
SUBMISSION

NDIS processes and the Participant Service Guarantee – proposed
legislative improvements
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Lived Experience
A U S T R A L I A

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1. Introduction

Lived Experience Australia is a national representative organisation for Australian mental health consumers and carers, formed in 2002 with a focus on the private sector. Our core business is to advocate for systemic change, empowerment of consumers in their own care, promoting engagement and inclusion of consumers and carers within system design, planning and evaluation and most importantly, advocating for consumer choice and family and carer inclusion.

The Australian Government Department of Social Services (DSS) is proposing changes to the legislation underpinning the National Disability Insurance Scheme (NDIS) to make processes easier and better for NDIS participants. These changes are directly informed by the outcomes of the 2019 independent review of the NDIS legislation (the Tune Review), and the changes the government is proposing would give effect (in whole or part) to 14 of the 29 Tune Review recommendations.

LEA acknowledges and strongly supports the intent of these proposed changes and sees this process as a step in the right direction, in implementing recommendations from the Tune review. We particularly note the highly engaged and informed commitment shown by Senator the Hon Linda Reynolds CSC to NDIS system improvements that truly reflect and meet the needs of people with psychosocial disability. The work the Minister is doing to acknowledge lived experience perspectives is heartening and extremely important.

Whilst LEA welcomes the proposed legislative improvements to NDIS processes and the Participant Service, there are some aspects that we wish to highlight as concerns and for your consideration. Our comments are provided under each consultation area of focus below. We have responded briefly to each consultation question, followed by more detailed comments, where applicable, in the general comments sections in each consultation area of focus.

2. Comments on the proposed legislative improvements

Schedule 1 (Participant Service Guarantee) of the Bill

1. Does the particular Schedule clearly set out the key changes being made to improve participant experiences with the NDIS?

LEA commends the DSS for its focus on the importance of the principles of connectedness, responsiveness and transparency. We acknowledge though that the challenge is in operationalising these value-based principles into everyday practice, given the sector is complex, often fragmented, and slow to change.

2. Could the proposed amendments in this particular Schedule lead to any misinterpretation or unintended consequences?

We believe the values underpinning the principles are sound and should be fundamental to everyday engagement experiences with services, wherever they are delivered.

3. Are there any other changes which could improve the participant experience in the NDIS?

We suggest that greater acknowledgement and involvement by the person's natural support networks (family and carers) in assessment, decisions and plan development should be considered, given they are part of the person's lived experience and day-to-day environment, and so can be vicariously positively or negatively by these processes.

4. Any other general comments.

Principle of Connectedness: LEA commends the principle of connectedness and emphasises the need for a holistic approach that recognised the value of engaging with families, carers, and communities ie. all those involved in providing support to participants and who have lived experience knowledge and understanding of their lives and needs on a day-to-day basis.

Our experience is that there are complexities that can make connectedness across systems difficult, especially where the person may be in hospital and less able to communicate their support needs and any existing supports in place. Family carers are crucial at such times to ensure that fragmented communication is minimised, and clinicians can make their assessments and decisions based on the most current and accurate information. We are also aware that lack of knowledge of NDIS supports and plans across systems can be problematic and can lead to significant delays. Where the person's mental health conditions come to a crisis point quickly and/or unexpectedly, it is important that sectors work together to ensure consistent and holistic care is provided.

Principle of Responsiveness: LEA would like to stress the importance of timeliness to ensure that people with psychosocial disability can access supports when they need them. This is particularly important due to the fluctuating and sometimes unpredictable nature of mental health.

Schedule 2 (Flexibility Measures) of the Bill

1. Does the particular Schedule clearly set out the key changes being made to improve participant experiences with the NDIS?

There are several terms used in the section of fluctuating or episodic disability that are problematic and highly subjective and therefore open to variation in interpretation. These include: 'appropriate treatment', 'managing' a condition, 'substantial improvement' and 'reasonably available' which are all terms that are fraught with interpretation issues which can then lead to inconsistent decision-making by the NDIA which we understand is a key issue that these legislative improvements are aiming to overcome.

This concern is particularly so for the homeless community, people who are subject to orders under the various Mental Health Acts, and indeed any person with more significant psychosocial disability which are likely the very people who need NDIS support the most. Many of their circumstances are fluctuating and the nature of their mental health means that things like engagement and trust must be continually strived for; they are not finite actions that can be ticked off as one-off achievements. These matters go to the heart of psychosocial disability which is unique and different to the needs of other populations served by the NDIS (such as physical disability) where the disability has more finite parameters and known daily and future trajectories and more defined support needs.

2. Could the proposed amendments in this particular Schedule lead to any misinterpretation or unintended consequences?

Whilst these terms remain ambiguous, there is greater risk that they may be misinterpreted and this may lead to greater variation in how they are interpreted and then applied, leading to the development of unintentional inequalities in access across communities and for specific subgroups. It may have perverse consequences by creating these inequalities that are more based on how some individuals or their representatives are able to 'work the system' rather than creating a clear process based on equity of need and sound eligibility criteria.

3. Are there any other changes which could improve the participant experience in the NDIS?

Yes, greater clarity in defining these terms.

4. Any other general comments.

We also note on p.14 'The period of time which is reasonable will be guided by an appropriately qualified health professional and supported by medical evidence.....' Again, we wish to stress the absolute importance of evidence from the person's family, carers and close network supports who are part of their everyday lived environment and know them best, and also their history of needs. Our experience is that, whilst many health professionals have a clinical understanding of people's needs and psychosocial disability circumstances, far fewer have a holistic understanding from the person's lived perspective. Their understanding can be quite shallow and, in some cases, incorrect for a range of reasons. They may have a set view of the person, they may not have developed a relationship sufficiently with the person due to trust issues or issues related to the person's mental health, or they simply may not know the person well enough yet.

We applaud the intent of schedule 2 changes to reduce red tape and improve NDIA responsiveness. However, we have some concern about potential unintended consequences of the simplified payment system that will allow the Agency to make direct payments on behalf of participants so that self-managing participants would no longer be required to pay for supports up front and then seek reimbursement. My own personal experience of supporting my husband to self-manage his small NDIS package is that the service provider has made invoicing errors on more than one occasion and, if I had not picked them up, they wouldn't have been picked up at all. Over the course of 2 years, we have had 5-6 occasions where services that were billed for didn't actually occur amounting to >\$1000 (we were in the middle of the Tasman on a small holiday on one such occasion!). Making payments automatically means there is potential for incorrect billing to go unnoticed, for plan monies to be depleted sooner, and for potential rorts to be undetected. This is a significant concern, from my direct experience.

The ability to make quick changes to plans through a plan variation, without needing to go through a full plan review is very welcome.

LEA supports the implementation of the remaining Tune Review recommendations, in particular the following recommendations yet to be fully realised:

- Recommendation 3, p.45: The Commonwealth provides additional funding for people with disability to navigate the NDIS, with a review of demand to occur as part of the next review of NDIS costs, currently scheduled for 2023.
- Recommendation 5, p.57: The NDIA gives priority to ICT upgrades to enable online access processes and allow people with disability to track the status of NDIA processes relating to them.
- Recommendation 10, p.88: The NDIA develops a comprehensive national outreach strategy for engaging with people with disability who are unaware of, or are reluctant to seek support from the NDIS, with a dedicated focus on Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse communities, and people with psychosocial disability.

We wish to stress that it will be important to ensure that there are supports available to prospective participants during the 'reasonable period of time' while they await the outcome of their application.

Schedule 3 (Full Scheme) of the Bill

1. Does the Schedule clearly reflect the NDIS has moved into full scheme and is available across Australia?
2. Does the Schedule remove all of the parts of the legislation relevant only to the trial and transition periods?
3. Could the proposed amendments in the Schedule lead to any unintended consequences?
4. Any other general comments.

We have no comments to make on Schedule 3.

The new NDIS Participant Service Guarantee Rules

1. Do the Rules provide clarity to participants on the timeframes that will apply to NDIA decision-making? (See Part 3 of the NDIS PSG Rules)

We believe that they appear to do so.

2. Are the timeframes within which things must be done appropriate? Are they too long or too short?

The timeframes seem Ok, though have some concern for the time needed to gather evidence, source health professionals to provide the necessary evidence, and so forth. The welfare of the person must be the first priority when considering timeframes.

3. Are the proposed engagement principles and service standards that will underpin how the NDIA works alongside people with disability in delivering the NDIS appropriate? Are there additional particular types of consultation or engagement important to consider? (See Part 2 of the NDIS PSG Rules)

The proposed engagement principles are welcome, as stated above. People with lived experience of psychosocial disability must be included as partners at each and all levels of decision-making. This includes their full involvement in research design and conduct of research with people with psychosocial disability who are involved with NDIA and seeking or in receipt of NDIS packages.

4. The Commonwealth Ombudsman will provide an annual report to Government on the NDIA's performance in delivering the Guarantee. The Rules set out what will be in that report. The Rules also set out the things the NDIA must report on in its quarterly report to Governments. Do the Rules clearly explain how both of those reports will ensure the NDIA delivers on the promises of the Guarantee? (See Part 4 of the NDIS PSG Rules) NDIS processes and the Participant Service Guarantee – proposed legislative improvements
5. Any other general comments.

The new NDIS Plan Administration Rules

The Rules include parts of the law originally contained in the Plan Management Rules – e.g. grace periods (section 6 of these Rules), payment of NDIS amounts (section 9 of these Rules). These parts do not constitute new policy.

1. Do the Rules clearly set out the circumstances in which a participant’s plan can be varied, and the circumstances in which the NDIA would ordinarily first conduct a reassessment? (sections 10, 11 and 12 of the Rules)

These circumstances appear to be clear.

2. Do the Rules clearly explain the options a participant has to work with the NDIA to ensure their plan remains fit-for-purpose? (sections 10, 11 and 12 of the Rules)

These options appear to be explained clearly. We wish to stress the importance of the person being informed at each and every step, and to emphasise the importance of maintaining genuine choice and control in relation to decisions made about their plans, given the perceived power imbalances that can exist between service providers and service recipients.

3. Does the proposed alternative commissioning power clearly set out the circumstances under which the NDIA could support a participant to maximise choice and control? (section 5 of the Rules)
4. The Rules include details on the responsibilities of persons receiving NDIS funding to keep records about how those funds were spent. Is it clear what their responsibilities are? (section 9 of the Rules)

These responsibilities appear to be clear.

5. Any other general comments

Changes to the NDIS Plan Management Rules

1. Do the Rules clearly set out the circumstances in which a support must be specifically identified in a plan? (section 6 of the Rules)
2. Do the Rules clearly set out the things the NDIA will consider in protecting participants from provider conflicts of interest and help them maximise the benefits of their NDIS funding? (Section 8 of the Rules)

We believe these are clearly set out in the rules. We wish to emphasise though that the greatest challenge will be in how the rules are then operationalised and monitored. We believe this is difficult to achieve at the interpersonal level and recognise that many abuses of power can occur on a continuum from persuasion to outright coercion. Many people with psychosocial disability fear speaking out about incidents where COI and abuse of power relationships occur for fear of losing their support, or simply because of the disruption and inconvenience that it can cause, and the energy required in changing support providers. Some individuals may struggle with understanding boundaries due to their psychosocial circumstances, particularly if they are more social isolated and marginalised. This makes them more vulnerable and less likely to report issues of concern.

3. The Rules set out the considerations taken into account when a participant or their representative request to self-manage their NDIS funding, or use the support of a registered plan management provider. Is it clear how these considerations are designed to protect participants from unreasonable risk or harm? (sections 9 and 10 of the Rules)

These considerations appear to be clear.

4. Any other general comments

3. Further comments

It is unclear how the new eligibility criteria for psychosocial disability interact with the Psychosocial Disability Recovery-Oriented Framework which is being developed.

The proposed legislation changes do not solve the issue of people with psychosocial disability not being able to meet access requirements - those who have fallen through the gaps and have limited 'evidence', including people who, due to their disability, are reluctant to access ANY services. Our Missing Middle reports captured the experiences of many people with psychosocial disability who have disengaged with services for a broad range of reasons. Gathering evidence for the NDIS requires that records are available and that life is organised, links to professionals who likely hold that 'official' evidence are established and maintained, and that they are accurate and trusted by the person too as sources of their needs. Our experience, and what people told us in our Missing Middle research, is that many of these requirements simply don't exist or are problematic for many people with psychosocial disability. Please see: <https://www.livedexperienceaustralia.com.au/missingmiddlemedia>

We believe the proposed changes could go further in clarifying the ability to swap and change core and capacity building supports which is an essential aspect of flexibility and responsiveness for people with psychosocial disability. These possible changes were discarded when Independent Assessments were taken off the table.

We are also concerned about the requirement that the Minister will now need to ensure the financial sustainability of the Scheme. This opens the door for government to review the funding of the scheme which may have unforeseen consequences for individuals and providers. Existing NDIA pricing means that lower skills workers, and those in transition to other roles and employment, are likely to be the norm in provider organisations. This means that people with psychosocial disability may not be receiving very good quality services. Our experience is that, whilst some providers and their workers are brilliant, others have lower skills and some are quite paternalistic, which undermines the very purpose and philosophy of the Scheme.

Related to the above concern, we are aware of more plans coming through without Support Coordination or plans with Level 2 Support Coordination but the participants have extreme complexity. There also seems to be no consistency in how these decisions are being applied, or in the plans derived from these processes.

We propose that one solution to solving the issue of bureaucracy and red tape is for the NDIA to provide funding in plans for a case manager who can assist participants and their families to navigate NDIS and state-based services.

4. Conclusion

Lived Experience Australia thanks the Department of Social Services for the opportunity to consider the proposed legislative changes to the NDIS Process and Participant Services Guarantee as they relate to people with psychosocial disability. We hope that these comments are useful in your deliberations and next steps.

We would be very pleased to provide any clarification of the issues raised by Lived Experience Australia on behalf of our more than 3500 members and friends across Australia.

4. Contact

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