tandem representing Victorian mental health carers

Tandem Submission to National Disability Insurance Costs – Productivity Commission Position Paper 2017

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SUBMISSION DETAILS

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Organisation's aims and objectives

Tandem Carers is the Victorian peak body representing families and carers of people living with mental health issues. Tandem advocates for carer involvement in planning and carer, participation in system change, and support for families and carers.

Tandem is committed to ensuring that the importance of the contribution, expertise, experiences and needs of families and other carers is recognised, that these needs are addressed with families and other carers of people with mental health issues and psychosocial disability will be partners in treatment, service delivery, planning, research and evaluation.

Tandem welcomes the ongoing opportunity to contribute to the discussions on the NDIS and the NDIA costings and implementation. Tandem would like to highlight the particular needs of families and carers of people experiencing mental illness in relation to the scheme roll out and long term financial sustainability.

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Terminology

Carers – There is no single definition of a carer (Clements, 1996). For the purpose of this submission, the term 'mental health carer' is used to define someone who provides practical and emotional support to someone with a mental health issue including relatives, friends or neighbours. A carer may or may not live with the person they support nor do they have to be identified by the individual with a mental illness to be their 'carer' (NCCSDO, 2005).

Impacts on families and carers

There is clear evidence that carers face ongoing difficulties beyond accessing support and care for the person they support. Living with a person with a severe mental illness impacts significantly upon the family and it can affect relationships, financial status, work, leisure and the mental and physical health of the carer. Carers often feel a sense of distress and isolation as they strive on two fronts: first to understand their relative, who may have confused thoughts and show erratic behaviour, and second, to advocate on their behalf during intermittent contacts with the health service (Purves, 2002). Physical and emotional exhaustion, chronic stress, depression and grief are commonly experienced. Social isolation and low self-esteem, economic losses, decreased life opportunities, and difficulties accessing effective treatment and support services add to the pressures that carers and families experience.

The largest, comprehensive study of subjective wellbeing of family carers in Australia (Cummins, et al., 2007) showed that carers had the lowest collective wellbeing score of any group sampled utilizing the wellbeing scale. 56% of carers were also found to have moderate depression. Cummins et al. (2007) also identified that carers face stressors in employment, with over one third of surveyed carers being concerned about job loss as a consequence of caring, greater vulnerability to physical pain, and greater likelihood of chronic pain (to be carrying an injury and/or a significant medical or psychological condition).

We note that the scheme inception was to improve the lives of family and carers, yet for most of the policy document the outputs, impacts and evaluation of long-term benefits of the NDIS for carers is silent.

> The initiating aim of the NDIS included:
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> - *improved wellbeing of people with disability (and their families and carers)*
> - *better options for people with disability for education, employment, independent living and community participation*
> - *efficiency gains and cost savings in the disability support system and savings to other government services.*
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Funding relies on the scheme making it easier for families and carers to play a supporting role. Further emphasis is required to support carers as a *fundamental scheme enabler*.

As noted by the NDS in their 2017 State of the Sector report, a fundamental platform for the development of the NDIS was co-design, a tenement that has been impacted by issues associated with the speed and ambition of achieving full roll out. We recommend that greater co-design with carers; of all major disability groups be considered.

Mental Illness – prevalence and social impact

Mental illness is the leading cause of non-fatal disease burden in Australia (Mathers, Vos & Stevenson, 1999), a significant cause of death (suicide in 2% of cases) and has major implications regarding economic and productivity burden, reflected in data on lost work days (Lim, Sanderson & Andrews, 2000). The number of people accessing the NDIS for supports related to psychosocial disability, and the translation rates for access requests (80%), highlights that people meet the eligibility criteria in terms of lifetime impacts. We support the excellent recommendations in the policy paper, to better understand psychosocial disability, prevalence and characteristics. As the Victorian peak organisation for mental health carers, we would be happy to actively contribute to the development of case studies that could inform the modelling of reference packages, resource development and greater understanding of psychosocial disability and the needs of carers. In particular Tandem recommends:

1. Greater documentation in relation to supporting people to access the NDIS and participate in planning.
2. We agree with the recommendation to support face to face planning for people with psychosocial disability.
3. Greater clarity about the skills required by planners in engaging with people with psychosocial disability and their families and carers.
4. Greater clarity about the role of support coordinators, in enabling plan implementation and more consistent application of support coordination across roll out jurisdictions.

The role of carers

Deinstitutionalisation, social policy involving a shift away from long term institutionalised care as well as government policy shifts, and shorter periods of hospitalisation, have led to an ever increasing demand for community care. Lefley (1997) states that 'the movement towards deinstitutionalisation has in general imposed on families a caregiving role for which they are unprepared, untrained and from which they have been systematically excluded from in the past' (p.1). The NDIS provides opportunity for carers to be better trained and prepared to support people with psychosocial disability to achieve life outcomes. There needs to be greater consistency in the understanding of fundable items and their need in relation to family training and support. The NDIS has implicit in its financial and philosophical modelling that families, carers and informal supports will continue to maintain a role in care. It is noted that the speed of roll out, lack of scheme transparency, poor planning and lack of appropriate workforce considerations – have been identified as increasing the burden on families and carers. Whilst we note that the NDIS can reduce carer burden long term, through indirect benefits of participants attaining better outcomes – the research highlights the burden of supporting access, administration and enabling plan implementation are further adding to the demand on carers. For mental health carers in particular, further actions are required to:

1. develop clear reference materials specific to psychosocial disability to assist access and planning;
2. develop strategies to support people who cannot access scheme;
3. develop workforce capacity to work with people with complex needs; and
4. provide clarity for families and carers of people with complex needs who may interface several systems (homelessness, justice, drug and alcohol and clinical services) to improve transition arrangements and reduction of risk.

"An independent review of the capabilities of the NDIA described the Agency as 'a plane that took off before it had been fully built and is being completed while it is in the air'."

"…some people with disability are experiencing poorer outcomes under the NDIS and receiving fewer services than previously. Often these are people who cannot effectively advocate for themselves, particularly people with psychosocial disability, and those who find it difficult to navigate NDIS processes."

The findings of the pricing and policy paper are consistent with the findings of International pay as you go schemes of social care – particularly in relation to gaps for people with psychosocial disability and hard to reach participants. Without further focus on psychosocial disability, it will be mental health carers that are again forced to take up the gap in care. Tandem applauds the Commission in its constant investigation to improve the scheme.

The contribution of unpaid families and carers

Most people with a mental illness live in the community with informal carers such as family, friends, neighbours and co-tenants. The Australian Bureau of Statistics data indicates that 60% of carers provide ongoing care for periods of five years or more. The cost of caring and the economic, social and psychological consequences are major social health issues represented across major population surveys. Research released in February 2017

(Diminic, S. et al, 2017) highlights that mental health carers contribute an estimated 13.2 $ billion in care.[1] Most of the support (67%) carers provided is emotional support. Tandem notes that young carers, in particular, were identified in the report as a significant contributor to informal care in Australia. Young carers are often hidden carers, who may find supporting access to the scheme difficult at the same time as major changes within the carer payment framework.

Without investment in maintaining the contribution of carers, this vital network of support is at risk. This is particularly exacerbated by the issues identified within the implementation phase of the NDIS, with the policy paper highlighting a broad range of prolonged risk whilst achieving an ambitious schedule. We note the ILC does not sufficiently address the needs of families and carers, nor does the NDIS priced items. Tandem recommends that a measure to maintain informal supports throughout transition would include the continuation of emotional, educational and respite supports to mental health carers. This measure was missing in the exploration in particular of thin markets, where services may not be available due to lack of skilled workforce. The model introduced in my aged care, which enables carers of people who may not be able to access the scheme, to have easy and quick access to a range of supports would appear worthy of further cost effective exploration.

We recommend:

1. Greater focus on evaluation of outcomes for mental health families and carers (wellbeing, economic outputs).
2. Retention of fully funded carer support strategies through transition, with evaluation at full scheme influencing policy and decision-making.
3. Better targeting of ILC to families and carers in a more consistent manner, rather than ad hoc small grants.
4. Increased focus in plans on the support and training for families and carers as a funded item – so that they can maintain care and develop strategies to support the plan participant.
5. Greater training for planners and Local Area Coordinators (LAC) providers in responding to the needs of carers.
6. Systemic inclusion of families and carers, with assessment of carer need.

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[1] The economic value of informal mental health caring in Australia https://www.mindaustralia.org.au/assets/docs/Mind_value_of_informal_caring_full_report.pdf

7. Greater pricing flexibility to address gaps in regional and rural areas; and for services to take up working with high risk and people with complex needs.

"Of organisations unable to meet demand, 10% reported that clients went without any service, over a third said the needs of clients were only partially met by other organisations and **14% stated clients' needs had to be met (at least in part) by family or other supporters"** NDS state of the disability sector 2016. P.16

Response to areas for consideration

The complexity and intensity of scaling up from 30,000 NDIS participants to 460,000 by mid-2019 is challenging governments, the NDIA, participants with psychosocial disability, families and carers and service providers. Trial sites had unique approaches and systems have not been transferable to the scale up at such a rapid pace. Withdrawal of state funding at the same time has created added pressure and service gaps for participants and their families / carers. Service providers, participants and families have born the brunt of substantial problems associated with roll out in North Eastern Melbourne Area (NEMA), Central Highlands and Loddon. The introduction of on-line payment platform 'myplace portal' interrupted payments for supports, and had particular impact on self- managing participants and their families and carers as they built substantial arrears with service providers.

The introduction of My first plan, telephone planning and implementation of LAC at the same time as roll out – has further added to the uncertainty, and lack of cohesive approach to access and planning. Tandem has received considerable feedback that this changeability makes it very hard to support participants and families and carers to properly navigate and transition to the NDIS, on top of specific issues that are related to mental ill health.

Tandem has reviewed the policy paper in detail and offers the following comments in relation to key proposals and areas of discussion:

Comment 1: Estimating the number of participants with psychosocial disability

Agreed. Transparency of the model will enable families and carers to understand how decisions are made in the case of rejected applications and plan reviews, enabling them to support the person they care for. It would also enable a more consistent approach for Tandem to advise members and broader carers, and provide advocacy in the context of mental health and the NDIS.

Comment 2: Application of reasonable and necessary

Tandem notes the difficulty in the application of 'reasonable and necessary' in the NDIS framework. In relation to episodic illness, carer input into determining what is reasonable and necessary is advantageous if not essential. Families and carers report that the determination of this appears to vary with planners, and NDIA. Greater consistency would be helpful, but flexibility may be required. Transparency in the guidelines and feedback processes from NDIA reviews and appeals would be useful within a legislative framework.

Comment 3: Greater focus on pre planning

Agreed. Tandem supports the earlier implementation of LAC providers to enable participants and their families and carers to be supported prior to NDIS roll out and have a more consistent approach to pre-planning.

Comment 4: Improve transparency and clarity around planning processes

Agreed. Tandem notes that in a Victorian context, there is a lack of consistency in approaches across LAC providers which have impacted our ability to advise families and carers in what to expect from the NDIS access pathway. This variation includes phone planning; full end to end planning and minimal planning approached across 3 roll out areas thus far. Many people with psychosocial disability have been exited as 'withdrawn – four phone contacts' or 'phase in decline: declined service' – simply because of behaviours associated with mental ill health (frequent moves or changes of phone number, not answering the phone, not understanding the purpose of the call – declining an insurance sale, paranoia about phone calls, lack of insight or elevated mood). A more comprehensive approach should be developed in relation to eligibility calls and processes to ensure illness is not escalated and families have appropriate support in the early roll out periods across Victoria.

Planners should, at a minimum, have a general understanding about different types of disability. The Commission recommends specialised planning teams for some types of disability, such as psychosocial.

Comment 5: Planning expertise

Agreed. It would be sensible to leverage expertise from within the industry, and gain specialist input. Tandem supports both the use of specialist teams for the assessment and planning processes with people with psychosocial disability; and the gathering of specialist input from disability (mental health) organisations in the planning process. An oversite or advisory role filled by a person with specialist experience within the NDIA would be useful, and would not likely give rise to competition with the sector. We note that families, carers and people with psychosocial disability and their supports, do not only liaise with LAC planners, they have multiple contacts with agency representatives. General mental health training may be useful to consider as part of induction, alongside training in family sensitive practice. We recommend the latter also be mandated for LAC providers in the application framework.

Comment 6: Interface between supports and withdrawal of existing services

"It is important that governments do not withdraw from services too quickly, as any gaps that emerge will place added burdens on people with disability and their families".

Agreed. Tandem notes that Victorian mental health programs including outreach support and housing will have all funding withdrawn as the NDIS rolls out. Whilst continuity of care for people who are not eligible has theoretically been negotiated, families and carers are facing difficulties for people who have been cancelled or found ineligible for the scheme for a variety of reasons. We support a slower withdrawal of support which ensures the burden of care does not fall on carers in any gap period.

Comment 7: Effectiveness of ILC

Agreed. Tandem notes the lack of focus on families and carers in the context of ILC and the withdrawal of National respite programs. For ILC to be effective, it needs to support the wellbeing of people with psychosocial disability and their families and carers.

Comment 8: Considered and timely approach is needed to address access issues in thin markets

Tandem agrees that a more considered approach to supporting thin markets and supports to people with more complex mental health presentations. Our members report difficulties in finding providers for high risk participants, which means families and carers may be unable to support connection with services at a minimum price point as services do not have the qualified staff, or are unwilling to enter the risk of claims at the price offered. Urgent discussion is required to assist people with psychosocial disability to reduce the level of disability over time and to assure families and carers of much needed support.

Comment 9: Mitigating the potential workforce shortage over the short term

Tandem believes there are other measures that warrant exploration in helping build workforces in thin markets. This may include a broader review of rural and regional designations for pricing. Many of our carers live in rural and regional Victoria, where support would be 1 – 5 hours away. Our current systems including state services and PHaMs allow workers to travel distance to provide psychosocial supports. For family members to take people to regional hubs would add to carer burden, and many participants lack transport (a member provider reported at least 70% of current participants do not have a car). The use of market attraction techniques, consideration of transport within packages, higher rates and some block grant funding for people with complex needs could mitigate gaps short term. Alternatively the phasing decline of PHaMs and Respite programs could be reviewed to enable to service provider market to establish in the short term. Skills and relationships are important, and bringing in overseas workforce is not an adequate solution for rural areas.

We recommend that the Commission review the work of Laragy, Brophy and Sanders, 2017[2] for a comprehensive literature review of risks associated with employment of families and carers in pay as you go schemes. In particular we feel concern that lack of market stimulation could lead to little choice for families to feel forced into low paid carer roles, contribute to stress given the need to administer and seek payments, do bookkeeping etc. and ultimately risk as carers are carers not small business people. This latter risk features heavily in overseas data where carers made mistakes in payments; and schemes were open to abuse.

A further option to consider is greater focus on supporting self- management for participants, families and carers; which may broaden options in terms of attracting or negotiating flexible support options. Training and support in self-management and consideration of administrative burden would further assist this.

We note that people become carers, not through choice, but by necessity. Mechanisms that limit the choice and control of families and carers to exercise the right to not play an active caring role has its own distinct implications which requires consideration.

Comment 10: Workforce development responsibilities

Agreed. Tandem notes that the Victorian Government is withdrawing funding as part of the NDIS roll out, having committed all of its funds as part of the bilateral agreement. Whilst considerable gains have been made in the Victorian workforce policy area to include family sensitive practice, Tandem is concerned that pressures within the pricing model will reduce service provider willingness to recruit and train appropriately qualified staff. The NDIA or the State and Territory governments should take a lead in providing free training to LAC, NDIA planners and the emerging market sector in the development of appropriate skills to support people with psychosocial disability and their families and carers. This would seem in keeping with the market stewardship role of the NDIA.

Comment 11: Assistance to participants to implement their plans

Agreed. Tandem notes that access to the scheme, the ad hoc responses from planners, the need for review and appeal of plans (and access) and the timely connection with support coordinators and services have added to the distress of families and carers. The estimated timeframe (from plan approval to supports being provided) in the roll out regions is currently 12 – 16 weeks, leaving participants with no supports and families and carers vulnerable. Tandem applauds the work of NDIA in NEMA in its advocacy and market steward approach, ensuring that all people with psychosocial disability were to be provided with support coordination and face to face

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[2] Implications for family carers when people with psychosocial disability have individualised funding packages – literature review. https://www.mindaustralia.org.au/about-mind/research/mind-reports-and-presentations.html

planning. Whilst this did not occur early in roll out, families and carers appreciated the development and implementation of this approach in NEMA.

Greater consistency of such approaches is required across regions. We also note sector feedback that people are withdrawing from the service delivery end of the market, in favour of only higher costed service items (support coordination, counselling). There is some anxiety that support coordinators are facing difficulties with finding appropriately skilled services to refer people to for support. The issues of pricing and market levers needs to drill down into the specifics of what systems is the NDIS replacing, and what were the skills of that workforce. This is of particular urgency for people with complex needs, where the cost of delivery and risks attenuate, may mean that people choose not to work with highly complex clients. This again will have flow on impacts for families and carers.

The administrative burden is high for families and carers – as they are often left to be the ones who ring services and negotiate changes. Carers report that relationships can be difficult for participants to form; and that the lack of specialist services available for appropriate support and the disruption to existing support providers is leading to escalation of disability and flow on effects for families. The use of disability agencies with specialist knowledge of mental health would be supportive; and the guarantee of support coordination and intermediaries would reduce burden. We recommend reviewing of International scheme data (Laragy, Brophy & Sanders, 2016) on the impacts of administration and plan implementation, and models that have offered the most support. We acknowledge that the NDIA by offering three levels of management has shown best practice[3].

Comment 12: Strengthening clarity and transparency of governance arrangements and processes

Tandem agrees that the lack of clarity in governance arrangements and the relationship between the NDIA, LAC, planning agents and the broader mainstream sector is adding to the distress and burden of navigation for families and carers. We draw particular attention to the need to clarify the relationship between NDIS and clinical, forensic, drug and alcohol and housing / homelessness services to reduce the fragmentation of approach for people with psychosocial disability and their families and carers.

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[3] Implications for family carers when people with psychosocial disability have individualised funding packages – literature review. https://www.mindaustralia.org.au/about-mind/research/mind-reports-and-presentations.html

Comment 13: Enabling agreement between the Australian Government and host jurisdictions

Agreed. Tandem supports better alignment of decision making to ensure that NDIS rules are established in an expedient manner. For families and carers, the delay in rules around SDA has meant uncertainty in relation to housing development and appropriate supported housing options. Tandem supports many ageing carers, and anticipates an increase in the need for suitable supported independent living arrangements over the next ten years.

Comment 14: Improvement to review processes

Agreed. Tandem supports the improvement of review processes and greater transparency of outcomes. Tandem has supported a number of carers who report that the review process lacks clarity, transparency and also the ability to adequately assess and address the support needs of people with psycho-social disability. The distress this leads to, impacts mental health and has negative flow on effects for families and carers.

Comment 15: Performance reporting framework and quality, including the quality of participants' plans

Agreed. Tandem supports better reporting of NDIS performance, and suggests that measures of family and carer well-being be included as a parameter for measurement. The flow on effect of the NDIS on families and carers; and the reliance of the scheme on families and carers to be available to provide ongoing care is unsustainable given the additional burden associated with planning, access and maintenance of supports. We recommend also that the Commission takes note of the report produced in 2017 on the economic costs of caring for mental health carers and suggest that this research is replicated to monitor change in the impacts and ongoing contribution of carers.

In addition to the comments outlined, Tandem recommends the Commission should address the following issues identified in the Heads of Agreement for the review of scheme costs:

- the sustainability of scheme costs that may mean a future increase on reliance on families and carers to fill gaps in care;
- cost pressures (including wages pressures) and whether specialist providers diminish from the market – meaning that families and carers would not find appropriate support services for their family member / friend;
- whether there has been any impact on mainstream services (for example an increase in hospitalisation rates for people with psychosocial disability; access for people with dual diagnosis); and
- estimate the ongoing cost of reductions in carer wellbeing and economic outputs (loss or inability to work due to expected carer burden in administration of the scheme and support to participant).

Summary

Tandem appreciates the opportunity to provide feedback on the NDIS policy paper Costs, and NDIA's ongoing commitment to seeking feedback. In particular we encourage and applaud the recognition of issues associated with the scheme and opportunities to shape future roll out.

The roll out has been difficult across areas, and as a Peak it has been difficult to navigate and support families and carers of people with psychosocial disability due to the changeable nature of roll out, and differences between planners and NDIA personnel responses. Greater transparency, governance and stewardship in the role of NDIA, LAC and other bodies employed in the process of determining eligibility and planning would be helpful. Families and carers fought to have the NDIS and we support its implementation and ongoing success. The inclusion of psychosocial disability happened later in scheme inception, and this is evident in the current implementation, design of supports and understanding of the needs of people with psychosocial disability and their families and carers. Early implementation has left us with concerns however, that the NDIS will add greater burden without any real recognition of carers long term. A shift in practice philosophy from seeing carers as 'free available labour' to partners in planning and implementation is required.

References

Australian Bureau of Statistics (2004). *Disability, Ageing and Carers: Summary of Findings, 2003. ABS Catalogue no. 4430.0*. Canberra.

Carmel Laragy, Frances Sanders & Lisa Brophy (2015). Mind Australia. Implications for family carers when people with psychosocial disability have individualised funding packages – literature review

Cummins, R. A., Hughes, J., Tomyn, A., Gibson, A., Woerner, J., & Lai, L. (2007). *The Wellbeing of Australians – Carer Health and Wellbeing. Australian Unity Wellbeing Index Survey Report 17.1.* Melbourne: Australian Centre on Quality of Life and School of Psychology, Deakin University, Australian Unity and Carers Australia

Diminic S, Hielscher E, Lee YY, Harris M, Schess J, Kealton J & Whiteford H. The economic value of informal mental health caring in Australia: summary report. Brisbane: The University of Queensland; 2016

Lim, D., Sanderson, K., & Andrews, G. (2000). Lost productivity among full time workers with mental disorders. *Journal of Mental Health Policy and Economics*, *3* 139-146.

Lefley, H. P. (1997). Synthesising the family caregiving studies: implications for service planning, social policy and further research. *Family Relations, 46*(4), 443-450.

Mathers, C., Vos, T., & Stevenson, C. (1999). *The burden of disease and injury in Australia*. Canberra: Australian Institute of Health and Welfare.