



DLD & THE NDIS

COMMUNITY UPDATE

www.thedldproject.com



ACKNOWLEDGEMENT OF COUNTRY

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.



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AGENDA

1. Understanding DLD & the NDIS
2. NDIS Review Recommendations (2022 - 2023)
3. Disability Royal Commission Recommendations
4. Applying to access the NDIS
5. Resources & Advocacy



- Lack of agreement about criteria and terminology for children's language difficulties has affected access to services, as well as hindering research and practice.
- An international group of 59 experts (the CATALISE Consortium) included speech language therapists/pathologists, (educational) psychologists, paediatricians, psychiatrists, specialist teachers and charity representatives, led by Professor Dorothy Bishop.
- Two aims (via Delphi process):
 - Consensus for identification (Bishop et al., 2016)
 - Consensus for terminology (Bishop et al., 2017)



disability

DLD

is a developmental
~~condition~~ that causes
difficulties with
understanding
and/or talking

- The NDIS Act 2013 is the legislation that governs the National Disability Insurance Scheme (NDIS) and the National Disability Insurance Agency (NDIA).
- The term “Developmental Language Disorder” was implemented in 2017 and endorsed by Speech Pathology Australia (SPA).
- There has been limited access to the NDIS for people with DLD. Some success in 2020-2021.
- SPA and The DLD Project have been advocating for consistent access to the NDIS for people with DLD. Issues with access tend to go in themes- permanence, treatment, planner understanding.

Primary Condition	Prevalence*	Number of NDIS Participants**
Foetal Alcohol Syndrome	0.1%	1134
Cerebral Palsy	0.15%	17468
Down Syndrome	0.16%	11595
Autism Spectrum Disorder	0.65%	207385
Intellectual Disability	5.5%	88132
Developmental Language Disorder	7.4%	191

* prevalence from McGregor (2020).



2. NDIS Review

- In 2022, the Minister for the NDIS, the Hon Bill Shorten MP, established the independent NDIS Review.
- The report was handed down to Minister Shorten on 31 October 2023 and released to the public on 7 December 2023.
- The review identified **26 recommendations** and **139 actions** to provide a NDIS reform blueprint.
- The key finding was the NDIS should be one part of an overarching unified system of support for people with disability.





IMPORTANT

Disclaimer: The following slides include recommendations from the NDIS review. There is no guarantee that these recommendations will be approved.

We believe we will know more by mid year.

Recommendation 1 - Foundational Supports

- The NDIS Review committee recommends the Australian Government, and state and territory governments, jointly invest in **foundational supports**, particularly for children with disability and developmental concerns.
- Foundational supports should include people with disability (under 65 years) who are **not eligible** for the NDIS, but need additional support.
- Targeted supports could include: home and community care-type supports, aids and equipment, early childhood supports, psychosocial supports and supports for adolescents & young adults.



Recommendation 3 - Participant Pathway

- Problems with the access and planning process were the **most common issues** raised during the NDIS Review.
- A new participant pathway has been recommended. It is suggested that applicants have access to a **Navigator** that will replace the role of **Local Area Coordinators**.
- They would help link people with disability with supports, **even if they do not qualify for the NDIS**.
- Would not be NDIA staff, but employed by non-government organisations.
- The NDIA aim to introduce a new **Access Request and Supporting Evidence Form** to make applying for NDIS access more transparent and simple.

Recommendation 3 - Participant Pathway continued

- Access to the NDIS should be based first and foremost on **significant functional impairment and need** - and only secondly on medical diagnosis.
- A focus on functional impairment will enable **multiple disabilities to be considered** - which when taken together, result in significant functional impairment. For example, DLD, ADHD, Dyslexia, etc.
- Many participants receive automatic access to the NDIS through an access list. **The NDIS recommend removing automatic access under the access lists.**



Recommendation 3 - Brief Overview of the Proposed Participant Pathway



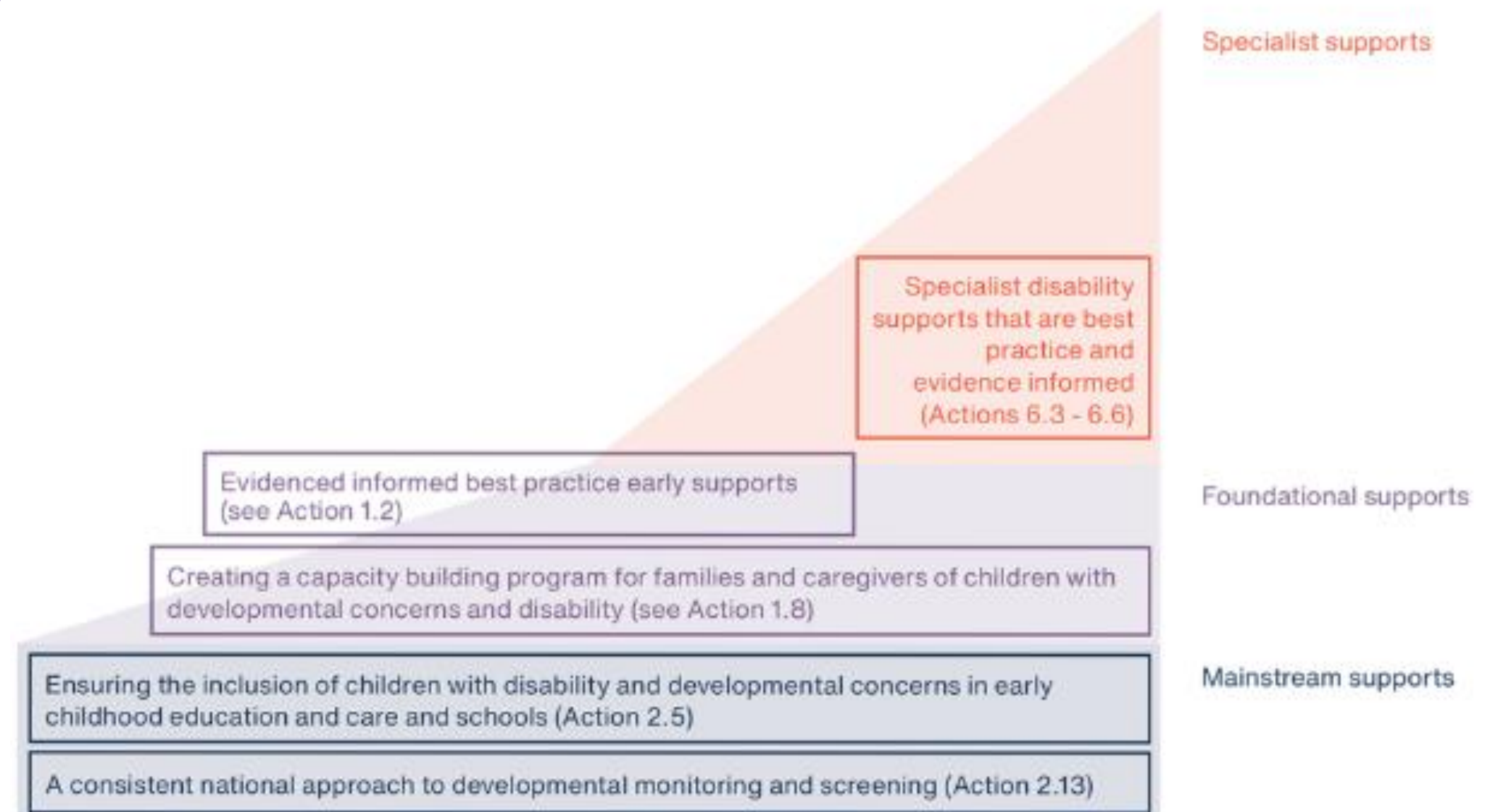
Recommendation 6 - Create a continuum of support for children under the age of 9 and their families



Supports provided outside the NDIS should include mainstream supports such as:

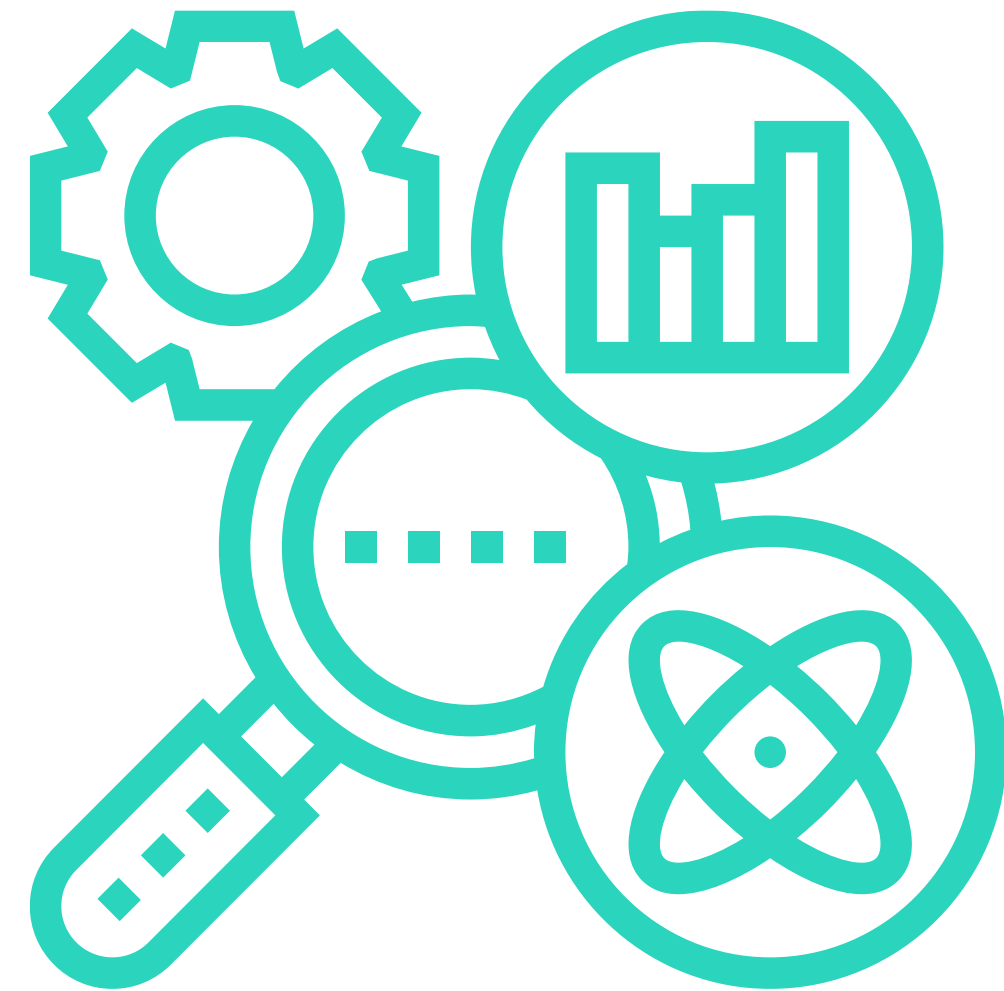
- early identification of children with developmental concerns
- inclusive education
- foundational support

Within the NDIS, **children under the age of 9** with higher levels of need should receive specialist support through a reformed early intervention pathway.



Recommendation 23 - Measure what matters, build an evidence base of what works, and create a learning system

- Action 23.2*: Establish and manage an **NDIS Evidence Committee** to provide guidance on reasonable and necessary disability supports.



Changes to the early intervention pathway

- It appears that early childhood intervention partners will be replaced by **Navigators** in terms of accessing the NDIS.
- The NDIS wish to implement a key worker model using Lead Practitioners (with an allied health or education background) to support the family and work with them to develop a plan for supports for their child.
- The Lead Practitioners will be commissioned by the NDIA but work for other organisations.
- They will lead the provision of supports for the child, working with other providers and the child's education or other community setting/s in a wholistic manner.



transition
timeline

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) was established in 2019.

It is the largest royal commission to have occurred within Australia.

On 29 September 2023 the Disability Royal Commission released its final report to the public. The final report has 12 volumes on specific issues concerning people with disability in addition to a 356 page executive summary.

The executive summary outlines the 222 recommendations the Disability Royal Commission has made to try and ensure a more inclusive and just society to improve the lives of people with disability.

<https://disability.royalcommission.gov.au/publications/final-report>

Findings & Recommendations

- Strong focus on communication accessibility and the need for improved supports in education and health sectors
- 4.9 recommends that all people with disability have the right to equitable access to health services, including assuming capacity, and provisions for supported decision-making. They should also be provided with accessible information and have the right to adjustments to enable them to access episodes of care.
- In 7.3 (b) it is recommended that state and territory educational departments should ensure there are greater tools and resources to assist education staff to adapt their curriculum, teaching and assessment practices to support students with complex communication needs and increase their participation.

Findings & Recommendations

- The Disability Royal Commission also recommended several changes to strengthen the existing Disability Discrimination Act 1992 including a positive duty to end disability discrimination and making it unlawful to not provide adjustments for people with disability, except when this would cause unjustifiable hardship.
- They have proposed that the existing Act should be amended to give effect to Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities.
- This would mean that the Act be interpreted consistent with rights outlined in the UN-CRPD, including [Article 21](#).

Findings & Recommendations - NDIS

- The NDIS was not specifically investigated by the DRC but they heard a lot from NDIS participants. So there were several recommendations made regarding the NDIS Quality and Safeguarding Commission
- Recommendation 10.6 discusses that the NDIS Quality Indicators should be amended to reflect that every participant has the right to make decisions and should be supported to communicate their will and preferences.
- Recommendation 10.20 states that the NDIS Quality and Safeguards Commission must improve their complaints processes, including accommodating a person's preferred method of communication.

- The government has not yet responded to the Final Report. They have established a taskforce where they have employed government workers from a range of departments and agencies (including the NDIA and the Department of Health and Aged Care) to review the recommendations and consider the next steps in implementation. The taskforce will be in place until at least June 2025.
- The taskforce have said they will be releasing a response, taking in to account the NDIS Review in mid 2024.
- They released a progress update in March 2024 outlining all of the things that are already in motion with regard to many of the recommendations in different sectors.

<https://www.dss.gov.au/disability-and-carers-disability-royal-commission-taskforce/australian-government-progress-update-on-the-disability-royal-commission-0>

To meet the disability requirements there must be evidence of all of the following:

- Your disability is caused by an **impairment**.
- Your impairment is likely to be **permanent**.
- Your permanent impairment **substantially reduces your functional capacity** to undertake one or more of the following activities: moving around, communicating, socialising, learning, or undertaking self-care or self-management tasks.
- Your permanent impairment **affects your ability to work, study or take part in social life**.
- You'll likely need support under the NDIS for your whole life.



<https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/do-you-meet-disability-requirements>

Impairment

- An impairment is a loss or significant change in at least one of:
 - your body's functions
 - your body structure
 - how you think and learn.
- To meet the disability requirements, there must be evidence your disability is caused by at least one of the impairments below:
 - intellectual - such as how you speak and listen, read and write, solve problems, and process and remember information
 - cognitive - such as how you think, learn new things, use judgment to make decisions, and pay attention
 - **neurological - such as how your body functions**
 - sensory - such as how you see or hear
 - physical - such as the ability to move parts of your body.

Impairment

ICD 11 - World Health Organisation

DLD is classified as a **neurodevelopmental condition** in the ICD 11. Therefore-best fits under the **neurological** section for NDIS.

The NDIS use the ICF framework for their Rules-also WHO produced.

“... Developmental Language Disorder is...likely to be maintained throughout development and into adulthood: approximately 75% of individuals diagnosed with Developmental Language Disorder in childhood continue to meet the diagnostic requirements for the disorder in late adolescence. The impact of these impairments continues to be evident into early adulthood as behavioural, social, adaptive, and communication problems, often with life-long social consequences.”
(ICD, 2023)

Permanence

- Evidence is needed that you'll likely have your impairment for **your whole life**.
- Even when your **condition or diagnosis is permanent**, the NDIS check if your **impairment is permanent too**. For example, you may not be eligible if your impairment is temporary, **still being treated**, or if there are remaining treatment options.
- The NDIS will consider whether your impairment is likely to be permanent after **all available and appropriate treatment options** have been pursued.
- The supports the NDIS fund can help you **reduce or overcome** the impact your impairment has on your daily life. They can also help you **increase your functional capacity, independence, and your ability** to work, study or take part in social life.

Functional Capacity

- The application needs to show reduced functional capacity/ability to undertake activities in one of the following areas:
 - **Communicating** - how you speak, write, or use sign language and gestures, to express yourself compared to other people your age.
 - **Socialising** - how you make and keep friends, or interact with the community, or how a young child plays with other children.
 - **Learning** - how you learn, understand and remember new things, and practise and use new skills.
 - **Mobility, or moving around** - how easily you move around your home and community, and how you get in and out of bed or a chair.
 - **Self-care** - personal care, hygiene, grooming, eating and drinking, and health.
 - **Self-management** (if older than 6) - how you organise your life such as how you make decisions, and look after yourself.

Functional Capacity

- Your impairment is considered to substantially reduce your functional capacity if you usually need disability-specific supports to participate in or complete these 6 domains.
- These disability-specific supports can include:
 - a high level of support from other people, such as physical assistance, guidance, supervision or prompting.
 - assistive technology, equipment or home modifications that are recommended by your doctor, specialist or allied health professional.

<https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/does-your-impairment-substantially-reduce-your-functional-capacity>

Living a meaningful life

Then, the NDIS looks at how your impairments affect your ability to work, study or take part in social life.

This means your permanent impairments affect how you can find and keep a job, contribute to your community, or join social activities.

The NDIS looks at your ability to do things like:

- Find and keep a job
- Study
- Play sport
- Go to the movies
- Volunteer



Lifelong Needs

- NDIS supports are investments that help **you build or maintain** your functional **capacity** and **independence**, and help you work, study or take part in social life.
- The NDIS decides whether your needs could be best met by the Scheme, or by other government and community services.
- For example, you may have an impairment which is caused by a chronic health condition. Many chronic health conditions are most effectively managed or remedied through medical management through the health system.



Early Intervention - Not just for Kids

- “The purpose of early intervention is to **lessen the impact** of a person's impairment upon their functional capacity by providing support at the earliest possible stage.”
- “Early intervention support is also intended to benefit a person by **reducing** their **future need for supports** and by strengthening the sustainability of their informal supports, e.g. **building the capacity of their carer**” (NDIS, 2021).
- Identical to the full Scheme - however **you can't apply directly for this** and you **get reviewed more often** for continued eligibility.

<https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/do-you-need-early-intervention/how-will-early-intervention-help-you>

Case Study 1

- 7 year old boy with DLD, gross/ fine motor delays, sensory and emotional dysregulation.
- Initial NDIS application (2017) was never responded to, in 2019 a second application was made. Application and appeal denied, and then family went to AAT;
- Outcome: Settled before hearing on Early Intervention Pathway - still on Scheme 3 year later.
- Key factors in success: Family impact report, OT involvement and report wording, speech pathologist supporting evidence with references.

Case Study 2

- 11 year old boy with DLD, CAS, DCD, dyslexia, anxiety and ADHD.
- Applied for NDIS twice, rejected twice, despite 3 health professionals involved.
- Encouraged family to appeal-family used evidence briefs on DLD and CAS and added own research articles for each condition.
- Successful upon appeal - DLD as primary disability

Case Study 3

- 13 year old boy with DLD, ADHD, dyslexia and anxiety.
- Had applied for NDIS 3 times, rejected 3 times.
- Gone to AAT, speech pathologist directed to answer questions from NDIS lawyer due to case complexity and all treatments not finalised.
- Assisted to answer questions based on DLD being lifelong, using evidence briefs and current research articles.
- Outcome: Settled before hearing, access to full Scheme.

- DLD Fact Sheet
- DLD Evidence Brief
- DLD & the NDIS: A Practical Guide for Families Blog
- Podcast - DLD & the NDIS with Erin West
- Podcast - A Parent's Journey to a Successful DLD NDIS Application
- NDIS events - More info to come

<https://thedldproject.com/developmental-language-disorder-dld/>

DLD Developmental Language Disorder

- 1 IN 14 people have Developmental Language Disorder (DLD), an invisible, lifelong disability.
- DLD is a diagnosis given to a person who has difficulty talking and/or understanding language.
- Diagnosis is made by a speech pathologist however a person with DLD may need support from other health professionals.
- DLD is the accepted term in English-speaking countries replacing specific language impairment, language disorder and language delay.
- DLD affects an individual's life, regardless of their nationality and language. Speaking more than one language does not cause DLD.
- DLD has a genetic and biological basis, but there is not a single known cause. DLD is not caused by how parents verbally interact with their children.
- Children with DLD are 4 times more likely to have math disabilities and 6 times more likely to have reading disabilities.
- People with DLD can succeed in life, with the right supports that meet their unique strengths and areas of need.
- Co-occurring conditions can include learning difficulties, ADHD, dyslexia, and mental health issues.

Learn more about DLD at TheDLDProject.com

EVIDENCE BRIEF DEVELOPMENTAL LANGUAGE DISORDER (DLD) - DECEMBER 2022



This document is a summary of the current evidence on the incidence, assessment, diagnosis and treatment of Developmental Language Disorder (DLD) within the Australian context.

Key Points

- Developmental Language Disorder (DLD) is a permanent, lifelong disability that affects 1 in 14 people (Norbury et al. 2016). A recent Australian prevalence study found 6.4% of children with DLD at 10 years of age (Calder et al., 2022). DLD is a hidden or invisible disability with less than 20% of Australians having heard of it (Kim et al., 2022), which adds to its stigma in the community. Those who receive a diagnosis often feel isolated and alone due to a lack of awareness and support.

- DLD is the internationally recognised diagnostic term for people who have difficulties understanding and using language. The criteria for diagnosis relate to these difficulties being lifelong, having a functional impact on daily life and cannot be explained by an associated biomedical condition (e.g. Autism, Deaf/Hard-of-Hearing). The term 'developmental' refers to the fact that the disorder is present from childhood rather than being an acquired condition (Bishop et al., 2017).

- DLD replaces previous terminology, such as Specific Language Impairment, Language Disorder and Language Delay, following an international consensus study in 2017. Speech pathologists are the primary diagnosticians of DLD and utilise the Bishop et al. (2017) criteria. While the DSM-5 still uses the term Language Disorder, the ICD-11 addresses DLD and categorises it as a neurodevelopmental disorder. For the purposes of the NDIS Act, DLD is best described as a "neurological" condition.



- The DLD Project is connecting with all NDIS Partner organisations to educate them on DLD and offer free training for their staff.
- We will shortly launch a crowd funding campaign to fund research into the '**Functional Impacts**' of DLD' to present to the NDIS evidence committee



Participant First

- Participant First is looking for participants, families, carers and people within the disability community to share their views about the best ways to improve how the NDIS work.
- Receive a weekly invitation to provide feedback, including completing surveys, joining focus groups or taking part in interviews.
- Some feedback opportunities are paid.

<https://www.ndis.gov.au/community/have-your-say/participant-first-help-improve-ndis>

The DLD Project will be connecting with State/Territory and Federal Health and Education Ministers to push for supports to be shared across all areas of government for people with DLD.

We do not believe the NDIS should be the only support avenue for people with DLD.





5. Resources & Advocacy

Speech Pathology Australia FAQ on the NDIS Review:

<https://www.speechpathologyaustralia.org.au/Public/About-Us/News-media-campaigns/Articles/Taking-a-closer-look-at-the-NDIS-Review-Final-Report.aspx>

Not all people with DLD will meet NDIS access criteria.

Other support options:

- **Chronic Disease Management Plans** - This is a GP managed plan that provides a Medicare rebate for allied health services. The CDM plan provides a maximum of 5 total rebates per calendar year for all allied health services (including speech pathology).
- **Private health insurance** - Limited.
- **Educational Funding** - Australian students with disability must be able to access and participate in education on the same basis as their peers. Some states/territories will utilise Federal and State/Territory educational budget to provide specific services.



**THANK
YOU!**

www.thedldproject.com

