**DSA Submission**

**Independent Assessments: Access and Planning**

February 2021

**About Down Syndrome Australia**

Down Syndrome Australia was established in 2011 as the peak body for people with Down syndrome in Australia. Our purpose is to influence social and policy change and provide a national profile and voice for people living with Down syndrome. Our vision is an Australia where people living with Down syndrome are valued, reach their potential and enjoy social and economic inclusion.

Down Syndrome Australia is making this submission on behalf of its members. Down Syndrome Australia and its members work together to provide support for people with Down syndrome and to make Australian society inclusive for people with Down syndrome.  We work in partnership to maximise the opportunities and support for people with Down syndrome, their families and support networks.

Down syndrome is a genetic condition in which the person has an extra copy of some or all of chromosome 21. This additional chromosome results in a number of physical and developmental characteristics and some level of intellectual disability. There are more than 15,000 Australians who have Down syndrome and approximately 1 in every 1,100 babies in Australia are born with Down syndrome.[[1]](#footnote-1)

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# Submission: Independent Assessments - Access and Planning

Down Syndrome Australia (DSA) welcomes the opportunity to provide a submission to the National Disability Insurance Agency on Independent Assessments. DSA has chosen to provide a single submission to cover the two policy papers on Independent Assessments due to considerable overlap in the key issues. We are providing a separate response to the consultation on the ECEI approach.

As outlined by the discussion paper, the NDIA is working to address several challenges based on the current approach to access and planning, including:

* Difficulties faced by participants in gathering information to support their application or review meeting, including issues with wait times and costs.
* Inconsistent access / planning decisions with no consistent approach to assessment of the impact of a person’s disability.
* Differences in access / plan amounts correlating with participant location, knowledge of NDIS and socio-economic status.
* Perception amongst some participants that plan outcomes / funding levels are ‘luck of the draw’ or dependent on the quality of the staff involved in the plan review.

DSA acknowledges these concerns and agrees that action needs to be taken to ensure that the NDIS provides equitable access and consistent supports for participants. This must be done, however, without taking away participants’ choice and control and ability to receive the funding they need to meet their goals.

The proposed changes are the most fundamental changes to the Scheme since its inception. We are concerned that there is not sufficient evidence to suggest that this new approach will resolve the issues which have been outlined. There are a range of other approaches which could have been considered to deal with these concerns regarding consistency and equity such as allowing individuals’ health professionals to complete specific structured assessments. We are also concerned that the assessments and new planning approach may lead to participants not being able to access the level of supports that they require to meet their goals.

DSA recognises the important work that the NDIA has been doing to consult with the sector and participants about these new changes. However, we remain concerned that the timeframes for implementation do not allow for appropriate piloting, testing, and refinement of the new approach. Consideration must also be given to workforce issues and the potential impact of the new assessment approach on availability of therapy services. The timeframes also do not allow for the significant changes to implementation which will be required if the feedback from the consultations is considered and incorporated into the roll-out of this new approach.

DSA is seriously concerned that there is no publicly available information about how the assessments will be used to determine plan amounts. This is a critical component of the new reform that has yet to be tested or consulted with the sector. There needs to be adequate time for the NDIA to test this new approach and to work with the sector to ensure that the proposed algorithm will provide sufficient funding for participants.

DSA strongly urges the NDIA to ensure that the feedback received from the consultations is used to refine the proposed approach. The NDIA must reconsider the timeframes for the roll-out of the Independent Assessments to ensure that there is sufficient testing and refinement of this process. NDIS participants and the sector will only have confidence in the Scheme and the Independent Assessments if this new approach has been adequately tested and refined.

## Evidence of Disability

One of the issues identified by the NDIA was around the difficulties and costs faced by participants in gathering information to support their application. DSA is concerned that these difficulties will continue due to the pre-access requirements. Participants will continue to have to provide evidence of their disability. This will include information about what interventions and treatments have been administered and that the participant’s impairment is - or is likely to be - permanent. For participants with Down syndrome a letter from a GP noting that the participant has Down syndrome should be considered sufficient to meet this requirement. If participants are required to provide evidence of IQ testing or other assessments, it will negate any advantage that the Independent Assessments provide in reducing the hardship faced by participants in gathering evidence.

Recommendation:

1. Requirements to prove evidence of disability should not require involvement of specialists or reports which would put undue costs/delays for participants. If an individual is required to procure a specialist report - the costs should be paid for by the NDIA.

## Implementation of Independent Assessments

The Independent Assessments will be the primary information that is used to determine a participant’s NDIS funding package. It is therefore essential that the assessments are accurate, reliable and capture all the aspects of the participant’s life that may impact on their need for supports. The information provided to date on the Independent Assessments does not provide our community with confidence that this will be the case.

The assessments must be accessible for all people with a disability. For people with Down syndrome, it is important that the professionals administering the assessments are highly skilled and use best practice approaches in working with people with an intellectual disability. It is critical that the assessment focuses on the participant, not just on responses from a parent or support person. Participants must be provided with accessible information prior to the assessment (including in Easy Read). Assessors need to have a solid understanding of Down syndrome and how to assess individuals who may have a range of complex disabilities and communication requirements (including using Easy-Read documents and other visual aids). Participants must also be given options about the location of their assessment, as not everyone will be comfortable with someone they do not know coming into their home for the assessment.

It is important that consideration is given to the impact of the assessments on the wellbeing of participants and their families. Many families have expressed to us that the deficit-approach taken by current planners can leave families feeling sad and, in some cases, traumatised by having to focus on the deficits of their family member. Therefore, the assessment should take a strength-based approach rather than focusing solely on deficits.

The assessments must also capture the impact of different environments on the person’s functional capacity as well as the variability which can occur on any individual day. An assessment which is conducted within the person’s home may lead to a very different outcome than if the assessment was to be done in an unfamiliar environment. Similarly issues such as fatigue, time of day, health, comfort with strangers may all impact on how the person with a disability responds to an assessment on a single occasion.

The NDIS has provided details about the tools which will be used for the functional assessments. They have also discussed that individuals’ circumstances will be considered. However, there is no detail provided about how the information about personal circumstances will be collected or how that information will be utilised to inform decisions around plan budgets. For example, two participants with the same results on a standardised tool may need very different supports depending on what informal supports they have available, their age, other environmental issues (housing situation etc), as well as any major goals they may have for the immediate future (plans to move out of home, upskilling for a job etc).

For the assessments to lead to a funding package that meets the needs of a participant, information about the person’s circumstances and high-level goals must be factored in to determining participants funding packages. The methodology of how this additional information will be utilised must be tested and should have been part of the pilot which is currently being completed. If funding levels are tied simply to the outcome of standardized functional assessments, then this cookie-cutter approach will mean that participants are unable to achieve goals and invest in key areas (housing or employment) and will likely lead to worse outcomes for both the participants and the scheme.

There is also currently a lack of clarity about how additional information from specialists will be used as part of the assessment. For example, it is unclear how the NDIS would resolve an issue if the Independent Assessment conflicts with advice from a health professional report. The NDIA needs to provide clear information about how this information will be utilised and incorporated into decisions.

All participants should be given a copy of their full report as a default, rather than having to request it. Given the report is being used to determine funding packages it is essential that there is transparency about this process.

**Recommendations:**

1. Staff undertaking assessments must have knowledge and skills around intellectual disability and communication.
2. Participants must have access to accessible information about the assessments and be supported to take part in the assessments
3. Assessments must be done in a way that takes into account the variability in function dependent on location, time of day, fatigue, and comfort with strangers.
4. Participants must continue to have an opportunity to identify goals and to have choice and control about their packages. Information about a participant’s circumstances and high-level goals must be included as part of the assessment and determination of funding packages.
5. NDIA must clarify how additional external information will be incorporated into the assessments and funding decisions.
6. All participants should be given a copy of their full assessment report.

## Links to Funding

DSA is extremely concerned about the lack of information and transparency about how the outcome of Independent Assessments will be used to determine funding package levels. Linking these assessments to funding has never been done before in Australia or in any other country. Presumably, there will be an algorithm which will match the outcome of the Independent Assessment to a funding level. The NDIA has not indicated whether they expect this approach to have a significant impact on plan values or whether it will just address issues of inconsistency. As a result, some in the community fear that this is a cost-saving exercise rather than being focused on consistency. There has been no publicly available information or consultation on this process to date.

Matching the outcome of Independent Assessments to funding is not a straightforward task. It will need to consider the outcome of the assessments in the different domain areas, as well as the additional circumstances and potential major life goals/transitions that a participant may be considering. The complexity of this task is immense. The use of an automated algorithm based on functional assessments with no human intervention is incongruent with an outcome that provides participants with assurance that their package is fair and reasonable given their needs for support. It is also problematic as it has been proposed that plan budgets can only be revised with a new independent assessment. This means that if a participant’s circumstances changes (e.g., in terms of wanting to start employment) they will need a new assessment even though the required funding change is due to change in circumstances not functional capacity. It is not in the interest of people with a disability or the NDIA for the NDIA to implement such an approach without adequate consultation, testing, and refinement of the methodology.

The Independent Assessment pilots have focused on participant satisfaction but have not evaluated the impact of the Independent Assessments on funding packages. The NDIA has provided information on the current pilot stating that the pilot will “test how we make evidence-based decisions to build plan budgets”. From our understanding, the participants in the pilot will not be given any information about what plan budget would have resulted if the assessment were used to determine plan amounts. This is a critical gap in the pilot. We have no information about what participants views are about the use of the assessments to determine funding and whether the packages they receive will enable them to access reasonable and necessary supports. This testing needs to be done before the algorithm is implemented.

**Recommendations:**

8. NDIA to release information about the funding algorithm and conduct a consultation and pilot regarding the outcomes of this algorithm. This must include an assessment of participants’ perception of whether the funding amounts will be sufficient to access reasonable and necessary supports.

## Planning

The discussion paper provides an overview of how the planning process will occur under the proposed arrangements. This includes that after an independent assessment an NDIS delegate will consider a budget informed by the assessment. The participant then receives a draft plan including a draft budget. Under the proposed arrangements it is clear how a draft budget is developed but there is a lack of clarity around what a ‘plan’ looks like that would be developed by the delegate without input from the Participant. This plan is received before the participant has any opportunity to provide input or to share their views about their goals. This approach goes against the principles of choice and control.

It is also unclear about the role of the ‘planning conversation’ which occurs after a draft plan is received. This is the opportunity for the participant to talk about their goals and consider how their funds can be used to meet those goals. Instead, this should be an opportunity for the planner to revise the budget based on the participant’s goals and circumstances. As proposed, this is a plan implementation meeting not a planning conversation, given the funding amounts have already been determined.

**Recommendations**

1. Ensure that participants have an opportunity to provide input to the planning process before a final budget is determined. This could potentially occur during the assessment meeting.

## Removal of Lists

DSA is concerned that the removal of lists as part of the access process may have unintended consequences. List-D has been used to assist in determining whether someone’s condition met the early intervention requirement. For children with Down syndrome, List D has been essential to facilitate an easy and early entry into NDIS.

The evidence clearly shows that children with Down syndrome benefit from early access to therapies and supports. All children with Down syndrome will have some developmental delays and will be eligible for NDIS Early Intervention. List D has meant that families are not required to prove that a delay already exists to access the Scheme. DSA has a number of cases where families with babies with Down syndrome were initially told that they would have to wait to access the scheme until their baby showed a 6-month delay in milestones. After contacting DSA, we supported them to advocate for their child’s right to access the Scheme under List D.

Data from the NDIS on the number of participants by age group suggests that less than 50% of children under the age of one with Down syndrome are accessing NDIS. If List D is removed, we would anticipate that this will fall dramatically to perhaps only 5-10% of children under one year of age. This delay in access to the scheme (and therefore delay in access to supports) has the potential to have negative impacts on both participants and future costs to the Scheme.

**Recommendation**

1. List D be retained to ensure that children with disabilities have early access to the Scheme.

## Timing of Release of Funds

One of the changes outlined in the discussion paper is the timing of the release of funds. Currently funds are allocated in a participant plan immediately on the approval of a plan. This means that participants can have the flexibility and control to utilise the funds as they require them. The discussion paper proposes that this approach be changed so that participants only have access to funds released within monthly or quarterly intervals. It is noted that this approach does not apply for certain supports such as assistive technology or home modifications. Unused funds will rollover into the next month or quarter up to 12 months.

This approach assumes that participants will have a consistent need for funds/support from month to month and ignores the reality that support requirements change over time dependent on availability of informal supports, health issues, school holidays, amongst many other factors. Unless a specific risk has been identified, there should be no change from the current process which allows participants to access their funds as they require them over a 12-month period. The loss of individual choice and responsiveness to individual need is of grave concern. There is no clear rationale about how the new flexibility poses any greater risk in terms of overspending funds in comparison to the current participants who self-manage their plan.

Limiting the release of funds will result in participants not being able to access funds in a timely manner during an emergency, where their informal supports have changed, or enable them to invest in some initial higher level supports to achieve a particular goal. This approach will simply limit the flexibility and choice that participants currently have and provides no real benefit to participants or the NDIA.

Recommendation:

1. NDIA to release funds on a yearly basis as the default unless any specific risk has been identified.

## Review Process

The discussion papers have indicated that the results of the assessment cannot be challenged or appealed. Given the central role that these assessments have in determining the access and planning decisions this is extremely concerning. If an individual believes that the Independent Assessment does not accurately reflect their circumstances, there is no recourse to access another assessment. Participants will only have access to a second assessment where there is a significant change to their circumstances or capacity (or if the assessments are not administered in line with the Independent Assessment Framework). The proposed approach means that participants have no way to challenge an inaccurate Assessment which may occur due to Assessor error or inaccurate information being provided.

The inability to challenge the outcome of the assessment is extremely problematic particularly given the assessment relies in part on the subjective report of family member or support. The NDIA indicates “If you are over 18, the assessor will complete the assessment with you, and talk to someone who knows you and the impact of your disability well.” For example, if the Vineland Assessment is conducted it has been noted that “a large part of the Vineland assessment is done without you in the room. Once you have left the room the assessor will ask the person you brought with you questions about your daily living skills, communication, and activities outside the home. This person does not have to be a plan nominee”[[2]](#footnote-2) The outcome of the assessment may be quite different depending on the perspective or relationship between the participant and that support. If the participant does not believe that these responses accurately reflect their needs, then they should have the right to challenge the validity of this assessment.

To have an adult participant’s outcome so reliant on the subjective reporting of a support/family member without any option for challenging the outcome puts the participant in an extremely vulnerable position.

**Recommendation**

1. NDIA to provide a process for results of the Independent Assessments to be challenged or reviewed including providing the option of completing another Independent Assessment with a different provider.

## Duplication

It is important to ensure that participants are not required to undergo multiple assessments for different Government programs and funding. For example, the Victorian Department of Education and Training has indicated that they will being introducing individual assessments as part of their Program for Students with Disabilities. It is essential that the NDIA coordinate with other Government agencies (federal or state) to ensure that families are not facing having to access multiple assessments in a short period of time.

Recommendation

1. NDIA to work with other Government agencies to ensure families are not having to undertake multiple functional assessments.
1. Down Syndrome Australia (2020). Down Syndrome Population Statistics. Retrieved from <https://www.downsyndrome.org.au/about-down-syndrome/statistics/> [↑](#footnote-ref-1)
2. [My independent assessment | NDIS](https://www.ndis.gov.au/participants/independent-assessments/second-independent-assessment-pilot/participants-second-independent-assessment-pilot/my-independent-assessment) [↑](#footnote-ref-2)