



Submission | February 2021

Proposed changes to the NDIS &  
their anticipated impact on people with  
Developmental Language Disorder



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# Acknowledgement

'In the spirit of reconciliation, The DLD Project acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.'

# Introduction

The DLD Project is an impact focused social enterprise founded to elevate awareness and understanding of Developmental Language Disorder (DLD) in Australia. This submission has been prepared by The DLD Project in consultation with the 1 in 14 Australians with DLD, a hidden but common, lifelong communication disability.

DLD has been previously known as Specific Language Impairment or Language Disorder, in addition to many other terms over the past 200 years. However, an international consensus study was published in 2017 with the recommendation to use DLD to describe language difficulties that occur for no known cause. DLD is endorsed by Speech Pathology Australia, researchers and practitioners across the country.

DLD refers to difficulties learning language and affects approximately 7% of the population. This makes it 7 times more common than autism and 46 times more common than childhood hearing impairment.

People with DLD are 6 times more likely to suffer from anxiety and 3 times more likely to have clinical depression. They are also at significant risk of struggling with reading, spelling and mathematics. Although DLD is a common condition affecting many areas of life, children with DLD are unlikely to receive access to services.

DLD causes difficulties with speaking and understanding for no known reason. There are serious and long-term impacts, as it puts children at greater risk of failing at school and struggling with mental health and future employment. The biggest challenge with DLD is you can't tell by looking at a person that they have DLD and therefore, people with DLD often get overlooked for support.

**DLD is a lifelong, permanent disability.** However, it is important to know that with the right supports, people with DLD can thrive!

The fact is there are 2 children in the average classroom in Australia with this condition and they are being overlooked due to low awareness of their disability. The DLD Project is the voice of people with DLD and their families in Australia and the health professionals and educators who seek to support them.

This submission seeks to outline our collective thoughts on the upcoming NDIS 'reset' in the hope that we can collaborate to deliver a scheme that is accessible to all.

## Current State: DLD & the NDIS

We wish to bring to your attention the challenges affecting people with DLD and their families when accessing the National Disability Insurance Scheme (NDIS). The DLD Project has received a significant amount of correspondence from parents who have been declined access to NDIS funding for their child with DLD. Sadly, this has left many Australians with DLD left without vital intervention and supports.

The NDIS website states:

"The main objective of the NDIS is to provide all Australians who acquire a permanent disability before the age of 65 which substantially impacts how they manage everyday activities with the reasonable and necessary supports they need to live an ordinary life."

***DLD is a lifelong, permanent disability that significantly impacts on a person's everyday activities. So, the question is, why have people with DLD been repeatedly declined by the NDIS?***

An investigation conducted by The DLD Project into this issue found that families were:

- Not attaching the required health professional reports to their application or understanding the need for multiple, multidisciplinary assessments to be included
- Unaware they were able to attach a personal account of their loved ones needs with their application explaining the 'functional impacts' of their disability
- Disillusioned by the hoops they had to jump through to apply only to find that planners were often not aware of DLD and;
- Exasperated that DLD was not included on the funded Disability Lists A & B.

The DLD Project notes with interest that the proposed changes coming to the NDIS as part of the 'reset' will go some way to seemingly address some of these challenges. However, after reviewing the consultation papers our community has raised a number of concerns which we will now discuss.

# Consultation Paper: Access and Eligibility Policy with Independent Assessments

## **Proposed Change 1: The removal of the disability access lists (List A and List B) from the access process.**

Our families have expressed their frustrations at the ongoing challenges they face when accessing the NDIS as DLD is not on the disability access lists. Therefore, the removal of the lists should in theory also remove a barrier to accessing the NDIS for people with DLD. However, this will only be achieved if the 'independent assessors' have a thorough understanding of DLD and its lifetime impacts.

### **Question for NDIA:**

1. How will NDIA ensure that the 'independent assessors' have a thorough understanding of DLD and for that matter, all disabilities and their individual impacts?



## **Proposed Change 2: The introduction of independent assessments**

In our experience, people with disabilities build trusting relationships with their chosen allied-health and medical staff, developing a mutual relationship and understanding of the disability and the individual's needs.

Our understanding is that with independent assessments, individuals are expected to work through standardised tools to capture their circumstances within a 1–4-hour time frame, with an NDIS appointed assessor. This can place pressure on participants who may not feel comfortable disclosing information to individual assessors who they do not know.

Like many in the disability community, The DLD Project is highly concerned about the additional announcement of “independent assessments”, to be conducted by healthcare professionals using standardised tools.

We are trying to ascertain why independent assessments are necessary if health professionals such as speech pathologists, paediatricians, etc. have confirmed in reports submitted to the NDIA that a person has a lifelong, permanent disability and requires supports. **Does this not demonstrate a lack of confidence in the reporting of Australian health professionals?**

We do not believe the consultation paper clearly demonstrates a need for independent assessments to be introduced.

#### Questions for NDIA:

1. Why is the NDIS introducing independent assessments?
2. Can the NDIA explain to people with DLD why an independent assessment is needed if they have been assessed by health professionals who work closely with them and understand their individual needs?
3. What measures will be put in place to ensure people with DLD and other disabilities are not left feeling as though they are taking a ‘test’ causing anxiety?
4. Additionally, we request clarification on the level of independence, qualifications, training, and expertise of the independent assessors.
5. How will the accuracy and reliability of assessors be monitored, and what will happen if there is inconsistency in how assessments are done?
6. Will all necessary supports be provided to enable participation in assessments, such as transport and communication supports?



7. What is the potential for independent assessments to have punitive effects on marginalised communities (regional and remote Australians, Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds ...)?

### **Proposed Change 3: The introduction of standardised assessment tools**

Our community is concerned whether these tools are appropriate for individuals with disabilities such as DLD. Therapists have also stated they feel standardised assessment tools are unsuitable for individuals who are culturally and linguistically diverse.

We understand that as part of the independent assessment, NDIS participants will undertake 3 or 4 of these assessment tools based on their age and life stage. DLD presents differently in each individual and changes across the lifespan which makes using standardised assessments problematic. For example, people with DLD can have strong expressive language skills but poor comprehension. Will the standard assessment tools pick this up? Factors like this may adversely impact the assessment, producing inaccurate results and creating barriers to accessing appropriate supports and funding.

Criteria for the assessment toolkit states that “it should be possible to use the assessment tools across all disabilities” and that the toolkit “assesses functioning and not impairment”. Unfortunately, we do not see how this is possible given that to diagnose DLD a number of assessments are generally undertaken by multiple health professionals as part of a multidisciplinary team. We do not see how a ‘one size fits all’ approach will fairly assess the needs of people with disability in Australia.

## **Proposed Change 4: The Provision of Guidance from the NDIA on what Evidence is Required**

One of the reasons people with DLD find applying for the scheme so difficult is that there is no real guidance about what the NDIA are looking for when it comes to 'evidence' or the reports to include. We support the recommendation for the NDIA to make it much clearer about what you are looking for in that evidence, and who you regard as qualified to provide it.

Additionally, we would like to make the following recommendations:

- The online Access Request Form does not provide enough space for families to share their needs. The form also needs to more clearly encourage attachments.
- The website requires too many clicks to locate the information you need. This can add to the feeling of 'overwhelm' people have arriving at the NDIS website.

# Consultation Paper: Planning Policy for Personalised Budgets and Plan Flexibility

## Proposed Change 5: The potential for NDIS Plans to run for up to five years or the next life stage.

The NDIS website states that “from time-to-time, you’ll need to complete a new independent assessment, to make sure the funding in your NDIS plan is still right.” Whilst we welcome that with the proposed changes in place plans can be up to five years or the next life stage, we are seeking clarity on what might trigger the ‘need’ to complete a new independent assessment. Plan reviews are a very stressful time for families and we would like to see that they are not sprung on families without fair warning or a structured approach.

**Question for NDIA:** What will trigger the need to complete a new independent assessment? This needs to be clear to help people with DLD and their families feel supported without concerns their funding might be cut at any moment. Simply stating ‘from time-to-time, you’ll need to complete a new independent assessment’ is too vague and inconsiderate to the significant impact changes in funding has on the life of a person with DLD or any disability for that matter.

# Consultation Paper: Supporting Young Children and Their Families Early, to Reach Their Full Potential

## **Proposed Change 6: The expansion of the Early Childhood Early Intervention (ECEI) approach from seven to nine years of age.**

The DLD Project supports the shift from seven years to nine years for the ECEI approach as we can see the value in the continuity of supports and funding as a child heads off to school.

## **Proposed Change 7: All children entering the NDIS via the early intervention criteria.**

Currently, children can access the NDIS through the early intervention criteria or the disability criteria of the Act but the report recommends that children only enter through the early intervention criteria. Our understanding is that this will require all children to have their access reassessed at regular intervals. For families of children who require life-long support, such as people with DLD, this seems an unnecessary burden and poorly thought through. Again, one size does not fit all.

# Additional Comments

Our DLD community has asked for us to provide the following points for further consideration by the NDIA:

- For families of people with DLD it feels we are being 'over assessed' due to the lack of understanding by NDIS planners about DLD.
- The current window of time of 12 months between assessments is not relevant as the diagnosis of DLD will not change, they will still have it.
- NDIS seems to have a 'defect' language approach where families are encouraged to describe their worst day possible. The NDIS needs to consider how this makes families feel to revisit their trauma on an ongoing basis.
- Families would like to see the NDIS allow funds to be used to support equipment purchases such as phones, applications, Laser readers, to the same value of access to therapists and assessment schedules.
- Set up a system where DLD people over the age of 18 aren't expected to be "fixed" and can still access supports.
- Cover the cost of assessments needed to obtain documents required for the NDIS application.
- Cap the number of assessments children are subjected to for the sole outcome of funding issues.
- Allow funding for any programs including literacy for home use which is particularly important for people with DLD.

# Conclusion

Thank you for the opportunity to contribute the thoughts of our community on these major changes to the NDIS which we know will have a significant impact on people with DLD in Australia.

Importantly, these concerns are not exhaustive, and we need clear answers. The proposal to introduce “independent assessments” should not go ahead until we know exactly how the model will impact people participating in the scheme. The aim to introduce “individual assessments” in 2021 feels rushed given the current evidence.

We need significant and widespread consultation with people with disability on this program.

We look forward to hearing from the NDIA in relation to our submission. We can be reached at [connect@thedldproject.com](mailto:connect@thedldproject.com) or [www.thedldproject.com](http://www.thedldproject.com).