Improving the NDIS Experience:

NDIS Participant Service Guarantee Discussion Paper

Tandem Inc.
Representing Victoria's mental health carers

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tandem representing Victorian 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 DSS 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 Victorian Council of Social Services, Mental Health Carers Australia.

Tandem appreciates the opportunity to provide feedback on behalf of mental health carers. We commend the Federal Government for their review of the processes and timeframes of the National Disability Insurance Scheme, and the inception of the Participant Service Guarantee.

This discussion paper speaks to opportunities for reform across Access, Planning, Review and Appeal processes. We refer to our ongoing direct engagement with mental health family and friends (carers) and our recent consultation on October 15 2019 with families and workforce. Tandem welcomes the recent announcement of the 'psychosocial disability stream' and recent changes within the NDIA to improve timelines, and the broader experience of the NDIS for participants and those supporting them.

Carers face significant challenges in accessing the NDIS with, or on behalf of, a person they support. It is difficult at times for carers to speak directly to the NDIA on behalf of a family member, where service providers have initiated the NDIS Access process without consulting the carer for their input. In such instances, the primary carer has not been registered as Plan Nominee.

There is clear evidence that psychosocial participants' healthcare outcomes are linked to the capacity of a family to advocate and speak up and the NDIS has compounded this. (Olasoji, Maude & McCauley, 2017) When writing a Carer Statement to represent their own needs in an NDIS plan, carers have expressed shock and sheer exhaustion regarding the extent to which they are relied upon to administer and coordinate within the NDIS. Carers face this additional workload alongside existing responsibilities in supporting communication, daily prompting, assisting with health management, and providing emotional support to a family member with mental health issues.

In outlining their story to an NDIS planner to ensure a person's needs are met, a carer will need to retell the story of family illness, which can trigger grief, loss, and overwhelm. A recognition of overall family strain at the time of the meeting as a component of the assessment is also important such as risk assessments to carers, siblings and others to gather information about their wellbeing.

Tandem and other organisations providing services to mental health families work within the frame of 'relational recovery' which considers whole family need and wellbeing. The NDIS Access Pathway is designed in a way that prioritises the need of one family member above the needs of all others. This individualistic approach does not align with typical family group functioning and can be detrimental to healthy family life. A clearer outline of ways in which NDIS may be utilised to support whole family outcomes, improved social connections, and to redress trauma from whole family experiences of health systems, would allow carers to see themselves in the discourse around NDIS. At this point in time, carers have difficulty identifying a starting point for accessing services even after receiving a plan due to this individualistic approach.

There has been no explicit outline of the purpose of a Carer Statement and how it is used within the NDIS process to inform the outcome of a plan. Carers face barriers in articulating the needs of the immediate family around the person, ensuring their own needs, and the needs of siblings, children, partners etc. might be considered within the planning process. Further, carers report that both Carer and Participant statements are not being accepted within Planning Meetings. This has been true both with Local Area Coordinator (LAC) information gatherers, and NDIA delegates.

When families raise the topic of Support Coordination within a Planning Meeting, Tandem has observed a lack of objective information gathering including an effort to persuade families that the support proposed will be reasonable for them. Families are experiencing an increasingly adversarial approach in this regard, including a disregard of the impact of family strain on their own life.

Families would feel further supported to be assured of Support Coordination as an age-appropriate mechanism for adults to manage their own health services, and for this not to unduly fall to families. Clarity regarding the likelihood of receiving this service would reduce carer anxiety leading up to review meetings. An understanding of provider of last resort arrangements would also support this group.

Inconsistencies in the approach to assessing need and inconsistencies in how Carer and Participant statements are utilised to inform the funded package of supports create increased demand for review, inefficiencies in the Access and Review process, and in turn, increased distress and delays for carers in achieving good outcomes for their family member. Greater transparency and clarity within the NDIS Act to further name carer rights and reasonable limits, and echoed in the Participant Service Guarantee, would improve the NDIS experience for carers.

Section 34 (e) states 'the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;'

Tandem have found that Section 34 (e) is interpreted by LAC / NDIA staff in two ways.

1. In some jurisdictions it is interpreted as though the informal supports are in place to provide assistance first, and then an NDIS package supplements this.
2. In other regions, the emphasis is to consider first, what is reasonable for families in an age appropriate sense – and the sustainability of this role over time, including the impact of this additional role on relationships in the participant's life. This second approach appears to be the way in which the Act is intended to be interpreted.

Clarity regarding the expectations of carer involvement and reasonable limits, and further, regulation to ensure implementation is in keeping with the principles of the Scheme across processes of Access, Planning, Review and Appeal, would improve family experiences.

The streaming of an NDIS participant occurs at the time of Access. This is not a transparent process. Families do not have the opportunity to discuss the detail of family circumstances, the functional impairment of their family member, or how that impacts their role at this early phase of engagement in the Scheme. Streaming impacts the likelihood that the planning meeting is held with a Local Area Coordinator (LAC) rather than an NDIA planner. As families are not aware of this distinction, they are unable to advocate for their individual circumstances effectively. This is one such example of a lack of transparency, increasing the likelihood that the participants' needs are not appropriately assessed.

Clarity around the scope and meaning of Section 34 (f) of the Act regarding ensuring that the NDIS is the most appropriate system to fund supports would improve the family self-advocacy experience. Particularly in complex circumstances, this has been wrongly interpreted by some service providers as a reference to the COAG agreement with some refusing to offer service within a health setting, for example, to a resident of a secure residential unit, even though other residents in the same facility have access to those supports. Families find themselves interpreting these types of situations at great cost to their own wellbeing, in an effort to improve the quality of life and range of services available to their family member. This highlights a gap in Care Coordination across the scheme, and clarity around how systems can reasonably overlap to offer services. It is heartening to hear some progress may be on the way in this area with Mental Health Coaches and other supports to reduce strain on families. Tandem would be pleased to hear further information about these developments.

Broadly, our consultation with families found that concerns exist in the lengthy timeframes, bureaucratic nature of processes, and communication style of the scheme. Families would appreciate an ongoing collaborative approach to all aspects of NDIS systems improvement, plain language in all communications and consistency across regions in ways families are valued and considered. Improved integration with existing and emerging services to this group, such as carer services and broader State and Federal systems, would also improve family experiences.

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.

Carer inclusive practice is core business

R1 Family-inclusive practice training for NDIA and LAC staff

Trauma-informed engagement

R2 Reviews and Planning meetings to be conducted face to face. No further phone-based Reviews

Reduce red tape to increase access and plan utilisation

R3 Improve clarity regarding appropriate supported decision making within Access and Implementation to reduce barriers to holistic support to consumers and their carers

Clarity regarding the carer role and reasonable supports

R4 The following amendments to Section 34 of the NDIS Act:

- That the Carer Statement is accepted by a planner and given equal weighting in decision making as other reports and evidence provided in relation to the circumstances of the participant
- To more clearly outline the extent of the role of informal supports and limit expectations of carers
- To include clarity regarding the provision of Support Coordination, and other Capacity Building supports with a reporting and care coordination role to directly supplement or replace carer administration of the Scheme

Transparent, accessible and honest processes

R5 Improved transparency regarding:

- ‘Streaming’, to allow improved family and participant self-advocacy at the beginning of Scheme access
- Provisions for families supporting a person with complex needs in their own right, including but not limited to the support provided to family members with psychosocial disability and co-occurring disability
- Access to the Complex Support Pathway and Psychosocial Pathway and other specialist streams
- Instances where a family may be unduly disadvantaged if technical knowledge of the scheme rather than plain English plays a role in self-advocacy