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Level 2, 22 Horne Street,  
Elsternwick Victoria 3185  
T +61 (3) 9519 7000

ABN 79 174 342 927

## Submission to the Review of the NDIS Act and the new NDIS Participant Service Guarantee

### Mental Health Victoria

Mental Health Victoria (MHV) is the peak body for organisations that work within or intersect with the mental health system in Victoria. We advocate for reforming the mental health system to ensure that people living with mental health issues can access the care they need, when they need it.

Reflecting the composition of the mental health system itself, our members come from a mix of clinical and non-clinical, acute and community-based, and public and private organisations. In addition, we work closely with stakeholders from a broad range of intersecting systems including aged care, disability, housing, public safety and legal services.

### Key Points

- Improvements are urgently required to better support people with psychosocial disability to ensure quality and safety standards are guaranteed and more providers are not lost from the National Disability Insurance Scheme (NDIS) market.
- MHV welcomes the extensive work currently underway in the National Disability Insurance Agency (NDIA) but improvements must be fast tracked and implementation well timed and monitored.

The following are also required:

- Improved education and training for NDIS and other professionals that provides for a recovery oriented approach allowing for fluctuating needs.
- Improved transparency and communication so that small problems are addressed early, for example, allow participants to see a draft plan before it is sent to the NDIA for approval.
- Improved integration of the NDIS both internally and with other service systems, including:
  - Assistance for 'hard to reach' cohorts to engage, sustain engagement and if they are ineligible, to access alternative supports
  - Adequate role delineation, training and resourcing of NDIA Planners, LAC staff and support coordinators
  - Application of known good practice across the NDIS

- Specific contextualised timeframes and resources to reduce wait times. Include timelines in communication strategy.
- Improved responsiveness, flexibility and adequate supports when a participants needs change or a review is underway, including provider of last resort arrangements.
- Pricing that allows for:
  - supervision, training and professional development of relevant workers
  - the costs of delivering supports to people with complex needs and those living in rural and remote areas
  - the Temporary Transformation Payment
- Mandated periodic and publicly available reporting, including specific reference to people with psychosocial disability across different regions.
- Targets that address unreasonable variances in reporting and mandated reporting of progress towards those.

In addition to the above points, the Participant Service Guarantee should:

- Recognise the expertise of people with a disability and family/carers in the Participant Service Guarantee and co-design associated measures.
- Ensure the Service Guarantee covers all NDIS staff, regardless of whether they are employed by the Agency directly or contracted by NDIS providers.
- Recognise the role of the NDIA and Government as market steward and in provider of last resort arrangements.
- Address the need to provide transparent written and verbal information about the reasons behind a decision, the next steps in the process and ensure the avenues of appeal are understood and available to the participant.

## **Introduction**

MHV commends the Federal Government for undertaking this review and for committing to develop a Service Guarantee for participants of the National Disability Insurance Scheme (NDIS). This is an opportune time to closely examine the Scheme from the perspective of the people it was set up to support and to address the problems that are inhibiting it from fully achieving its objectives.

To date some changes have been made that have improved participants experience of NDIS, however significant work is still to be done, particularly in the following stages of participants' interaction with the Scheme: Understanding, access and eligibility; Planning and plan utilisation; Reviews, appeals and red tape.

Equally important to participants' experience is the NDIS market and the role of the NDIA and other government agencies as market stewards. Transparency and accountability are also integral to ensuring the Scheme's ongoing performance, especially data and reporting. The principles of the NDIS Participant Service Guarantee should be framed with these issues in mind.

MHV acknowledges the work the NDIA has done and is currently doing to improve the experience of people with a psychosocial disability. We note the Government's announcement on 10 October 2019 about the implementation of a 'psychosocial disability stream' within the NDIS, including:

- the employment of specialised planners and Local Area Coordinators (LACs);
- better linkages between mental health services and NDIA staff, partners and;
- a focus on recovery-based planning and episodic needs.

We welcome this announcement and look forward to further details. This and subsequent work by the NDIA and partners may well address some of the concerns outlined in this submission, however to meet the purposes of this review we have fully documented the issues currently experienced by mental health stakeholders.

## **1. Understanding, access and eligibility**

Despite the considerable work being done by the NDIA and LACs (and others) informing and assisting people to access the NDIS, a large number of potentially eligible people with mental illness have not tested their eligibility. The provision of information and support to access the NDIS must be more readily available and tailored to the needs of people with mental illness, especially those from culturally and linguistically diverse backgrounds and those with complex needs (such as people who are homeless or hard to reach).

Some of the continuing barriers people with mental illness reportedly face in applying for the NDIS are:

- A lack of understanding of psychosocial disability by NDIA/LAC staff and professionals who are responsible for providing evidence
- The limited or lack of evidence available because of a person's limited engagement with services
- Fluctuating mental health which impacts one's ability to manage application process
- The prohibitive cost of gaining expert evidence
- People not identifying as having a disability or a need for the NDIS

There are also large numbers of people with psychosocial disability who have tested their eligibility but have been found ineligible. As at 30 June 2019, more than 14,000 (33% of the 42,814) people with mental illness were found not to meet the access requirements or were awaiting a decision<sup>1</sup>. Only 50% of people with mental illness who were transferring from State/Territory services were found to be eligible<sup>2</sup>. Many applicants report that they were found ineligible because they lack adequate or acceptable evidence of: functional impairment or disability; life-long impairment or disability; or an inability to treat the impairment elsewhere.

We continue to receive reports from people with mental illness and their supporters that they are not willing to apply for the NDIS or go through the eligibility process again because they:

- Lack trust or have lost faith in the system
- Are currently too unwell
- Are overwhelmed by the process
- Are unwilling to identify as 'disabled'
- Have more urgent things to sort out, such as housing, stabilising their mental health
- Cannot afford the often prohibitive cost of getting further evidence
- Disengaged from the support service assisting their application following rejection

Some people with psychosocial disability will always require significant support to enter and sustain their involvement with the Scheme, particularly those people who are homeless or have multiple or complex support needs.

<sup>1</sup> NDIS (2019) "People with a psychosocial disability in the NDIS", 30 June 2019.

<sup>2</sup> Handcock, N., Smith-Merry, J. & Borlovic, J. (2019) "Tracking transitions of people from PIR, PHaMs and D2DL into the NDIS: Commonwealth Mental Health Programs Monitoring Project", Community Mental Health Australia & University of Sydney, April 2019.

There are large variances in the proportion of people assessed as eligible and the length of time people are waiting for applications to be assessed. Some people are being told by the NDIA that it is quicker to lodge a new application rather than appeal an eligibility decision. Lengthy, uncertain waits have a considerable negative impact on people's mental health and their trust in the Scheme. People are going long periods of time without adequate support, placing some at considerable risk.

There remain large variations in access and planning decisions for people with psychosocial disability. The Independent Assessment Pilot (IAP) enabled potential participants to complete a functional impact assessment using standardised tools to inform access and planning process improvements. This work should be extended in collaboration with people with psychosocial disabilities and their family and friend carers to address unreasonable variances.

### **Recommendations**

- 1.1. Better fund programs that educate professionals providing evidence for people with a psychosocial disability about access requirements.**
- 1.2. Map the availability of culturally appropriate information about the NDIS for specific cohorts who might be eligible, and make this catalogue publicly available and easily accessible.**
- 1.3. Review roles and responsibilities and levels of support provided to potential participants in the pre and post access request period, especially for people and cohorts who require more support to engage and sustain engagement.**
- 1.4. Ensure assessments are financially accessible and participants are not disadvantaged in applying for the NDIS.**
- 1.5. Support ineligible participants to access alternative supports.**
- 1.6. Extend the work started by the Independent Assessment Pilot in collaboration with people with psychosocial disability.**

## **2. Planning and plan utilisation**

Victorian mental health stakeholders have reported a noticeable improvement over the past 18 months in the planning process for participants with psychosocial disability. Stakeholders have welcomed the following:

- Planning meetings can now take place at a location of the participants' choice and the problematic phone planning seems to be no longer occurring.
- The new plan format is reportedly clearer and easier than before to navigate.
- Participant packages seem to be improving over time with more appropriate supports and funding – although this remains inconsistent across regions.
- NDIA/LAC staff knowledge and understanding of psychosocial disability appears to be improving as the Scheme matures, albeit unevenly across roll-out regions.
- The streamlined access process for PHaMs has been positively received, as has the extension of the time to gather evidence beyond 28 days.
- The option for PIR support workers to remain as support coordinators for their clients due to the introduction of the in-kind funding, although there are some examples of errors being made in relation to this
- Work being undertaken in relation to a psychosocial disability capability framework
- Foundational psychosocial disability training for planners and LACs
- Plans for a specific psychosocial disability pathway within the Scheme

There are however considerable areas for improvement, including:

- Participants sometimes lack understanding of and do not know what to expect from the planning process (at the access stage, 67% of participants with a psychosocial disability said they understood what would happen next with their plan, as opposed to 70% of all Scheme participants<sup>3</sup>).
- There are currently large variances in the length of time people with psychosocial disability wait before receiving their first plan.
- Some participants feel they do not have enough say about what supports are in their plan and that planners value the formal evidence provided or their own view over the participant's.
- People who have more support (from advocates or service providers which are largely unfunded or underfunded) before and during a planning meeting are reportedly getting higher quality plans.
- A recent study of about 1000 participants with psychosocial disability found one quarter of the plans were judged as inappropriate by the mental health staff supporting those participants to access the NDIS<sup>4</sup>. There is an apparent lack of consistency and variation in the planning process and plan appropriateness.
- Consistent underfunding of Support Coordination in plans, despite it being flagged by participants, families and workers as a crucial line item for people with psychosocial disability to help them navigate and access their NDIS supports. Also underfunding of capacity building supports which are more in line with being recovery oriented.
- A large number of people with NDIS plans are (for a range of reasons) not engaging and are therefore without services. Many charitable organisations are responding to hard-to-reach participants by doing unfunded outreach – a commendable response, but in no way sustainable in the longer term.
- Many plans are unresponsive to the changing needs of participants, particularly where a person's mental health deteriorates or they have had another significant change in circumstances (such as moving/loosing housing or relationship changes) since their planning meetings.
- Low plan utilisation occurs because:
  - participants lack of knowledge about how to utilise plans
  - of inadequate support to utilise plans (i.e. support coordination)
  - of waiting lists or lack of providers in the area (see thin markets below)
- We continue to hear reports from participants and providers that plans unexpectedly differ greatly from what was discussed at planning meetings. This increases the likelihood that the review/appeal processes will be triggered.

## **Recommendations**

**2.1 Fast track the roll-out of the NDIA psychosocial disability capability framework and subsequent training / capacity building for NDIS staff.**

**2.2 Ensure quality and consistency of the planning process so that all participants with psychosocial disability, across all regions, receive plans that adequately address their needs. This includes ensuring all NDIA, LAC staff, Support Coordinators and where relevant Support Workers are adequately trained to:**

<sup>3</sup> NDIS (2019) "People with a psychosocial disability in the NDIS", 30 June 2019.

<sup>4</sup> Handcock, N., Smith-Merry, J. & Borlovic, J. (2019) "Tracking transitions of people from PIR, PHaMs and D2DL into the NDIS: Commonwealth Mental Health Programs Monitoring Project", Community Mental Health Australia & University of Sydney, April 2019.

- **Adequately fund Support Co-ordination in plans and recognise that some participants will need this in an ongoing capacity**
- **Adopt a recovery oriented approach in the development of plans, which would include more capacity building supports**
- **Adequate fund plans so they allow for the fluctuating needs of people with mental illness**
- **Where appropriate, ensure advocates, family and carers are active collaborators in the development (and activation) of plans and to manage conflicts of interest**
- **Provide clear and consistent information throughout the process about what is meant by 'reasonable and necessary'**
- **Take timely action to assess and intervene where there are risks to the participant or others by, for example:**
  - **reconciling duty of care and dignity of risk**
  - **reconciling confidentiality and information sharing**
  - **where relevant, implementing participant's pre-arranged plans**

**2.3 Fund an approach that provides support to those NDIS participants who have disengaged from supports or who require additional supports to remain engaged and provide a process of compensation for providers who are already doing this work unpaid**

**2.4 Ensure participants see a draft plan before it is sent to the NDIA for approval, giving the participant the opportunity to discuss plan's rationale with the Planner**

### **3. Integration**

More consideration needs to be given to how the NDIS can be better integrated, both internally, and with other service systems. Integration is a necessary principle to meet the NDIS's commitment to safety and quality.

Along with low level of psychosocial expertise among various NDIS roles, there is an inadequate flow of quality information about participants needs between planners, support coordinators and support workers. Support coordinators and therefore support workers can lack the information required to safely provide support and quite often, where all three roles are involved, there is a lack of communication and consistency between them. This is significantly more problematic when participants' circumstances change and there is an increased need for support, because without a timely response the participant is placed at considerably increased risk.

There is also a need for the NDIS to work better with other service systems to ensure that people who have support needs across various sectors are not left worse off because of their involvement with the NDIS. People who have or develop support needs across other areas of state and federal service provision, such as mental health, justice, health, alcohol and other drugs, and housing require NDIS support providers to be able to recognise these needs and respond safely and appropriately.

Many NDIS participants will need support to recognise such support needs and assistance to access and maintain such supports. In cases where participants are already receiving these services, some level of collaboration/communication between providers is required to ensure supports are providing continuity and in line with the participant's goals.

The Complex Needs pathway, although difficult to access, has had some success across both internal and external integration for some participants and may have some learnings that can be applied to the Scheme more generally.



### **Recommendations**

- 3.1 Develop more effective protocols with other services systems, such as health, justice, mental health, AOD, housing etc. to ensure seamless transitions and role delineation across systems. One example might be, commencing support earlier for people in prison or in inpatient units to plan for release/discharge, which will greatly reduce the risk of reoffending or readmission.**
- 3.2 Review of the roles and responsibilities, training and resourcing of NDIA Planners, LAC staff and support coordinators to ensure improved internal integration, continuity, consistency and responsiveness to the changing needs of participants.**
- 3.3 Examine the successes of the complex needs pathway in providing more integrated support and scale up good practice across the NDIS.**

## **4. Reviews, appeals and red tape**

Many people are finding the review process confusing, frustrating and time consuming. People with psychosocial disability have a need for more information about what they can expect, including timeframes and the reasons behind decisions. The following have been particularly problematic:

- Lack of specified timeframes for the NDIA to make a decision in relation to: a participant requested plan review (NDIS Act 2013 Section 4.8) or a 'reviewable decision' (NDIS Act 2013 Sections 99 – 103). Across different regions, people are waiting very varied amounts of time for reviews to occur (from days/weeks to over a year). There are also instances of people seeing out the life of a plan (often with inadequate or inappropriate supports) before a review has begun.
- The current design of the NDIS doesn't allow for even minor changes or modifications. Any variations to plans trigger replacement of the plan, which is an unnecessarily cumbersome process for a relatively minor change in resources.
- There is growing anecdotal evidence that for many the supports in follow-up plans have been reduced without adequate reason which is leading to a loss of trust in NDIS as a source of 'reasonable and necessary' supports. Carers feel uncertain about the future of the supports provided to their loved ones, which also impacts their own social and economic participation.
- The Administrative Appeals Tribunal (AAT) is an important avenue for appeal. However, at present there are an unreasonable number of NDIS cases before the Tribunal suggesting the review and appeals processes within the Scheme are not working well. This avenue is burdensome for participants, intimidating and costly (legal fees). More needs to be done to ensure that people have access to a fair and transparent process before their only option is to appeal to the AAT.

### **Recommendations**

- 4.1 Ensure resources are directed within the Scheme to reduce wait times.**
- 4.2 Allow amendments to plans in the case of minor changes or additions.**
- 4.3 Allow participants to trigger a review when their needs change.**
- 4.4 Ensure that the higher value plan (or the participant's preferred plan) remains in place when a plan has been reviewed but disputed or is awaiting approval.**
- 4.5 Consider longer plan durations when participants' needs are likely to be more static.**
- 4.6 Specify contextualized timeframes in relevant legislation and regulations, including where it currently specifies actions be undertaken by the NDIA "as soon as reasonably practicable". Action should be required to be completed within a certain timeframe.**

## **5. Thin Markets and Quality and Safety**

Regional and remote areas are disproportionately disadvantaged and market failure is a real possibility. Even metropolitan Melbourne is becoming a thin market for service provision for people with a psychosocial disability, with major providers withdrawing from core support provision. Providers are finding that the NDIS pricing structure does not allow them to engage qualified mental health support workers to provide services. Core support funding only allows for lesser-skilled workers (often with no background experience in mental health), placing risk on the participant, worker and the service provider.

Since Scheme inception service providers, participants, families and peak bodies have been advocating for the need for a skilled and qualified psychosocial disability workforce in order to ensure NDIS supports meet quality and safety standards. Despite modest price increases for some line items, the pricing is still insufficient to ensure an appropriately skilled, qualified and supported workforce.

Similarly, the NDIS still lacks the responsiveness, flexibility and clarity of process to intervene when a person's circumstances change. This is especially problematic for participants who have complex needs and who are in receipt of a larger package, for example, with supports over the weekend. Restrictions placed on planning more flexibly for fluctuations in need and LACs' lack of responsiveness to urgent cases are leaving providers and State Governments to intervene to avoid catastrophic risks. This is unsustainable in the long term.

A service safety net that is responsive, accessible and has clear accountability is urgently required. If a participant cannot secure support for reasons related to the market or a provider withdrawing, the roles and responsibilities of the agencies involved in ensuring the participant does not bear the burden of system failure must be clarified and communicated.

MHV welcomes the NDIA's introduction of the Temporary Transformation Payment (TTP) in the last Annual Price Review. The TTP is a loading that replaces the TSO (Temporary Support of Overheads), designed to assist providers with the costs associated with transitioning to the NDIS. According to the NDIA, the TTP is currently set at 7.5 per cent on the relevant Level 1 Support Item and will reduce by 1.5 per cent each year. Providers must comply with certain requirements to claim the higher price limits. The payment has some potential to financial support providers to sustain service provision while the NDIS market is in transition. However, we urge the Government to ensure that the top up funds are built into participants' plans, rather than forcing providers to seek permission from participants to use their own plan funds and forcing participants to a review if they overspend on their plans because of the TTP.

### **Recommendations**

- 5.1 Introduce NDIS service items that better meet the needs of people with psychosocial disability. This includes an associated pricing structure that allows for better continuity of care and for certain supports to be reliably delivered by people with skill, experience and qualifications in mental health.**
- 5.2 The 'psychosocial disability pathway' and associated measures need to be fast tracked to ensure quality and safety standards are guaranteed and more providers are not lost from the market.**
- 5.3 Ensure pricing is adequate to sustain the ongoing supervision, training and professional development of support workers and support coordinators.**
- 5.4 Pricing should contemplate the costs of delivering supports to people with high and complex needs, as well as the costs of delivering supports in rural and remote areas.**
- 5.5 The NDIA and government urgently clarify the roles and responsibilities in relation to market stewardship and provider of last resort arrangements.**



**5.6 Ensure the funding for the TTP is built into participants' plans rather than expecting participants to go to a plan review if they overspend because of the TTP.**

## 6. Data and reporting

There is insufficient publicly available statistical information to monitor the progress of participants with a psychosocial disability. The data that is available usually covers the entire Scheme at either a national or state level – it is not granular enough to monitor how individual cohorts are faring. Where data is available, more needs to be done to adjust unreasonable variances.

### Recommendations

**6.1 Mandate the NDIA to provide periodic reports covering the following areas and others covered by the NDIS Participant Service Guarantee:**

- **Participant numbers**
- **A breakdown of plan amounts into more specific funding and support categories**
- **A reflection of plan activity (i.e. how plans are being spent across core and capacity building supports)**
- **Wait times for all stages of participants' engagement with the NDIS, including:**
  - **Access requests**
  - **Eligibility and ineligibility rates**
  - **Planning meetings**
  - **Plan approvals (including with SDA and AT)**
  - **Internal reviews**
  - **Participant requested reviews/appeals**

**6.2 Make these reports publicly available and specific to different regions (states/territories) and cohorts, including people with a psychosocial disability.**

**6.3 Where there is considerable variation between regions and if relevant between different cohorts, set targets to address the variance and report on these targets.**

## 7. Potential Principles

The above discussion has raised a number of points relevant to the development of the NDIS Participant Service Guarantee, however the following outlines some additional considerations specifically in relation to the principles proposed in the "Improving the NDIS Experience" discussion paper (red indicates a complete change).

PRINCIPLE	DESCRIPTION	SERVICE STANDARD
Timely		Provide more contextualised timeframes Include timelines in communication strategy Require periodic reporting that demonstrates performance.
Engaged – change to Collaborative		Co-design measures of "valued" Require periodic reporting that demonstrates performance.
Expert	Refer to "NDIS" as opposed to "NDIA" (to ensure all staff and participants and family/carers are covered).	Amend the service standard to recognise: <ul style="list-style-type: none"> <li>- The expertise of people with a disability and family/carers</li> </ul>

	<p>Amend the potential description to recognise:</p> <ul style="list-style-type: none"> <li>- The expertise of people with a disability and family/carers</li> <li>- The expertise of all service providers the participant comes into contact with (LACs, support staff etc.)</li> <li>- The most effective supports may be out of scope.</li> </ul>	<ul style="list-style-type: none"> <li>- The expertise of all service providers the participant comes into contact with (LACs, support staff etc.)</li> <li>- The most effective supports may be out of scope of the NDIS.</li> </ul> <p>Require periodic reporting that demonstrates performance.</p>
Connected – change to <b>Integrated</b>	<p>Amend the potential description to recognise:</p> <ul style="list-style-type: none"> <li>- Carers services</li> </ul>	<p>Amend the service standard to recognise:</p> <ul style="list-style-type: none"> <li>- NDIA/government as market steward</li> <li>- Provider of last resort arrangements</li> </ul> <p>Require periodic reporting that demonstrates performance.</p>
Valued	<p>Significantly expand to cover participants and carers/families.</p> <p>Remove 'and know where to go if they need further assistance'</p>	<p>Replace 'The NDIA ensures that the broad community understands the purpose of the NDIS and where to go if they need further assistance'. This relates to communication. Consider moving this to 'engaged' (below).</p> <p>Co-design measures of "valued"</p> <p>Require periodic reporting that demonstrates performance.</p>
Decisions made on merit	<p><b>Participants and applicants understand why decisions are made.</b></p>	<p><b>The NDIA provide transparent written and verbal information about the reasons behind a decision, the next steps in the process and ensure the avenues of appeal are understood and available to the participant.</b></p>
Accessible	<p>Consider accessibility from a cultural, financial, geographical and disability type perspective.</p>	<p>Recognise that many people require more than just information to make the NDIS accessible.</p> <p>Require periodic reporting that demonstrates performance.</p>
Engaged	<p><b>Potential participants, participants and the broader community understand the purpose of the NDIS and where to go if they need further assistance.</b></p>	

## Concluding Remarks

MHV would like to thank the Government for this opportunity to comment on the development of the NDIS Participant Service Guarantee and NDIS processes under the NDIS Act. We would welcome any opportunity to discuss any of the points raised in this Submission or discuss any future improvements to the NDIS for people with mental illness.