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MATERIALS



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DLD & THE NDIS – ACCESS DENIED?



Speech
Pathology
Australia



ACKNOWLEDGEMENT OF COUNTRY



We acknowledge the unceded sovereignty of the Traditional Custodians of the lands on which we meet today, the Muwinina People of nipaluna, and pay respect to Elders past and present.

We recognise that the health and social and emotional wellbeing of Aboriginal and Torres Strait Islander Peoples are grounded in continued connection to culture, country, language and community, and acknowledge that sovereignty was never ceded.

We would also like to pay our respects to Aboriginal and Torres Strait Islander Peoples attending the conference this week and also acknowledge the unceded lands in which you come from.

ABOUT US



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THE DLD PROJECT



Extensive and evolving research tells us what works best for people with Developmental Language Disorder (DLD) but unfortunately these learnings and insights sit in the hands of a few.

The DLD Project addresses these roadblocks by establishing an online platform to distribute evidence-based information, resources and training.

We believe the saying “it takes a village” is the best way to describe our model of engaging families, educators and health professionals to work in partnership to change the lifelong outlook for people with DLD. Everyone has an important role to play.

In addition to offering lots of free and paid tools and resources to support the Australian DLD community, a portion of proceeds goes to funding game changing DLD advocacy and research initiatives.



www.TheDLDProject.com

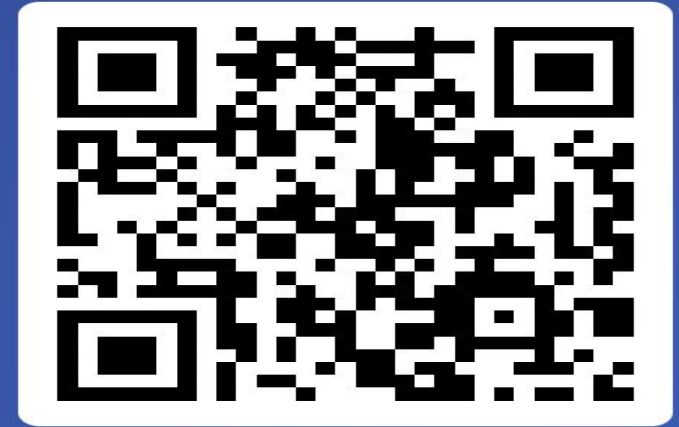


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ABOUT YOU



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AGENDA



- DLD and the current situation
- NDIS Act 2013
- Case studies
- Other pathways for funding
- Moving forward
- Resources
- Survey



DLD & THE CURRENT SITUATION

DLD RECAP

- 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):
 1. Consensus for identification (Bishop et al., 2016)
 2. Consensus for terminology (Bishop et al., 2017)

DLD RECAP



DLD

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

disability

THE CURRENT SITUATION

- The NDIS Act 2013 is the legislation that establishes 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).
- 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.

THE CURRENT SITUATION



- **October 2020** – The DLD Project published resources and podcast to support clinicians and families with support from SPA
- **November 2020** – contacted then NDIS CEO, Martin Hoffman, regarding challenges. He puts us in contact with General Manager. Explored training for assessors, planners and LACs.
- **March 2021** – Paper submitted in response to Independent Assessments.
- **May 2021** – First DLD and NDIS webinar for families
- **October 2021** – Emailed every politician in Australia with the help of Parker (young Ambassador). Meetings with politicians around DLD Awareness Day.
- **October 2021** – Letter from NDIS stating DLD will not be added to List A or B. Funding dependent on the person's ability to show they have multiple functional impacts.

THE CURRENT SITUATION



- **October 2021 – Letter from NDIS stating DLD will not be added to List A or B. Funding dependent on the person’s ability to show they have multiple functional impacts.**

THE CURRENT SITUATION



- **November 2021** - Second DLD and NDIS webinar for families. People reported successful applications.
- **June 2022** – Hon. Bill Shorten is sworn in as Minister for NDIS. Families and advocates are invited to contact him.
- **July 2022** – DLD Fact Sheet launched and shared with NDIS for their Access Team. Again raised issues about inconsistent access to the NDIS.
- **October 2022** - Hon. Bill Shorten’s office contacted again with no response.
- **December 2022** – Evidence Brief for DLD published and shared with Hon. Bill Shorten’s office with no response.
- **January 2023** – Contacted Hon. Bill Shorten’s office again and secured a meeting. Advised to direct families to specialist team at their office. Families report they have been turned away since this time.
- **February 2023** – The DLD Project asked to prepare paper regarding access.

THE CURRENT SITUATION

Primary Condition	Prevalence*	# of NDIS Participants**
Fetal Alcohol Syndrome	0.1%	931
Cerebral Palsy	0.15%	17575
Down Syndrome	0.16%	11602
Autism Spectrum Disorder	0.65%	207385
Intellectual Disability	5.5%	88132
Dyslexia	6%	<20
Developmental Language Disorder	7.4%	147

* prevalence from McGregor (2020). **Data current as of 31/03/2023



NDIS ACT 2013

SUCCESSFUL APPLICATIONS

- You meet the disability requirements if there is 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**.

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.

ICD 11- World Health Organisation

DLD is classified as a **neurodevelopmental condition** in the ICD 11, along with **autism**. 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)

IMPAIRMENT



This is considered a Primary Disability “other”.

Treating health professionals for “other” include:

Speech Pathologist, Occupational Therapist, Social Worker & Physio

Recommended assessments for eligibility:

- PEDICAT (under 16)
- Another useful option - Vineland (in conjunction with multidisciplinary team)

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.

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
- It doesn't matter how much your ability to work, study or socialise is affected by your impairment. It only needs to affect your social or work life in some way for you to meet the criteria.

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.

- ADHD- (18-61%)
- Developmental Coordination Disorder- (30-71%)
- Dyslexia- (48-87%)
- Dyscalculia- (62%)

(Cleaton and Kirby, 2018)

- Mental Health Conditions- anxiety, depression and conduct disorders associated strongly with DLD over time (Levickis et. al, 2018).

This can be used to highlight the need for **co-ordinated care** and a **multidisciplinary team approach**.

BUT YOU'RE NOT ON THE LIST



- A disability being placed on a List means automatic acceptance to the Scheme.
- Due to Scheme sustainability issues and the introduction of Independent Assessments, SPA and The DLD Project have been told that no conditions were being added to the Lists.
- However, there are “unofficial lists” that Planners have access to, with information sheets about common conditions.
- Our common goal is to raise awareness of the lifelong and permanent nature of DLD as a neurological condition.

EARLY INTERVENTION-NOT 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.



CASE STUDIES

RECIPE FOR SUCCESS



- *Case 1: Early Intervention-AAT settlement*
- *Case 2: Full access-Internal Review*
- *Case 3: Full access-AAT settlement*

CASE 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 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 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.

APPEALS AND TRIBUNAL

- There is an internal appeal process to help people with disability affected by reviewable decisions. This leads to an **internal review**.
- If the applicant isn't satisfied by the internal appeal process, this can lead to an **external review** by the **Administrative Appeals Tribunal (AAT)**.
- There are 2 types of supports available:
 - Access to skilled advocates.
 - Access to funding for legal services.
- Independent Expert Review supports are currently being trialled.

A word of warning...



OTHER PATHWAYS FOR FUNDING

OTHER PATHWAYS FOR FUNDING



- **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.



MOVING FORWARD

MOVING FORWARD

- **Assessment & Diagnostics**
 - Use standardised and non-standardised tools for evaluating language.
 - Include impact statements from key stakeholders (e.g. parents/caregivers, teachers etc).
 - Describe the functional impact of DLD in the home and community.
 - Identify co-occurring conditions.
 - Diagnose Developmental Language Disorder.

MOVING FORWARD



- **Supports**
 - Support families to apply for the NDIS +/- seek other funding
 - Connect families with available funding and services in your area
 - Connect families with support (e.g Facebook groups)
- **Interventions**
 - Speech pathology services is the evidence based intervention for DLD.
 - Intervention DOES NOT cure DLD.

DLD vs Language Disorder Associated with...



Co-Occurring Conditions

- Attention Deficit Hyperactivity Disorder (ADHD)
- Developmental Coordination Disorder (DCD)
- Auditory Processing Disorder (APD)
- Specific Learning Disorder (e.g. dyslexia, dyscalculia)
- Speech Sound Disorder

Differentiating Conditions

- Traumatic Brain Injury
- Sensori-neural hearing loss
- Autism Spectrum Disorder (ASD)
- Intellectual Disability
- Cerebral Palsy
- Epilepsy (result in aphasia)
- Down Syndrome and other genetic conditions
- Rett Syndrome and other neurodegenerative conditions

RAISE AWARENESS



Visit RADLD.org to find out more

RAISE AWARENESS



WHAT ABOUT
DLD?

- Sign the Change.org petition
- Share your story
- Wear purple and yellow
- Light up a landmark
- Become a RADLD Ambassador

1 IN 14
AUSTRALIANS HAVE
DEVELOPMENTAL
LANGUAGE DISORDER



RESOURCES

RESOURCES



- **DLD Evidence Brief**
- **DLD & the NDIS: A Practical Guide for Families**
- **Podcast – DLD & the NDIS with Erin West**
- **Podcast – A Parent’s Journey to a Successful DLD NDIS Application**
- **Legal Briefing (coming soon)**
- **Case Study Reports (coming soon)**
- **SPA’s Communication Hub articles**

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SURVEY





Access Request Form - Let's Have a Go!

<https://www.ndis.gov.au/how-apply-ndis/what-access-request-form>



QUESTIONS