

Tandem response to the NDIA regarding Access and Eligibility Policy with Independent Assessments

National Disability Insurance Agency
And by online submission

Tandem Inc.
Representing Victoria's mental health carers

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About Tandem

Who we are

Tandem is the peak Victorian not-for-profit body for carers of people with mental health issues and organisations with a carer-support focus.

What we do

- Tandem helps raise community awareness about mental health issues and the challenges faced by carers of people with mental health issues;
- provides information, education and training to Members and others involved in caring for people with mental health issues;
- ensures state and federal governments recognise the role, contribution and needs of the carers of people with mental health issues;
- facilitates communication between carers, government and other stakeholders in the mental health system;
- advocates for policy changes and improved services to address carer needs;
- supports carer participation in the planning, delivery and evaluation of services for people with mental health issues and their carers;
- facilitates the development of relationships between carers and carer-focussed organisations and other stakeholders in the mental health service system, and facilitate the establishment of partnerships between carers and service providers; and
- encourages research on best practice in carer support.

Who is a mental health carer?

- a) a family member, partner, friend or other person;
- b) of any age; who will commonly:
- c) be actively involved in caring for and supporting a person with mental health issues, with this role not necessarily a static role, but rather a role that is capable of fluctuation over time according to the needs of the person with mental health issues and the carer;
- d) have their life impacted by the wellbeing of the person with mental health issues; and
- e) undertake for the care of and support of a person with mental health from *Tandem's Rules of Association, 2019 p.2*

Details

Name and address of applicant:

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Authorised by: Marie Piu

Position in organisation: Chief Executive Officer

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 welcomes the opportunity to provide feedback to the NDIA on its consultation paper regarding access and eligibility with independent assessments.

In this response, we outline our concerns regarding the proposed change, as it relates to individuals with psychosocial disability who are in the Scheme or attempting to access it with the support of their family and friends.

Our response has been informed through consultation with our members (Victorian mental health family and friends) and the wider sector, and we provide in this response recommendations for the NDIA act upon to address our concerns and improve the accessibility, equity and fairness of the Scheme for those with psychosocial disability and the family and friends who support them.

Access and Eligibility Policy with Independent Assessments

Tandem has the following concerns with the proposed policy to introduce Independent Assessments. Our concerns address the Terms of Reference as set out in the Joint Standing Committee's submission invitation:

Summary of Key Concerns

- They will create additional barriers to access and adequate funding in plans for people with psychosocial disability
- They will place additional stress on mental health carers and families who already struggle to navigate NDIS process
- A brief point-in-time assessment with an unknown assessor will not adequately capture the needs of those with psychosocial disability whose needs often vary and are complex
- Conducting an assessment with an unknown person could produce distress or discomfort in the person (as well as for the carer) thereby impacting assessment and plan outcomes
- Introducing independent assessments aims to apply a limited range of functional assessment tools to all disability types, and how this can measure psychosocial disability in the time frame of anywhere between 20 minutes to 3 hours is unclear
- It is unclear and there is a concern around how people's existing reports and assessment from treating health professionals, including carer/family statements, will be included and given weight in access and plan outcomes
- Concerns about the validity and appropriateness of assessments when applied to those with psychosocial disability
- Limited avenues for review or to contest assessment outcomes and the impact this will have on people's access to adequate and timely support
- Concerns around availability of suitably qualified and skilled assessors in psychosocial disability and complex needs

The need for NDIS reform is paramount. Issues of equity of access and support budgets are constant themes from people with psychosocial disability and their carers, families and supporters. Access to the NDIS remains a challenging and complicated process for people with psychosocial disability and their families to undertake and navigate. For many people with a psychosocial disability it is just that – the terminology of disability.

Many people living with mental health challenges do not identify with a disability. The language in the mental health sector is not deficit-based, but rather recovery orientated and stigma reducing. There is a carer and consumer lived experience workforce that aims to reduce the stigma of mental health issues and work to people's strengths to promote recovery and hope. By introducing an additional process in independent assessments, there is a risk of creating more barriers for people, as well as additional stress and stigma for the family and friends supporting them.

As with many in the mental health sector, Tandem members expressed concern around the fact that independent assessments will fail to adequately capture the unique and individual needs and circumstances of people with a psychosocial disability. If assessments begin with the person's impairments, how can this foster a person's goals and aspirations going forward?

For someone living with a psychosocial disability, starting the process with what they cannot do is disempowering and dismisses their hopes and aspirations.

In a recent carer consultation, Tandem members expressed concern that independent assessors would be unknown to the person they care for. Up until this year, those applying to participate in the NDIS, or continued participants had evidence from their treating health professionals, who are predominately known and trusted.

“We support people at the pointy end of mental illness. Introducing independent assessments is dangerous for highly vulnerable people” – Quote from a carer participating in the Tandem consultation.

Members expressed concern that this would potentially be very distressing for the person, provoke a level of discomfort and anxiousness in them (as well as for the carers themselves), thereby potentially jeopardising the session and impacting on the assessment outcome. For people living with a psychosocial disability, a high percentage will not articulate the impact of their diagnosis, and therefore run the risk of being left out of the scheme to those participants and their advocates who are able to identify every impairment in order to increase the likelihood of a sufficient resource allocation.¹

This process will further impact the already disproportionate numbers of people with a psychosocial disability who are not or cannot access the scheme. Over one third of people living with a psychosocial disability who apply for the NDIS have their application rejected.² There is an extremely high percentage of those people who do not have English as a first language or those First Nations peoples for whom accessing and understanding the NDIS process is a hurdle too high. Independent assessors need to be culturally aware, sensitive and drawn from these communities to better engage and build trust with participants and their families, carers and supporters.

All carers participating in the Tandem consultation stated they preferred assessments to be done by health professionals known to the person; someone who has built a rapport with the person, who understands them, their needs and history, as opposed to an unknown person completing a brief minimum 20 minute or 3 hour point in time assessment. This does not give sufficient time for the assessor to develop a connection with the participant or engage in a meaningful conversation with the participant’s carer, support person or friend. Questions as to ‘can you dress yourself or feed yourself’ are not simply answered yes or no. There may be considerable time coaching from the carer to encourage the person to dress appropriately for the weather conditions or that the food is safe to eat. These nuances are not picked up in the first instance. This level of communication takes time and trust.

Understanding the nuances and details of a person’s situational context has a substantial bearing on their functional capacity, and ultimately their eligibility for NDIS. This includes their health, additional disabilities, education, work and life experiences, physical or built environment, community environment, family and social supports and economic situation.³ There are no functional impairment tools which have been designed to provide accurate and reliable estimates of reasonable and necessary funding for all impairments/disability types.⁴

The proposed independent assessment toolkit is largely based on self-report measures. For someone with a psychosocial disability this can impact on the outcome of assessment and ultimately the funding allocation. Many people will give the best possible scenario as people living with mental health challenges often do not associate themselves with a disability. OTA (Occupational Therapy Australia) has concluded that the independent assessment toolkit is not fit for this purpose and is concerned that this process impinges on the rights of people with a disability and limits their choice and control.⁵ Tandem agrees with the submission from OTA and add our voice to their concerns that there is also the potential for harm due to inappropriate activity

¹ ABC News, ‘NDIS architect Bruce Bonyhady urges rethink of independent assessments’, Pat McGrath and Alison McClymont, Thursday 18 March 2021.

² NDIA, *NDIS Quarterly Report to disability ministers*, Q2 2020-2021 December 2020, p. 96.

³ Occupational Therapy Australia, Consultation Paper: Access and Eligibility Policy with Independent Assessments, February 2021.

⁴ An analysis of the NDIA’s proposed approach to Independent Assessments: a response to the National Disability Insurance Agency Consultation, Professor Bruce Bonyhady AM, February 2021.

⁵ OTA, February 2021.

choice and failure to draw appropriate conclusions from observations of tasks that were not to be included in the toolkit.

What we heard from carer participants, and what we hear broadly from Tandem members, as well as from our partners in the mental health sector, is that, when it comes to psychosocial disability in particular, the existing and trusted relationships people have with their treating health professionals is vital. As such, their evidence and input should be valued and thoroughly considered in determining access, needs and support funding allocation. Carers state that many of these relationships with treating professionals for the person they care for have taken time to build and ongoing engagement is crucial to a therapeutic relationship where the treating health professional has an understanding of the impact of a psychosocial disability on the person and the families they are working with.

Tandem expresses concern that the independent assessments decision is not reviewable. This appears to be in contrast from the original principals of the scheme for people to have choice and control over supports and services they need to pursue life opportunities. How can the system continually improve and develop if independent assessments cannot be reviewed or tested? The NDIA consultation paper states: “Disagreeing with the results of an otherwise sound and robust independent assessment is not sufficient for the NDIA to fund another assessment. Applicants can only seek a second assessment where the assessment was not consistent with the independent assessment framework, or if the applicant has had a significant change to their functional capacity or circumstances”.⁶

The concern is this policy of introducing independent assessments to determine access and funding will not sufficiently accommodate or account for people’s actual and real needs that we know, where psychosocial disability is concerned, often varies, along with other complex and complicated factors.

Tandem argues, that *if* independent assessments are to proceed, a number of things need to happen, starting with assurance and full transparency from the NDIA about *how* people’s existing reports, evidence and assessments, *inclusive of carer statements*, will be included, thoroughly reviewed and considered as part of this proposed change.

At this point, it is important to note, that all of the carer participants expressed a mix of frustration, opposition, despondence and apprehension about having to potentially go through this process. In part, this speaks to the feeling of stress and pressure many mental health carers and families experience in navigating and journeying through the NDIS system, with this process being another hurdle.

Furthermore, many carer participants vocalised why this process with independent assessments needs to be taken in the first place, where known health professionals can and do provide evidence sufficient to indicate a person’s functional capacity, needs, and circumstances. This feedback confirms scepticism and apprehension from mental health carers about independent assessments, as well as raises questions about who and in which circumstances people with psychosocial disability will be exempt from this process. Currently, this appears only to apply in “exceptional” circumstances of high risk.

Tandem remains concerned about the validity and appropriateness of these assessments when applied to those with psychosocial disability. The evidence base through pilots of independent assessments appears limited in determining how effective they will be for those with psychosocial disability. The pilot learnings

⁶ NDIA Consultation paper: Access and Eligibility Policy with independent assessments, November 2020, p. 23.

paper of September 2020 states: “The number of pilot participants with a psychosocial disability as their primary disability was too low to determine this percentage with any statistical relevance for the group”.⁷

Tandem feels that the lack of detail relating to environmental factors, especially sustainable care from family, friends and supporters must be investigated and requires consultation which includes participants, families and carers. Current proposed assessment tools may have them imbedded however, overall, the tools themselves collectively, are not fit for the proposed purpose of eligibility to the NDIS. Furthermore, there is no indication how the data will be collated from these tools or analysed to determine either eligibility or personalised budgets.⁸

“The assessments identified in the proposed reforms do not in themselves result in a recommendation for funding or supports”⁹ thereby perpetuating a lack of transparency in how a final plan budget is determined. That combined with the lack of any apparent planning discussion, prior to a participant receiving their plan in the new model, leads us to conclude that it is imperative that the proposed reforms are ceased until all factors of the model are released.

Mental health family and friends supporting someone with psychosocial disability want to know more and understand how these assessments will be fit for purpose and tailored to the needs of their loved ones, and people broadly, with psychosocial disability.

They further want to know what avenues will be available to them and their loved ones for review and to contest insufficient assessment outcomes (as these options appear limited), how exactly funding will be determined from these assessments, and what weight (if any) will be given to existing evidence from known supports, how much and how this will occur.

Additional concerns have been raised relating to the proposed development of a plan budget based only on the outcome of the proposed independent assessment process and in the absence of any transparent person-centred discussions with proposed or current participants.

There are additional concerns about the availability of suitably qualified and appropriately skilled assessors to match the needs of those with psychosocial disability, inclusive of any cultural needs, gender preferences, and other specifics, such as dual diagnosis or dual disability knowledge and skills; and what the scope and options will be for people to choose.

In summary, there are many concerns mental health family and friends have about this proposed policy, and with this, many questions remaining, and a need for clarity and transparency from the NDIA. In the first instance, Tandem would encourage more consultation exclusively with NDIS psychosocial participants and their carers and families before proceeding.

In the meantime, we provide here recommendations for best practice in completing assessments for those with psychosocial disability which are inclusive and considerate of the family and friends who support them, in the hope these will be strongly considered by the NDIA in any further decision making regarding independent assessment policy and process.

Best practice approach to completing assessments for those with psychosocial disability that is inclusive of family and friends:

⁷ NDIA, Independent Assessments: Pilot learnings and ongoing evaluation plan, September 2020, p. 15

⁸ OTA, February 2021.

⁹ Response to the Consultation on Proposed NDIS Reforms: Access and Independent Assessments Various Signatories, p. 15.

Summary of Key Points

- **Trauma awareness and a trauma informed approach** is vital when conducting assessments with individuals with psychosocial disability and their families. Assessors should be appropriately skilled and trained in this area and be afforded the time to assess and consult with existing supports (inclusive of people's informal support networks) in planning and preparing for assessment appointments
- **A relational recovery approach** must be adopted by assessors; one that considers the person in the context of their social environment and close familial relationships (a *whole of self*, *whole of family* and *whole of life* assessment)
- Assessors must adopt a **carer/ family inclusive approach** throughout the assessment process
- Assessors must **consider the assessment environment** to accommodate the needs and preferences of both the person and their family; and
- Afford a **flexible, relatable and collaborative approach** throughout the assessment process in support of people and their families.

A trauma informed approach

It is vital assessors adopt a trauma informed approach when engaging with people with psychosocial disability and their family and friends. As part of this, it is critical assessors understand any potential triggers with the person and appropriately plan to mitigate any risks for discomfort or distress for the person and their family.

Assessors must consult with people, their families and existing health professionals as part of safety planning to ensure any risks or triggers are identified and ways for effective engagement explored to ensure a safe and comfortable session.

A person's family is often well placed to advise on effective engagement and inform of any factors to consider in providing safety and a trauma informed response, and as such, they should be communicated with prior to any appointment taking place (with consent of the person).

In addition to the person, the assessor should seek to understand any needs and preferences of the carer or family member to ensure their safety and comfort during the session.

A thorough pre-appointment assessment should take place, including review of all existing information on the person's condition, situation and history, alongside pre-appointment consultation with the person, their family and/ or their treating health professional(s).

A relational recovery approach

Assessors should seek to understand the person and their needs in the context of their familial relationships and environment. This is to say an assessment process should be conducted through a relational lens; one that seeks to understand the person and their needs and goals in the context of those important close relationships around them. Such an approach provides a fuller picture; one that considers *whole of self*, *whole of family*, and *whole of life*.

A carer/ family inclusive approach

Communication

As abovementioned, people's carers and family members should be consulted as part of pre-appointment planning and preparation. Along with the person, they should be informed of the details of the assessment process and what to expect, as well as be afforded an opportunity to ask any questions or express any concerns.

In addition to pre-appointment communication with families, there should be post-appointment follow up, and an opportunity for families to debrief and ask any further questions.

Carer/family inclusion in assessment

During the assessment, appropriate time should be afforded to families to input to the process.

The perspective of families must be heard and respected, recognising that sometimes these perspectives will differ from the person's perspective of their own capacities.

In the proposed Independent Assessment process, peoples nominated "trusted person" is allocated time where the assessor is to ask a series of questions. There needs to be sufficient time with this process, and also care given to the type of questions asked to best provide information about the person from the carer or family member's perspective, as well as to provide a whole of family picture.

Of note, it is unclear to Tandem as to the type of assessment that will be used, and questions asked for this component of the assessment.

Tandem believes there should be more consultation with mental health carers and families about this particular aspect of the assessment to ensure appropriate questions are asked and framed to provide the most relevant and appropriate information.

Consideration of assessment environment

In the first instance, the location of assessment needs to be of the choosing of the person where they feel most safe and comfortable, not the preference of the assessor. For many people, this is the family home. But wherever the assessment takes place, consideration to the accessibility for family members must also be afforded.

A flexible, relatable and collaborative approach

Importantly, the approach of the assessor must be one that is *flexible* to the needs and preferences of the person and their carer and family. As indicated in Tandem's consultation, for people with severe and persistent mental health challenges (psychosocial disability), it may take multiple sessions for the person they care for to complete an assessment. The process must not be rushed. The assessor must also promote a relaxed, relatable and collaborative environment for the person and their carer/ family member(s).

Key Feedback and Actions for the NDIA:

1. We recommend the NDIA **as a matter of priority** further consult with participants and families on independent assessments. There needs to much more consultation with psychosocial participants and families about the design and implementation of independent assessments before they are introduced.

2. The NDIA must be clear and transparent about **avenues available to review** an independent assessment. The current course that independent assessments are *not reviewable decisions* without providing any other recourse for people to challenge an outcome is not sufficient.
3. The NDIA must be clear and transparent about how exactly people's **existing evidence** from known health professionals, and including carer/ family statements, will be included and considered as part of this process to determine access and plan funding.
4. The **assessments** must be **tailored** for psychosocial disability, and assessment tools and outcomes must demonstrate exactly how carer support is assessed. Appropriate carer assessment tools in this process must be scoped and reviewed.
5. The NDIA should consider *carefully* the **scope for exemptions** from independent assessments when it comes to psychosocial disability. Currently, this is proposed for "exceptional" circumstances of high risk or in the event someone is unwell. However, they should be broader than this, with full consideration to the potential impact on the person and their family.
6. Decisions to grant an exemption from independent assessments must be a reviewable decision. The process for applying for an exemption needs to be documented and within that process there should be a legislated **right to appeal** any decision not to grant and exemption.

References

1. ABC News, 'NDIS architect Bruce Bonyhady urges rethink of independent assessments', Pat McGrath and Alison McClymont, Thursday 18 March 2021.
2. NDIA, *NDIS Quarterly Report to disability ministers*, Q2 2020-2021 December 2020, p. 96.
3. Occupational Therapy Australia, Consultation Paper: Access and Eligibility Policy with Independent Assessments, February 2021.
4. An analysis of the NDIA's proposed approach to Independent Assessments: a response to the National Disability Insurance Agency Consultation, Professor Bruce Bonyhady AM, February 2021.
5. NDIA Consultation paper: Access and Eligibility Policy with independent assessments, November 2020, p. 23.
6. NDIA, Independent Assessments: Pilot learnings and ongoing evaluation plan, September 2020, p. 15.
7. Response to the Consultation on Proposed NDIS Reforms: Access and Independent Assessments Various Signatories, p. 15.