

Submission on the proposed NDIS independent functional assessments and personal budget setting process

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Who we are

NSW Council for Intellectual Disability (CID) is a disability rights organisation led by people with intellectual disability. For more than 60 years we have been working to ensure a community where all people with intellectual disability are valued.

We speak up on the big issues, we provide information and learning opportunities, we empower individuals and communities.

Introduction

We agree with the government that there is a major problem with equity of access and equity in NDIS budgets. We also appreciate that the NDIS Act requires the NDIS to be financially sustainable over time. However, we have major concerns about whether the proposed changes will fix these problems and about the adequacy of consultation in formulating the government's plans. The current consultation is about how to implement the government's plans rather than whether they are the right plans.

The government plans

The NDIA proposes that new applicants for access to the NDIS be required to have an "independent functional assessment" to show that they meet the access requirement of substantially reduced functional capacity or psychosocial functioning in one or more of communication, social interaction, learning, mobility, self-care and self-management.

These assessments would also be central to deciding the personal budget, that is the amount of funding for a participant's plan.

Existing participants in the NDIS would also be required to have periodic assessments (at least every five years) to confirm that they remain eligible for the NDIS and what funding they will receive.

There is a list of assessment tools that would be used. The one that would usually be used for people with intellectual disability would be the Vineland.

After the functional assessment has occurred, the NDIA would set a participant's personal budget and put it on draft plan. Then, there would be a planning meeting to consider the person's goals and how they can use their budget to achieve their goals.

The NDIA says that these proposals will lead to consistent and fair decisions about access to the NDIS and about funding in participant plans.

Where CID stands

CID welcomes that the proposals include the NDIA paying for functional assessments. Up until now, the cost and difficulty of obtaining a functional assessment has been a barrier to access to the NDIS for many people with intellectual disability, in particular people from poorer and marginal socio economic backgrounds. Difficulty obtaining adequate assessments also leads to inequity in plan budgets.

However, we have many concerns with the NDIA's proposals as outlined in the consultation papers released in late 2020.

Our concerns about the assessment proposals

• **Compulsion** - Should people be forced to have new assessments done by people they don't know if they have already had assessments done by well-qualified therapists who have the advantage of knowing the person well? The NDIA is concerned that a participant's own assessor may be biased but we argue this is countered by their professional ethics and their greater knowledge of the participant that a one-off assessor will have.

People with intellectual disability have emphasised to us that it is vital that they have a relationship with trust with an assessor. Otherwise, they may not feel comfortable to speak openly.

• **Exceptions**- The NDIA proposes that it should be able to exempt some people from Independent assessments, especially if the assessment will involve risk to the person or a valid assessment cannot currently be done.

However, the NDIA says that the person will still need to provide similar assessment information to show their functional impairment. The problem with this is that many people with intellectual disability will not be able to provide information because they do not have a reliable "informant" who can speak about their functional impairments. This is a particular problem if the person is in gaol where it is extremely difficult to assess functional impairments which are focused on how people can function in the ordinary community.

We say that, if a reliable formal assessment cannot currently be done, there should be scope for a person to enter the NDIS on lesser evidence and obtain a functional assessment later to confirm their eligibility. Reliability of assessments - There are a number of factors that will impact on the
reliability of the proposed assessments including the variation in ability of people with
disability and their families to provide full and accurate information about their
functioning. What support for decision making will the person have?

Also, the NDIA's expectation is that an assessment will take an average of three hours whereas a thorough Vineland assessment may often take as long as ten hours and much longer than that if a person has complex needs. A quality assessment requires not only the collection of data but sophisticated analysis of it. An average of three hours will not allow this.

There is a great danger of very inadequate assessments with very limited participation by the person with intellectual disability themselves.

We envisage particular problems with the reliability of assessments for people with complex needs and for people in gaol. Challenges in gaol include: access to a prisoner being denied on short notice for a range of reasons; gaol entry procedures being very time consuming; visits being cut short by gaol authorities; assessors not being allowed to take computers into gaols.

 Workforce – The NDIA's plans appear to be for all new applicants for access to have an independent assessment and for existing participants to have an assessment over the next five years. That may mean 80,000 assessments a year. Where will the skilled and experienced assessors come from to do this work? This is a massive workforce capability issue especially in view of the currently inadequate NDIS professional workforce across behaviour support and therapies.

The clear dangers are assessments being done by people who are not properly experienced and qualified to do them and the already inadequate professional service provider workforce being further depleted.

- Choice of assessor the NDIA is saying that where possible the person with
 disability will be able to choose from a number of assessment organisations. Choice
 needs to go further than this with assurance that a person can have an assessor that
 they feel comfortable with and who is well qualified to assess their particular
 functional capacity.
- Sharing the assessment with the person- the NDIA proposes that a summary of the assessment should be provided to the person. We say that the full assessment should be provided as well as a version suited to the person's communication needs, for example an Easy Read version.
- Appeals the NDIA is not proposing to make an assessment appellable to the Administrative Appeals Tribunal. However, access decisions and participant plans are already appellable. The validity of the assessment could be challenged as part of these appeals.

Our concerns about the changes to budget setting and planning

- Budget setting behind closed doors the NDIA proposes that a participant's
 budget and draft plan will be prepared by an NDIA official without any personal
 contact with the person with disability. We say this process should occur face-to-face
 where the issues can be talked through between the official and the participant and
 their supporters.
- The information base for setting a personal budget the NDIA proposes that the NDIA official should set a budget based on the independent assessment and relevant environmental factors which include things like what informal support the person has and the area where they live. It is proposed that the official be able to seek further information where needed and adjust the budget in special circumstances including where a participant has complex needs or additional high cost needs such as Specialist Disability Accommodation, high cost assistive technology or home modifications.

There are big problems here. First, functional assessments do not have a proven capacity to demonstrate the level of a person's support needs. Support needs assessment tools such as the ICAN are more suited to this. Second, will the official routinely seek out extra information that they need? This may include for example a communication assessment, a swallowing assessment and a behaviour assessment.

- The participant's goals won't be taken into account in setting the budget we say that a person's goals should be taken into account in deciding what level of support they need. Goals have been taken into account in budget setting up until now.
- The skills and available time of the person deciding the budget we are concerned about the adequacy of the current skill levels for these issues in the NDIA and wary of the time pressures that officials will be under to decide a certain number of budgets each month.
- Will there be scope to challenge the budget in the planning meeting? The
 consultation paper suggests that the budget will be set before the planning meeting
 and that a participant will not be able to argue that it is inadequate. However, a
 recent newsletter from the NDIA CEO says there may be scope to change the budget
 in the planning meeting. This needs to be clarified. Unless the budget has been set in
 close consultation with the participant, they should be able to challenge it in the
 planning meeting.
- Interface with mainstream services the NDIA proposes that the NDIA official
 setting the budget will make decisions about what it is reasonable to expect
 mainstream services to provide. These are often in fact complex and challenging
 decisions and in a number of cases the Administrative Appeals Tribunal has
 overridden the NDIA's view on it.

For example, there remain major unresolved issues in relation to the respective responsibilities of the NDIS and the justice system. These issues need to be resolved but, in individual cases, the NDIA also needs to consult with the participant and their

- supporters and justice agencies rather than potentially arbitrarily saying who has responsible for what.
- How will the proposed system affect the current complex needs pathway? The
 complex needs pathway was established in 2018 to address a myriad of problems
 that had been occurring in NDIS access and planning for people with complex needs.
 This led to some improvements. We would be loath to see these improvements lost
 and in fact the NDIA should be looking for ways to enhance them.

Conclusion – we call for a pause

In view of all the problems we have outlined, CID calls on the federal government to pause the implementation of the proposed independent functional assessments and changes to NDIS planning and consult with the disability sector on the problems that these changes are designed to address and how best to address the problems.