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evidence brief

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title **Developmental Language Disorder and the National Disability Insurance Scheme (NDIS)**

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developmental language disorder

Developmental language disorder (DLD) is diagnosed when a child has language difficulties that continue into school age and beyond. In DLD, language difficulties occur in the absence of a known biomedical condition, such as autism spectrum disorder (ASD), intellectual disability or Down syndrome. These difficulties have a negative impact on a child's ability to use words and sentences (expressive language development), understand language (receptive language development) and can have significant impact on everyday social interactions or education progress.

There is no known cause of DLD; it is likely the result of several interacting genetic and environmental factors. DLD is a lifelong disorder meaning that children with DLD will have language difficulties that persist into adulthood. There are multiple risk factors associated with persistent DLD, including:

- Family history of language or literacy deficits
- Socio-economic disadvantage
- Poor maternal education
- Lower non-verbal cognitive abilities
- Early developmental delays

There is considerable evidence that DLD is more common in children from socio-economically disadvantaged backgrounds, although this likely reflects both genetic and environmental vulnerabilities (D.V Bishop, 2014; as cited by Norbury, 2020).

Currently, there is limited available data about the prevalence of DLD within the Australian population (in the absence of a known biomedical condition); but available data report that DLD affects approximately 7.5% of the population (Norbury et al, 2016).

The Australian Bureau of Statistics 2015 Survey of Disability, Ageing and Carers (SDAC) reported that there were 278,100 children with disability, of whom almost half (46.0% or 127,900 people) had some level of communication disability (ABS, 2015). Of children with communication disability in 2015, over a third (36.7%) had 'autism and related disorders' reported as their main long-term health condition, (ABS, 2015).

Despite being more prevalent than other childhood disorders, such as autism spectrum disorder (ASD), DLD receives little public attention and there is no reference of this disorder within the SDAC. This is partly due to a historic lack of agreement on the criteria and terminology for DLD. The term 'DLD' was endorsed in a consensus study involving a panel of experts (CATALISE Consortium) in 2017. The panel agreed that 'disorder' conveyed the serious nature and potential consequences of persistent language deficits (Bishop et al., 2017).

Children, adolescents and adults diagnosed with DLD are at increased risk for poor social, emotional, and behavioural outcomes; including school failure (Tomblin et al., 2000), variable education provisions (Bao et al., 2016), poor peer negotiating skills

(Im-Bolter et al., 2013) and poor emotion recognition and regulation (Salmon et al., 2016). Children and young people with DLD are at risk to obtain lower academic and vocational qualifications and complete fewer years of formal education (Conti-Ramsden et al., 2018).

Few studies specifically examining the prevalence of DLD in adolescents. However, one study of students across NSW, Australia (>14,000 children in total) showed that approximately 11 per cent of students across the secondary school years were identified with communication disorder (McLeod and McKinnon, 2010). Data is skewed with only 4.6 per cent of students in years 11 and 12 being identified with communication disorder (McLeod and McKinnon, 2010). This likely reflects the very high drop-out rates of students who have communication disorders after year 10 - which has been demonstrated to occur internationally (Conti-Ramsden et al, 2009; as cited by SPA, 2016).

It has also been reported that most adolescents with a history of speech and/or language impairment were likely to complete vocational and employment training than complete higher years of schooling (Snowling et al., 2001). Nevertheless, the evidence suggests that the residual effects of DLD may be lifelong, impacting educational achievement, occupation, and ultimately socio-economic status (Johnson et al., 2010; as cited by Cronin, 2017).

There is a robust association between language disorder and poor psychosocial outcomes. DLD is frequently associated with a variety of forms of externalising difficulties; including conduct disorders (Van Daal et al., 2007), high rates of difficulties in attention and hyperactivity (Snowling et al., 2006) and dyslexia (Pennington and Bishop, 2009, Adlof and Hogan, 2018). DLD is also associated with internalising symptoms, such as anxiety and depression. Children with language problems are also at increased risk of being bullied (Redmond, 2011) and of having poorer emotional regulation (Fujiki et al., 2002). These have been identified as risk factors for mental health difficulties.

There is limited data on the effect of DLD on adult health and prospective associated costs within Australia. Current research does not consider accumulation of cognitive and non-cognitive skills or the impact of increased investment (such as early intervention) at critical time periods on long-term outcomes (Cronin, 2017).

Language problems also show relationships to involvement with the criminal justice system. Language-impaired youth have higher rates of arrests and convictions (Brownlie et al., 2004). Rates of individuals identified to present with a communication impairment within youth justice settings range from approximately 19% in U.S. research (Sanger et al., 2001) to over 60% (Bryan, 2004) in U.K. studies (cited by Snow, 2019). Australian research estimates that between 38% and 52% of individuals in youth justice services are diagnosed with DLD or associated language disorders (Snow et al., 2015, Snow and Powell, 2011; as cited by Snow, 2019).

In recent Australian studies, it has been demonstrated that such young people are able to show strong therapeutic engagement and make meaningful communication gains in response to relatively short-term, medium-intensity speech-language pathology interventions (Snow and Woodward, 2017).

policy issue

Cost to vulnerable populations and families

It is difficult for Australian children with DLD to access the services that they need in a timely and effective manner. Many factors contribute towards this including poor awareness of DLD, inequitable and inaccessible health services and unclear navigation of health and disability services. Studies indicate that children from vulnerable populations, including racial and ethnic minorities and socioeconomically disadvantaged groups, are more likely to experience barriers to accessing appropriate health care (Ou et al., 2010). In Australia, this group includes Aboriginal and Torres Strait Islander children.

As DLD is often linked to a family history of language or literacy deficits, these barriers are amplified for children with DLD as their parents may not have the skills and knowledge to be resourceful and access the services required (Law et al., 2017).

The consequences of a delayed assessment and intervention for individuals with DLD are considerable, yet families often face difficulties in obtaining a timely diagnosis and appropriate intervention (Bishop et al., 2016).

Children with DLD require ongoing and sustained speech pathology intervention; with many clinicians recommending weekly sessions. Although short periods of intervention may be sufficient to teach new vocabulary or grammatical forms (Ebbels et al., 2007), making significant improvements to a child's overall language function takes considerable time and sustained input (McCartney, 2017). The intensity and the duration of typical therapy interventions lacks systematic review, although these factors have been raised as potentially important determinants of outcomes (Law, 2000, Hoffman, 2009, Warren, 2007; as cited by Law, 2017).

All Australian families can self-refer to a GP, paediatrician, early childhood intervention and Community Child Health services in each state and territory. With a referral from a general practitioner, families will be eligible for a Medicare rebate if they are an Australian or New Zealand citizen, permanent resident, hold a permanent visa or are covered by a Reciprocal Health Care Agreement with another country (Services Australia, 2019).

Medicare and Enhanced Primary Care Plans

As part of the 2014 Senate inquiry, the national body, Speech Pathology Australia (SPA), reviewed access to early intervention in the public health and disability sectors (SPA, 2014). SPA summarised that to claim a Medicare rebate for a speech

pathology service (Chronic Disease Management Items), a person must have received an Enhanced Primary Care Plan from a GP.

Eligibility for an Enhanced Primary Care Plan is based on the presence of a chronic condition—one that has been present for six months or longer. For a rebate to be claimed, the speech pathologist must be registered with Medicare and have a Medicare provider number. A maximum of five sessions (across all relevant allied health professionals) can be claimed per calendar year. The rebate is currently \$54.60 for each 20-minute speech pathology session, (Department of Health, 2020). The scheduled fee for a 20-minute session is currently \$64.20 (Department of Health, 2020), with the rebate calculated at 85 per cent of this fee (Senate Community Affairs, 2014). The speech pathologist may recommend a longer session and charge accordingly. There will be a gap fee—the amount between what the speech pathologist charges and the rebate.

The cost of a standard consultation with a private speech pathologist is approximately \$170 per hour, but this fee may be higher if a complex consultation is required (All About Kids, 2020). Five Medicare funded sessions per calendar year is likely to be insufficient to adequately manage the treatment of children with DLD (SPA, 2014).

Private Health Insurance

Private health insurance rebates vary hugely but are usually less than half of the service fee, or are capped after very few services. For example; a basic hospital cover with medium extras starts at \$44.60 per week (Bupa, 2020). Under this policy, families can claim \$57.00 for an initial speech pathology visit and \$34.00 per subsequent sessions (Bupa, 2020). This is capped at \$400 per year and has a combined limit for speech pathology, eye therapy and occupational therapy (Bupa, 2020). The client may not claim a Medicare rebate and a private health insurance rebate for the same service.

'Eligible' disabilities

There are increased services available to support the early diagnosis and treatment of children with an 'eligible' disability, such as ASD, Cerebral Palsy and Down Syndrome. These packages are *The Helping Children with Autism Package* (HCWA, 2008) and *Better Start for Children with Disability Initiative* (Better Start, 2011).

Up to four Medicare Benefit Schedule (MBS) services in total will be available for eligible allied health professionals, including speech pathologists, to collaborate with the referring practitioner in the diagnosis of a child (aged under 13 years) and/or the development of a child's management plan (Department of Health, 2020).

A further twenty Medicare rebate services in total will also be available for eligible allied health professionals, including speech pathologists, to provide treatment for a

child under 15 years of age, providing a treatment and management plan is in place before their 13th birthday (Department of Health, 2020).

Despite evidence suggesting that the residual effects of DLD may be lifelong; impacting educational achievement, occupation, and ultimately socio-economic status (Johnson et al., 2010; as cited by Cronin, 2017), DLD has never been considered an 'eligible' disability and has always been excluded from such funding packages.

what does the evidence say

DLD and the NDIS

Individualised funding under the HCWA and Better Starts programs is transitioning to the National Disability Insurance Scheme (NDIS) and is due to cease on 31 March 2021 (Department of Social Services, 2020). The NDIS scheme was legislated in 2013 and went into full operation in 2020 (Department of Social Services, 2019).

The scheme entitles people with a "permanent and significant" disability (under the age of 65), to full funding for any "reasonable and necessary" support needs related to their disability (NDIS, 2019). Funding is allocated to the individual, and the individual or their guardian chooses which providers supply the funded goods and services (NDIS, 2019). There are two main entry points to the NDIS, through Early Childhood Early Intervention (ECEI) for children under 6 years old, and the general scheme for those between 6 and 65 years of age (May, et al., 2017).

The ECEI pathway is designed to be a 'gateway' to the NDIS for children up to six years of age, ensuring that only children who meet the eligibility criteria of the NDIS become participants of the Scheme (Senate Community Affairs, 2017). Children are eligible for early intervention supports as a Participant of the NDIS Scheme if they meet the following:

1. Resident requirements: Participant is an Australian citizen, or hold a Permanent Visa or a Protected Special Category Visa; and
2. Early Childhood Early Intervention Requirements: participant is a child aged less than six years of age with developmental delay, which results in:
 - (a) substantially reduced functional capacity in one or more of the areas of self-care, receptive and expressive language, cognitive development or motor development; and
 - (b) results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of extended duration, and are individually planned and coordinated; and
 - (c) these supports are most appropriately funded through the NDIS, and not through another service system; and

There is evidence that getting supports now will help by:

- (a) reducing how much help they will need to do things because of their impairment in the future; and improving or reducing deterioration of their functional capacity; or
- (b) helping their family and carers to keep helping; and these supports are most appropriately funded through the NDIS, and not through another service system (National Disability Insurance Scheme Act. 2013, s. 9).

Early Childhood (EC) Partners are employed under the ECEI and are the first point of contact for families/carers with a child aged under 7 years old who may have concerns about their development (Department of Social Services, 2020). Families do not require an assessment or report to contact an EC Partner. The EC Partner is responsible for connecting families with local supports and organising short-term early intervention (3-6 months) where possible. EC Partners are also responsible for assisting families to access NDIS support when longer-term early childhood intervention is required (Department of Social Services, 2020).

Since its full implementation in 2016, the ECEI scheme has been associated with significant delays, long waiting lists, poor understanding of communication disorders by EC Partners and subjective, unclear eligibility criteria (SPA, 2019). Specific data relating to the current number of children with DLD who are accessing the ECEI scheme is unknown.

Eligibility under Sections 24 and 25

In order to transition from ECEI to NDIS participant, the person will need to meet NDIS eligibility criteria through a reassessment period that demonstrates that the person is eligible under Section 24 (Disability) or Section 25 (Early Intervention). Section 24 allows access to the NDIS with a diagnosis that is considered a 'permanent' disability, including ASD, cerebral palsy and intellectual disability, (NDIS, 2020).

In the context of DLD, children are more likely to access NDIS funding under Section 25, if their individual planner agrees that the child:

- presents with a developmental delay (section 25(1)(a)(iii)); and
- the NDIA is satisfied that provision of early intervention supports is likely to benefit the person by reducing their future needs for disability related supports (section 25(1)(b)); and
- the NDIA is satisfied that provision of early intervention supports is likely to benefit the person by:
 - I. mitigating or alleviating the impact of the person's impairment upon their functional capacity to undertake communication, social interaction, learning, mobility, self-care or self-management (section 25(1)(c)(i)); or

- II. preventing the deterioration of such functional capacity (section 25(1)(c)(ii)); or
 - III. improving such functional capacity (section 25(1)(c)(iii)); or
 - IV. strengthening the sustainability of informal supports available to the person, including through building the capacity of the person's carer (section 25(1)(c)(iv)); and
- The NDIA is satisfied early intervention support for the person is most appropriately funded or provided through the NDIS (section 25(3)).

This process has been criticised as final decisions regarding eligibility are made by individual NDIS planners, who may have limited knowledge of life-long complexities associated to conditions like DLD. In 2019, SPA completed a submission to the Australian Government's Department of Social Services' regarding the NDIS Act Review and NDIS Participant Service Guarantee. SPA documented:

"We have received many reports of inconsistencies in access whereby a planner has determined that an individual referred to the NDIS by a Speech Pathology Australia member, is not eligible for the scheme, yet another person the member has also referred, with the same condition and similar functional needs, is determined to be eligible by a different planner" (SPA, 2019).

In this submission, there are documented cases of inconsistencies between individual planners regarding the interpretation of eligibility criteria outlined in Section 25. Some planners insist that a child must demonstrate therapy needs from more than one allied health profession and/or in more than one functional area (SPA, 2019). This may result in a child with DLD being excluded from the NDIS as often the primary intervention required is (long-term) speech pathology.

Socioeconomic disadvantage

Children with DLD often grow into adults who have relatively low educational attainments (Whitehouse, 2009) meaning that their children may share a familial risk for language disorder (Bishop, 2014). Complex criteria, as well as subjective assessment (and reassessment) protocols put added stress on vulnerable families who are required to navigate support services and advocate for their child's disability.

Evidence demonstrates that DLD is more common in areas of socio-economic disadvantage (Law et al., 2017). Children from lower-SES families often show slower vocabulary growth relative to their higher-SES peers (Arriaga, 1998) and these differences can persist into the school years (Morgan, 2015).

Issues of access

A diagnosis is not a requirement to access the NDIS and the term 'diagnosis' does not appear in section 24 of the NDIS Act. However, as outlined in one guide to accessing the NDIS;

“the NDIA respects a person’s right not to be labelled and as such a diagnosis is not essential to access the NDIS, although extremely helpful if available” (Masters and Shelby-James, 2017).

Australian and international guidelines recommend children wait no longer than three months for a developmental assessment (Zwaigenbaum, et al., 2008).

In 2020, investigations by the Australian Broadcasting Corporation (ABC) reported that children with disabilities such as DLD can wait almost two years for an appointment with specialist teams in disadvantaged areas, compared to as little as two months in richer areas (Dalzell, 2020). Further ABC investigations reported that paediatricians were providing diagnoses instead of referring children to specialist teams to help ‘forgotten children’ with disabilities gain faster access NDIS funding (Dalzell, 2020). Some paediatricians admitted to ‘bypassing best practice’ and providing children with ‘diagnoses of ASD on the spot’ rather than referring them to child assessment teams (Dalzell, 2020). In the context of DLD, parents and professionals may choose to pursue this route. The child will be able to access NDIS support under Section 24, despite being provided with an incorrect diagnosis (such as ASD).

Participants eligible for the NDIS are not excluded from complications. In 2019, the Australian Government commissioned a review of the NDIS Act to identify opportunities to make NDIS processes simpler and more straight-forward and remove legislative barriers to positive participant and provider experiences with the NDIS (Disability Intermediaries Australia, 2020). The Department of Social Services (2020) outlined that feedback to the review showed that some participants:

- found the transition to the NDIS confusing and frustrating, with some people saying they ‘missed’ the supports offered under state and territory systems, particularly active case management;
- are frustrated about delays and lack of transparency around how the NDIA makes decisions;
- feel the NDIS is too complex and difficult to navigate;
- feel they are not recognised as the experts in their disability; and
- feel NDIA staff do not understand disability or appreciate the challenges people with disability face as part of everyday life.

The Tune Review

The NDIS ‘Tune’ review report was made public in January 2020; it included 29 recommendations which aimed to cut wait times, improve services, enhance flexibility in the use of funds, and clarify access for people with a disability (Disability Intermediaries Australia, 2020).

The review recommended that participants – across all ages – wait less than 70 days from having their access confirmed to having a plan approved from 1 July 2020 and no more than 56 days from 1 July 2021.

According to the December 2019 Council of Australia Governments (COAG) NDIS Quarterly report, the number of children waiting greater than 50 days for an NDIS Plan after meeting access reduced from 4,208 at the beginning of June to 712 at 31 December 2019 (NDIS, 2020). The ‘Tune Review’ advised that,

“The NDIA should not implement a closed or deliberately limited panel of providers to undertake functional capacity assessments” (Tune, 2019).

To accurately diagnose DLD, speech pathologists require qualitative and quantitative information about a child’s language across multiple contexts, including home and education settings. Speech pathologists must assess multiple language domains; including grammar, syntax, semantics, discourse and pragmatics, as well as non-linguistic features; such as phonological short-term memory and working memory (Thomas et al., 2019). In addition to standardised assessment data, best practice recommends that clinicians review the child’s language through a series of observations and interviews with their primary communication partners.

On 28th August 2020, the Minister for the NDIS, Hon Stuart Robert announced the “most substantial” package of reforms to the NDIS since its establishment (Ministers for the Department of Social Services, 2020). The package includes the implementation of the Australian Government’s Response to the 2019 ‘Tune Review’ and the new NDIS Participant Service Guarantee. Currently, participants access assessment reports from multiple health providers of their choosing and this information is used to assess NDIS eligibility. As part of the reform, new independent assessments will be conducted by NDIS-appointed healthcare professionals using standardised tools. These will be progressively rolled out and, by 2021, independent assessments will be a mandatory procedure for any participant of the NDIS. Minister Robert stated that independent assessments will deliver a,

“simpler, faster and fairer approach for determining a person’s eligibility through more flexible and equitable support packages” (Ministers for the Department of Social Services, 2020).

However, disability advocates have criticised the introduction of independent assessments, stating that this eliminates individual choices and participants’ control of the system (Whyte, 2020).

The NDIS has stated that assessments will likely take between 1-4 hours and that assessors will consider evidence provided by external GPs or allied health professional(s) (NDIS, 2020).

It is known that there is a lack of public knowledge and advocacy about DLD; it is a disorder that impacts individuals across their lifespan and requires specialist support for all assessment and intervention processes. People with DLD require assessment teams that understand the nature and complexity of the disorder; it is highly likely that the introduction of independent assessors will result in a higher number of children ‘falling between the gaps’ of service supports.

what does this mean for policy makers

Challenges and Opportunities

Children with DLD require early and targeted intervention support to reduce the risk (and related costs) of poor social, education, emotional and mental health outcomes. Currently, children with DLD are being inconsistently excluded from NDIS funding support due to subjective assessment criteria, length waiting periods and unclear exclusion criteria. Language difficulties are likely to place an increasingly larger burden on the health and welfare system as these children move through school and after they leave school. The following recommendations are made:

- DLD be included in List A of Section 24 of the NDIS. This will allow families to access NDIS services in a timely and efficient manner. Early access to intervention may reduce the long-term economic costs associated with individuals diagnosed with language impairment. This will also reduce the need for parents (who may be experiencing language difficulties themselves) to be advocating for their children to be considered eligible for NDIS services under Section 25 criteria. Information about the NDIS scheme, including Access criteria, also needs to be available in communication accessible formats, including Easy English.
- If DLD is not included in Section 24 of the Act, eligibility criteria of Section 25, (9.2.1) need to be reviewed to ensure the inclusion of children with DLD. Currently, eligibility criteria are often interpreted by planners as meaning that a child requires intervention from more than one therapy discipline. Criteria outlines that developmental delay means a delay in the development of a child under six years of age that

“results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated” (NDIS, 2019).

This currently results in children who require one therapy, that is, children with DLD requiring speech pathology only, being excluded by some planners.

- Rather than using independent assessors, NDIS eligibility is considered following best-practice guidelines. This includes using qualitative and quantitative measures that are collected through multiple observations,

interviews with communication partners and administering standardised assessments.

- These assessments should be completed by a speech pathologist who understands DLD and the impact that it has across multiple domains and contexts.
- Specialist training be provided by speech pathologists to NDIS planners about the life-long impacts of DLD and supports required. NDIS planners must have the knowledge and understanding to apply eligibility and access criteria in an appropriate way for children when considering eligibility under Sections 24 and 25.
- Increased education be provided to the wider public about DLD. This would alleviate some of the issues in referral as many parents are currently unaware of the disorder and of the support services available. Education for paediatricians and specialist teams is also required as misunderstanding of the implications of assessment and diagnosis are common.
- Improved access to public health services be provided in areas of low socio-economic status to decrease prolonged waiting periods.

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