**. Deakin University October 2007 p. vi–vii

<sup>2</sup> Meltzer A, Davy L. **Opportunities to enhance relational well-being through the National Disability Insurance Scheme: Implications from research on relationships and a content analysis of NDIS documentation**. Aust J Publ Admin. 2019; 1–15

<sup>3</sup> Diminic, S. et al. 2017. **'The economic value of informal mental health caring in Australia: summary report'**. The University of Queensland, Brisbane.

Without a significant cultural shift and strong leadership alongside a significant increase in investment in the mental health system, including a conscious specific investment supporting the contribution of carers, this vital \$14.3 billion network of support is at risk.

**If a carer is no longer able to provide ongoing support, the person with mental illness can become more at risk of hospitalisation, homelessness and suicide. These impacts in turn, flow on to the federal, state and territory governments with cost blow outs in health, justice, housing and homelessness, and addiction services.**

Carers continue to meet resistance when trying to access information vital to the carer relationship, and involvement in care planning and discharge. **This must change.**

**Without adequate and appropriate support, carers can see a reduction in their own health and wellbeing, with some becoming at risk of developing their own mental health conditions<sup>4</sup>.**

Tandem applauds the acknowledgement of family and friends (mental health carers) and associated investments made by the Victorian Government in the past year including the release of the *Victorian Carer Strategy*<sup>5</sup> and updated Chief Psychiatrist Guideline *Working together with families and carers*<sup>6</sup>. We also note that no similar acknowledgement or investments have been made by the Commonwealth government. In the absence of adequate and appropriate support services, family members and friends are increasingly meeting the demand for intensive and complex care for people with mental illness. Mental health carers often face different challenges to those faced by other carer cohorts, and consequently, have their own unique support needs. Mental illness has a younger age of onset than most physical health conditions such as cardiovascular, musculoskeletal and neurological disorders. Mental health carers also tend to provide high levels of emotional and behavioural support to the person they care for, making up on average 67.9% of their caring role<sup>7</sup>. Providing these supports, and a range of other day-to-day supports, long-term can have a significant impact on their economic security, health and wellbeing and education.

Mental health carers have been significantly impacted by major reforms to Commonwealth Government funded mental health services over the last few years. These reforms have seen services shift from targeted and specialist mental health support services towards generalist disability solutions. This trend is illustrated by two major reforms to the delivery of community-based mental health services: The National Disability Insurance Scheme (NDIS) and the Integrated Carer Support Service (ICSS). The restriction of discussion on projects and services in the early stages of review and rollout, mean that it is difficult to meaningfully discuss issues around the Integrated Carer Support Service and related carer supports/interventions that fail to meet the evaluations threshold as to their effectiveness and value for money. It is important for the Commission to be aware that it seems highly unlikely that the ICSS will be in any way able to replace the supports that have been removed to make way for the NDIS. This is particularly true of respite services.

Among other issues, many mental health carers are experiencing a significant reduction in the support services available to them. Without adequate and appropriate support, carers can see a reduction in their own health and wellbeing, with some becoming at risk of developing their own mental health conditions<sup>8</sup>. Not only does this lack of support have consequences for the carer, it can also have negative consequences for the person they care for, particularly if it results in the carer being no longer able to perform their caring role<sup>9</sup>.

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<sup>4</sup> ibid

<sup>5</sup> <https://www2.health.vic.gov.au/about/publications/policiesandguidelines/victorian-carer-strategy-2018-2022>

<sup>6</sup> <https://www2.health.vic.gov.au/about/key-staff/chief-psychiatrist/chief-psychiatrist-guidelines/working-together-with-families-and-carers>

<sup>7</sup> Diminic, S et al, op cit

<sup>8</sup> Cummins, R. et al. op cit

<sup>9</sup> Shah, AJ., Wadoo, O. and Latoo, J. 2010. 'Psychological distress in carers of people with mental disorders'. British Journal of Medical Practitioners, 3:3.

If their carer is no longer able to provide them with ongoing support, the person with mental illness can become more at risk of hospitalisation, homelessness and suicide. These impacts in turn flow on to the federal, state and territory governments with cost blow outs in health, justice, housing and homelessness, and addiction services<sup>10</sup>.

Carers continue to meet resistance when trying to access information vital to the carer relationship, and involvement in care planning and discharge. These challenges cannot be met without much greater government acknowledgement and investment.

***“Mental health carers ‘are the unsung heroes in mental health in this country. They will remain the bedrock of the system.’ – Alan Fels, AO<sup>11</sup>***

## Tandem Recommendations

Tandem has identified five critical areas requiring urgent action, based on the specific consultation and advice received from members, Victorian family and friends in mental health, and makes associated recommendations.

### Family inclusive practice is core business

**R1** Carer Inclusive practice is ‘core’ business for commissioned mental health services. As part of their commissioning processes, all jurisdictions require certification against the revised National Standards for Mental Health Services, which includes carer inclusive practice standards.

### Safeguard funding for carer supports

**R2** Safeguard funding for the range of services, which support family and friends in their caring roles including mutual support and self-help, rehabilitation and respite services, which fall outside of the NDIS remit.

### Young Carers as an investment priority

**R3** Invest in young carers as a priority so they are safeguarded from intergenerational transmission of trauma and ensure they are supported to complete their education, obtain employment, and make a meaningful social and economic contribution to the community.

### Carer Payments system reform

**R4** Review the carer payments system, including the 25-hour rule to incentivise carers to re-enter the workforce, increase their hours or participate in educational and training opportunities.

### Address housing & homelessness crisis

**R5** Invest in a ‘Housing First’ approach, and the extension, improvement and accreditation of Supported Accommodation Services for people with acute mental health issues to combat homelessness.

<sup>10</sup> Smith-Merry, J. et al. 2018. **Mind the Gap: The National Disability Insurance Scheme and psychosocial disability**. University of Sydney.

<sup>11</sup> Mind Australia, Helping Minds, Private Mental Health Consumer Carer Network (Australia), Mental Health Carers Arafmi Australia and Mental Health Australia (2016) **A practical guide for working with carers of people with mental illness**

## Carer inclusive practice is core business

There is growing awareness and support for the adoption of carer inclusive practice at all levels of mental health service provision. In 2013 the Government released the national framework for recovery-oriented mental health services<sup>12</sup>. Importantly, this framework described recovery-oriented practice as involving families and friends in the recovery process while accessing their own needs for counselling, therapy, education, training, guidance, support services, peer support and advocacy.

In 2016, **A Practical Guide for Working with Carers of People with a Mental Illness**<sup>13</sup> (the Guide) was released to improve carer inclusive practice across mental health services. The Guide introduced six Partnership Standards designed to improve outcomes by combining the knowledge and skills of staff with the knowledge and lived experience of family and carers in a partnership approach to service delivery across all settings. To date, services around Australia that have used the Guide have reported strong improvement in engaging with carers across all six partnership standards.

Despite these gains, carers continue to tell us that they feel locked out of the system and marginalised in decision making processes that directly and indirectly affect them. Involving carers in all aspects of service planning has multiple benefits, including reducing stress and anxiety and improving the skills and knowledge of carers in providing support to the mental health consumer in their everyday life outside the clinical/therapeutic setting.

**Recommendation 1** Carer Inclusive practice is 'core' business for commissioned mental health services. As part of their commissioning processes, all jurisdictions require certification against the revised National Standards for Mental Health Services, which includes carer inclusive practice standards.

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<sup>12</sup>Australian Health Ministers' Advisory Council (2013), *A national framework for recovery oriented mental health services: Guide for practitioners and providers*

<sup>13</sup> **Practical Guide**, op cit

## Safeguard funding for carer supports

Tandem wishes to bring to the attention of the Inquiry the importance of safeguarding funding for the range of services which support mental health carers in their caring roles. These include those which fall outside of the NDIS remit including mutual support and self-help and respite services.

Tandem consultations with mental health carers throughout Victoria have resulted in a call for the Federal Government to remember that:

- People do not develop mental health issues in isolation. Families, friends and communities are also impacted.
- A safe, responsive and integrated clinical and non-clinical health system where physical and mental health, wellbeing and rehabilitation needs are addressed is essential.

At full capacity the NDIS will only provide support for 10% of Victoria's 180,000 people with severe mental health issues. This presents a problem for those who are ineligible or unwilling to participate in the scheme but still require care for mental health issues. The *Mind the Gap* report states many community-based services are reporting financial difficulties and are either discontinuing programs or running them without funding<sup>14</sup>. Tandem is concerned that as these services close, mental health carers will bear the brunt of these outcomes and that this strain will bring many families and supporters to breaking point.

A growing body of evidence points to the link between providing informal care for someone with mental health issues and developing a mental illness<sup>15</sup>. Without adequate investment in support for mental health carers, demand for mental health services will continue to grow. It is essential that carers and family members can access services that support the maintenance of their own emotional and physical wellbeing. We ask that Government review and safeguard funding for services on which mental health carers rely, including respite which must currently be linked to a consumer, peer support, psychosocial education, assessment, planning and direct service to assist carers in identifying their own support needs. The provision of brokerage for emergency and planned respite, social inclusion and financial assistance for those accessing community supports and not eligible for assistance through the Victorian Carer Support Fund would be an invaluable reform.

The restriction of discussion on projects and services that haven't yet been evaluated, or are in the early stages of review and rollout, mean that it is difficult to meaningfully discuss issues around the Integrated Carer Support Service and related carer supports/interventions that fail to meet the evaluations threshold as to their effectiveness and value for money. It is important for the Commission to be aware that it seems highly unlikely that the ICSS will be in any way able to replace the supports that have been removed to make way for the NDIS. This is particularly true of respite services.

**Recommendation 2** Safeguard funding for the range of services, which support family and friends in their caring roles Including mutual support and self-help, rehabilitation and respite services, which fall outside of the NDIS remit.

<sup>14</sup> University of Sydney. *Mind the Gap*, op cit. 24–25

<sup>15</sup> Savage, S. Bailey, S. The impact of caring on caregivers' mental health: a review of the literature. *Australian Health Review* Vol 27 No 11 2004 p. 104

## Young Carers as an investment priority

Early in 2019 at a face to face consultation, Tandem members expressed to the Commission representatives that it is important for government to be aware of, and make provision for, the needs of different carers - different age groups, different stages of caring, people for whom English is not a first language. Without losing sight of the importance of all of these different areas of need, Tandem would like at this point to particularly draw attention to the situation of younger carers. The terms 'hidden carer' 'secondary carer' and 'young carer' all highlight the fact that there is still a lack of understanding about the complex interplay of a mental health consumer's social support structure. Consumers do not exist in a social vacuum. Young carers face physical, social, economic and institutional barriers to participating. There is not enough support and information reaching young carers in the right way, at the right time, or services to help them. Tandem would suggest that there is a substantial social dividend to be gained in helping younger carers. Younger Australians who experience this barrier to social and economic participation experience compounded difficulty of trying to catch up to their peers in terms of professional and social development. This can begin before university during secondary and primary schools. Couple this with the effects of developing their own mental health issues via intergenerational transmission or trauma and this cohort clearly stands out as requiring particular intervention, but also the cohort with the most social and economic productivity to be regained.

**Recommendation 3** Invest in young carers as a priority so they are safeguarded from intergenerational transmission of trauma and ensure they are supported to complete their education, obtain employment, and make a meaningful social and economic contribution to the community.

## Carer Payments system reform

The Issue Paper framing the scope of the inquiry includes the question: *“Are DSP Carer Allowance/Payments providing adequate income support to those who need it?”*<sup>16</sup> The short answer to this is no. Financial assistance to mental health carers must be responsive to the type of acute and sudden need that mental health carers experience that distinguishes them from disability/frail and aged carers. Tandem would like to echo the points and recommendations provided by Mental Health Carers Australia and the Caring Fairly coalition.

Mental health carers face considerable barriers to participating in the workforce, education and training. The intense and episodic nature of mental illness, combined with a lack of adequate replacement care systems available for the person they care for, make it difficult for carers to balance employment, education and training with their caring roles. This is further compounded for those wanting to enter or remain in the workforce by inflexible or unsupportive workplace culture and design.

Another barrier for carers who currently rely on the Carer Payment from Centrelink for income can be its restriction on a carer’s participation in work and education to 25 hours per week (including travel time). For carers who need to provide care on an unpredictable or episodic basis, this can create challenges when carers need to transition in and out of work or education as their caring role intensifies or reduces. Carers can also find this rule disincentivises them pursuing new educational or employment opportunities as they come at a significant financial risk to them and their families.

Lower levels of employment, education and training for mental health carers, compared to their non-carer counterparts, can have a range of social, economic and health impacts on mental health carers. The financial impacts of limited participation in the workforce are both immediate and cumulative, including lower income, disrupted careers and lower savings and superannuation. Other negative effects of unemployment can include reduced social networks and poorer health outcomes. Reduced participation in the workforce also has negative consequences for government, including lower tax revenue, increased spending on health and income supports.

Tandem fully supports the proposal by MHCA that a full review of carer payments and allowances is undertaken to understand the impact on carer participation in the workforce and educational opportunities. We also suggest that alternative mechanisms are identified, in a co-design approach with mental health carers, to increase carer participation in work and study.

A revised payment system should take into account the unpredictable nature of episodic illness and should specifically address the needs of young mental health carers who face additional disadvantage when supporting a parent who is unable to work due to mental ill health.

**Recommendation 4** Review the carer payments system, including the 25-hour rule to support carers to re-enter the workforce, increase their hours or participate in educational and training opportunities.

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<sup>16</sup> Issue Paper p21

## Address housing & homelessness crisis

Many of the organisations responding to the Productivity Commission will have highlighted the central importance of the issues of housing and homelessness. In particular, submissions from Tandem member organisations, the **Inner South Family and Friends** carer support group in Melbourne, and the network of support groups that comprise the **Loddon Mallee Mental Health Carer Network**, have put the issues of housing and homelessness front and centre of their submission to the Inquiry. Tandem endorses submissions including both empirical observations, and accounts of personal experiences that they have retailed in their submission. Housing and homelessness are crucial issues for the social context of mental health system in Australia. The Issues Paper poses the question, “*What are non-financial means available that would improve the productivity and wellbeing of carers?*” one of the most important means to assist families is to address the housing situation throughout the country. Many Families list this as the most pressing impasse, and their own social disadvantage would be much alleviated by the introduction of a ‘Housing First’ approach, and the extension, improvement and accreditation of Supported Accommodation Services for people with acute mental health issues. In Tandem’s own area of operation, our administration of the Victorian Carer Support Fund, we find that over 50% of claims on the fund are accessed to meet costs relating to consumer/carers home.

Because this issue is one that is of fundamental and crucial importance to any improvement in the mental health crisis currently besetting Australia, Tandem is pleased to note that the Issues Paper includes acknowledgement of some models of the *Housing First* approach.<sup>17</sup> Further to this, and in support of this direction, Tandem would like to endorse points made in the Submission to the Inquiry by the **Council to Homeless Persons**, and the research underlying that submission. In particular, the submission outlines the enormous growth in percentage of presentations to acute services of people who are homeless, the percentage of people who are discharged to homelessness, and the growth in numbers discharged to homelessness services.

**Recommendation 5** Invest in a ‘Housing First’ approach, and the extension, improvement and accreditation of Supported Accommodation Services for people with acute mental health issues to combat homelessness.

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<sup>17</sup> Housing First has a substantial body of internationally conducted evaluation and costings analysis and already has some presence in Australia, with HACSI and The Haven Project running programs with Housing First principles with successes. Issues Paper p21