



**Inclusion Australia**

# **Inclusion Australia submission on NDIS Independent Assessments**

**February 2021**

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## Acknowledgements

Inclusion Australia acknowledges the traditional owners of the land on which this submission was produced. We acknowledge the deep spiritual connection to this land of Aboriginal and Torres Strait Islander people. We extend our respects to community members and Elders past, present and emerging.

## Submission preparation

This submission was prepared by Inclusion Australia. To write this submission, we listened to the views and concerns of people with intellectual disability and their families and advocates and we also spoke with some leading Australian academics and practitioners in intellectual disability about the changes. We looked at research into functional assessments, the legislation and other important documents to see whether and how the changes fit. This includes the NDIS Act 2013, the Productivity Commission Report 2011, and the Tune Review report 2019.

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# Inclusion Australia

## Submission on NDIS Independent Assessments

### Who we are

Inclusion Australia is the national voice for Australians with intellectual disability. We bring together groups across Australia who are connected to people with intellectual disability and who share the vision of inclusion in all parts of Australian life.

### What this submission is about

Inclusion Australia is very concerned about the new 'independent' assessments, planning and funding processes and how they will affect people with intellectual disability, who make up 21% of NDIS participants.

Inclusion Australia agrees that the NDIS needs to be a fair system and that people should have more say on how they use their support funding. We also agree that people should be able to get free assessments when they need them to get into the scheme or as part of working out what their support needs are.

However, we do not think compulsory independent assessments and changes to the NDIS planning process are the answer.

The NDIS has put out two consultation papers asking people to give feedback:

1. Consultation Paper: Access and Eligibility Policy with Independent Assessments
2. Consultation Paper: Planning Policy for Personalised Budgets and Plan Flexibility

When writing this submission, Inclusion Australia decided not to answer the questions in the consultation papers on how we think the changes should be made. This is because we fundamentally believe the changes:

- are not evidence-based and take the wrong approach
- will significantly disadvantage people with intellectual disability

### **Inclusion Australia urges the NDIS to:**

- Stop the rollout of compulsory assessments as they are currently planned
- Be fully transparent with all information about the problems and the changes
- Evaluate a range of solutions
- Properly consider solutions that work for people with intellectual and other cognitive disabilities, including people with complex support needs
- Co-design - from the beginning - a new access and planning process with people with disability, their families, supporters and the organisations who represent them

## Inclusion Australia's response

Inclusion Australia believes the proposed changes to NDIS access and planning are:

1. Not consistent with the NDIS Act, Productivity Commission recommendations, and the Tune Review
2. Based on assumptions or insufficient evidence
3. Based on mistrust of people with disability
4. Not fit-for-purpose for people with intellectual disability
5. More about scheme sustainability than fairness

### 1. Not consistent with the NDIS Act, Productivity Commission recommendations or the Tune Review

#### Equal partners

NDIS Act Guiding Principle 8 says that “people with disabilities have the right to engage as equal partners in decisions that will affect their lives”. The current NDIS Corporate Plan, on its cover, says that NDIS is ‘putting participants at the centre of everything we do’.

The Tune Review says the NDIS needs to co-design and consult properly with people with disability.

The consultation papers only ask people how they think NDIS can make these changes in the best way. They do not ask people whether any changes are needed or what they should be.

Inclusion Australia has been repeatedly told by the NDIA that these changes are going ahead, whether we disagree with them or not. Consultation for the purposes of refinement and finalisation is **not** engaging people with disability as equal partners. NDIS is not respecting people's rights by making these changes without them.

#### Reinterpretation

Inclusion Australia is very concerned that the NDIS is reinterpreting, even misinterpreting, the Tune recommendations and ignoring the important details about independent assessments in the Productivity Commission report to suit their own agenda.

The Tune Review said that the NDIS should have the power to require some people in some circumstances to have an independent assessment...and that this power should be discretionary – something they might sometimes think would be useful or necessary. Tune did not suggest compulsory independent assessments for everyone.

The Productivity Commission did recommend that independent assessments play a part in the NDIS. However, the Productivity Commission also talked about people's concerns about independent assessments and made recommendations about what the NDIS needed to consider. This includes people's aspirations and the collection of information from multiple sources.

## **2. Based on assumptions or insufficient evidence**

The NDIS says it is following the recommendations in the Tune Review. However, the Tune Review says that NDIS should be transparent and not hide information.

The NDIS has not provided any evidence to explain what has caused differences in support funding for people who have similar support needs. They say that people in higher socio-economic areas where people are better educated and have more money, get more funding than people in poorer areas. They say this is because they can advocate better, and this is probably part of the reason, but there could be other reasons for some people getting more funding. For example, better off areas are usually in cities, and less well-off areas include most country towns and remote areas, where there aren't many support services. One reason people in higher socio-economic groups might get better support funding is because they have more support services they could use.

It is likely there are a number of reasons why support funding is, or looks to be, unfair. But NDIS has not published any information, including economic modelling, to show that compulsory independent assessments will lead to people getting fair support budgets. NDIS needs to identify all the reasons for this and then work appropriately to find ways to fix them.

### **Why were tools suggested by the Productivity Commission excluded?**

The Independent Assessment: Selection of Assessment Tools report explains the steps NDIS took to choose the assessment tools to be used for independent assessments. The report does not include all the tools they looked at, or the reasoning for their rejection of other tools.

The Productivity Commission recognised that there was no single assessment tool that would be suitable for everyone. The report contained information about several assessment tools that could be part of a 'toolkit', including I-CAN, I-CAP and SIS. But these tools are not mentioned in the NDIS report.

### **No evidence provided about the NDIS designed tools**

Tables in the report show that the independent assessment process will also include a Participant Interview and Participant Information as well as the assessment tools. These are described as being NDIS-designed, but there is no other information in the report on what they contain and how they will be used.

No evidence has been provided that these will be designed according to the same rigorous scientific standards (including external scrutiny) that apply to the approved assessment tools.

"I cannot see any algorithm which would accurately transfer the test results of these tools to an index of support needs. This would need extensive psychometric analyses to ensure validity and reliability. We did this with the I-CAN".

Trevor R Parmenter AM | Professor Emeritus | Sydney Medical School | Faculty of Medicine and Health | University of Sydney

### **Use of functional assessment tools to determine budgets**

Inclusion Australia is extremely concerned that the NDIS appears to be disregarding and rejecting scientific evidence and expert opinion.

Inclusion Australia spoke with several leading Australian academics and practitioners who have many years of expertise in research about intellectual disability. They also have considerable expertise regarding functional assessment.

The academics we consulted with said that the selected independent assessment tools were not designed to provide the information needed to develop a support budget. They said that other tools, rejected by the NDIS, could provide information that would give transparency through from function to costing.

“The tools chosen are only valid for the purposes they were designed for. WHODAS is easy to administer but much of the literature indicates it has been used in national studies, especially in low-income countries, which is one of the WHO’s specific focus. Not unexpectedly, it has a heavy focus on health and disease.”

There is no current information available on exactly how the NDIS plans to calculate support budgets using data from the functional assessments.

Tools such as the *Scales of Independent Behaviour Revised*, the *ICAP*, the *Supports Intensity Scale*, and the *I-CAN* are all designed to bridge the gap between skills and abilities and subsequent support needs in the context of service provision, and have been shown valid and reliable for people with intellectual and developmental disabilities. The *I-CAN* (now in version 6) in particular has been developed with an Australian service and support context in mind, and has been subject to international scientific scrutiny and the focus of peer-reviewed publications.

### **3. Based on mistrust of people with disability**

The NDIS have told us that they are making these changes because doctors and allied health therapists have “sympathy bias” towards participants. The NDIS has not provided evidence that the cause of unfair access and planning decisions is due to inadequate or inaccurate reports from people’s doctors or therapists. We can see from many outcomes at the AAT where NDIS decisions are repeatedly overturned, that the issue is about NDIS staff decision-making, rather than the relationship between participants and the professionals that support them.

People told the Tune Review they felt NDIS staff did not understand the nature of their disability or appreciate the challenges they encountered in everyday life. They said that a big problem is that the NDIS doesn’t make it clear what information people need to give them. They also said that a big reason people get different and not enough support funding, is that NDIS staff often do not look at professional reports and other information that participants give them. The NDIA has never released guiding information for treating professionals on what information they want or how it should be presented.

### **Draft budgets**

People with disability have asked to see a draft budget before it is approved to allow for discussion prior to the delegate's decision. However, the draft budget process outlined shows the NDIS will have already decided on a person's plan budget (based on the independent assessment) before the planning meeting. They have said that the budget can only be changed in "specific circumstances".

### **Slow release of funds**

The NDIS says that funds will be released at monthly or quarterly intervals. NDIS planners will make this decision. If a participant needs a larger amount at different times for different purposes, they will have to arrange this with NDIS. There is no mention of how they will do this or how long it will take. This drip feeding of funds, with critical decisions in hands of NDIS planners who do not know the person well, reduces flexibility and looks very much like the NDIS thinks that people can't be trusted not to continually over draw on the funds. We have not seen evidence that this is a problem that needs fixing.

Unless the NDIS can justify why a participant should not be trusted with access to more of their funds, they should allow people to decide when and how spending works best for them.

## **4. Not fit-for-purpose for people with intellectual disability**

Inclusion Australia believes the new system will create more disadvantage, risk and harm for people with intellectual disability. We are concerned that people with intellectual disability are a specific target of the changes because many have complex support needs and comparatively large NDIS plans. Given high Supported Independent Living (SIL) costs are a specific concern to the NDIS, and people with intellectual disability are the biggest users of SIL, there is a risk that people with intellectual disability will experience the disproportionate reduction to plan budgets. This will put their lives at risk, and reduce their access to critical services.

Our experience (e.g. with Disability Employment Services) is that when systems are standardised, people with intellectual disability get left out and outcomes fall behind other people with disability.

"The dedifferentiated design of the NDIS, and the subsequent changes, have not taken good account of issues specific to adults with intellectual disabilities. This contention is supported by a consistent trend in the small body of evidence that suggests adults with intellectual disabilities experience poorer outcomes compared to other participant groups. The analysis has highlighted a fundamental mismatch between the type of planning most suited to people with intellectual disabilities (i.e., facilitated and drawing on multiple sources of knowledge about the person, their context and needs), and the administrative-standardised approach of the NDIS."

Professor Christine Bigby, PhD, GAICD | Director, Living with Disability Research Centre | Chair, Academic Board | School of Allied Health, Human Services & Sport | La Trobe University

The Productivity Commission said that an assessment tool “should only be used to assess the needs of particular groups where its reliability and validity have been established for that group”. They said that people had ‘raised concerns that the assessment tools used by the NDIS would fail to capture fully their particular needs’.

However, the assessment tools do not take into account issues that are critical for people with intellectual disability such as:

- the need for supported decision-making
- acquiescence (a tendency to respond with ‘Yes’)
- the impact of long-term segregation and institutionalisation
- the impact of being assessed by someone they don’t know
- the loss of dignity when others are answering for them about what they can’t do
- assumptions that success in one environment guarantees success in others (e.g. making a cup of tea at home might be easy, but impossible anywhere else)
- fear of strangers

We also know that many people with intellectual disability will refuse to actively participate in an independent assessment, and some may harm themselves or others if forced. The NDIS have said that the consequences of refusing to participate will be a forced exit of the Scheme.

### **Assessment of people with intellectual disability requires expertise and experience**

The concerns of foremost academics and practitioners, as well as official statements from peak allied health bodies, give Inclusion Australia cause for concern about the expertise and experience of the people administering the independent assessment tools and how they will be interpreted.

“These tools need to be administered and interpreted within the World Health Organisation’s bio-psycho-social assessment framework and the integrated model of human functioning and systems of support as developed by the American Association on Intellectual and Developmental Disabilities (2021), that takes into account multiple assessments and including historical documentation and consultation with those who know the person well across multiple environments. One-off or very time limited ‘independent’ assessment by a person who has no prior knowledge of the individual, and with minimal if any explicit reference to prior assessments by practitioners experienced with the person, are fraught with difficulty.”

Keith R. McVilly PhD MAPS FCCIP | Professor of Disability & Inclusion | Director – Master of Social Policy | School of Social & Political Sciences | The University of Melbourne

Other comments from key academics we spoke to include:

“People with intellectual disability are disadvantaged by assessment tools compared with other people with disability. The questions demand nuanced responses in the case of people with intellectual disability. It would also require a skilled and trained person to obtain an accurate profile on many of the items.”

“The tools don’t reflect the effect of having an intellectual disability on your capacity to meet your health and other needs, for example, taking your medications. They don’t reflect the amount of support and supervision people with intellectual disability need with these kinds of things.”

“I have concerns that one allied health person will do an assessment. Most people with intellectual disability need a trans-disciplinary approach to understand and assess function and identify supports. Who do you choose? Will an OT be the best person? What about someone who understands the supports you need for communication? Many people with intellectual disability also have psychosocial disability, or medical conditions, or have experiences of trauma; which allied health practitioner has expertise in this broad range?”

### **High need for exemptions**

People with intellectual disability are likely to be highly represented in the group requiring exemptions. This group is likely to include:

- people with intellectual disability and complex communication needs. If a person has little or no speech, chances are the assessor will not be experienced in using AAC and there is little chance their functional capacity will be fairly assessed. It is likely to be assumed they cannot communicate, and it will be entirely the views of others that contribute to the functional assessment.
- people with intellectual disability and complex behaviour support needs
- people with intellectual disability and other disabilities

NDIS says that people with complex support needs will be exempted, but where are the cut off points when so many people have multiple conditions and high support needs?

Given that people with intellectual disability are the second largest cohort in the NDIS, a high need for exemptions reveals that independent assessments are not fit for purpose.

There is also no information about what the process would be to decide on support budgets for people who are exempt. Most concerningly, the NDIS have said that they will decide, without transparent criteria or the right of appeal, who will be exempt.

## **Safeguards**

The consultation papers do not detail safeguards for these changes that uphold people's rights, recognise the risks, and protect people with intellectual disability from disadvantage and harm.

There is no evidence that NDIS has prioritised safeguards throughout the independent assessment process or understood the vulnerability of people completely reliant on informants, particularly for people who do not have any unpaid people in their lives. The lack of an appeal process profoundly underestimates the probability of unintended outcomes.

## **5. More about scheme sustainability than fairness**

The Productivity Commission made it clear that the cost of the NDIS to government was NOT the actual cost to the economy. In fact, they said that because the aim of the NDIS was social and economic inclusion for people with disability, the NDIS would not be a cost but a benefit to Australian society and the economy over time.

Inclusion Australia is very concerned that the real reasons NDIS wants to make these changes is less about fairness and flexibility and more about keeping costs down.

Using independent assessments to push down costs carries risks to individuals such as homelessness, congregate care and abuse. These, before too long, will create additional cost pressures for the NDIS. Independent assessments used in these ways are not only unfair, dangerous and risk a return to outdated and inhumane practices; they are a false economy and will harm the Scheme itself.

"If the process is to save money, then I fear the pool of support agencies prepared to take on high support needs clients will diminish and drive a move to the reinstitutionalisation of this population"

Trevor R Parmenter AM | Professor Emeritus | Sydney Medical School | Faculty of Medicine and Health | University of Sydney

## **Appeal rights and transparency**

NDIS says there will be no appeals on the independent assessments themselves, and you can't have a repeat assessment. What if the assessment result is very different to a person's reports from doctor, specialists, allied health?

NDIS will only give people a 'summary' of their independent assessment score, not the full report, and only if they ask for it. Where are people's rights to see information about themselves? What if the assessment was incorrect? How does this fit with the Tune Review's recommendations regarding transparency?

“People must have the right to appeal independent assessments and decisions that come from them. There is always potential for flaws in assessments, some groups are disadvantaged by testing/algorithms; appeal is essential for individual rights and to help sort out anomalies.”

### Inclusion Australia urges the NDIS to:

1. Stop the rollout of compulsory assessments as they are currently planned
2. Be fully transparent with all information about the problems and the changes
3. Evaluate a range of solutions
4. Properly consider solutions that work for people with intellectual and other cognitive disabilities, including people with complex support needs
5. Co-design - from the beginning - a new access and planning process with people with disability, their families, supporters and the organisations who represent them

Inclusion Australia has six state member organisations across Australia. Those members are: NSW Council for Intellectual Disability (CID, NSW), Parent to Parent (P2P, QLD), the South Australian Council on Intellectual Disability (SACID, SA), the Speak Out Association of Tasmania (Speak Out, TAS), the Victorian Advocacy League for Individuals with Disability (VALID, VIC), and Developmental Disability Western Australia (DDWA, WA). Inclusion Australia currently has an ILC grant to develop representation in the NT and ACT.

