

A vision for Developmental Language Disorder (DLD) for the UK

October 2023

How did we arrive at this vision?

Over a number of online sessions adults and young people with Developmental Language Disorder (DLD) and their families got together to talk about their experiences and what they wanted. The professionals listened. The information was pulled together into 5 key 'ambitions'. These 5 ambitions make up the vision for DLD for the UK and will guide the collaborative work of the organisations involved (Afasic, NAPLIC, RCSLT and Speech and Language UK).

We will be building a long-term plan that others can get involved in, including you.

What is our vision?

We [people with DLD] want a world in which:

1. EVERYONE KNOWS ABOUT DLD

- People with DLD want 'everyone to know what it is so we don't have to constantly explain it'.

Despite international efforts, such as the Raising Awareness of DLD campaign (www.radld.org), awareness of DLD among key groups such as education and health professions remains low. Awareness among the general public is lower again and many people first hear of DLD when they or a family member is diagnosed with the condition.

Families who took part in the consultation described DLD as an 'invisible condition.' Failure to comply in the classroom or at work was frequently attributed to 'not listening, being lazy, or causing trouble,' as staff did not recognise the individual's challenges with understanding and talking.

If more people were aware of DLD, services, policies, research and support would all grow. Day to day life for people with DLD would improve significantly and feel less of a battle.

2. WE ACCESS SUPPORT EASILY

- People with DLD want 'the right support at the right time' and 'a fair system for all no matter where you are or who you are'.

Many families report that speech and language therapy services have long waiting lists for initial appointments and no interim support is provided. In many cases services have been severely rationed and there is increasing reliance on 'consultative' models of provision rather than direct therapy services. Services vary significantly geographically, and even between neighbouring schools. In general less

support is available at secondary and less again in Further Education (FE) colleges. In England many families reported applying for Education Health and Care Plans (EHCP) because it was the only way to secure consistent support.

There are currently no DLD-specific support services for adults provided by the NHS.

If people with DLD were able to access support more easily, they would achieve better life outcomes and many of the negative impacts, such as mental health needs could be reduced.

3. WE ARE DIAGNOSED EARLY

- **People with DLD report: ‘There are far too many hoops to jump through’ and ‘diagnosis happens by chance’.**

One family reported their teenager received ‘detention every day for a year until she got her DLD diagnosis.’ If this diagnosis had been made earlier the negative impacts could have been avoided.

There is general recognition that early intervention is essential to meeting the needs of children with DLD, yet many parents report that getting a diagnosis on the NHS is ‘virtually impossible.’ They report that their concerns are not taken seriously by General Practitioners, who often claim that ‘children grow out of it’ or that language problems ‘are not as serious as other conditions, like autism.’ There are indications that speech and language therapists do not feel confident in providing a differential diagnosis when they are not working within a multidisciplinary team.

Early diagnosis should not just be about age, but rather about the timing in relation to need. The adults we have spoken to describe receiving a diagnosis of DLD in adulthood as ‘life-changing’ and helpful in ‘understanding the difficulties I have had all my life’, yet there are no NHS services for adults with DLD.

If timely diagnosis of DLD was available then not only would more people experience the transformative self awareness, but others around them would also increase understanding and learn how to make adjustments.

4. ALL SCHOOLS AND WORKPLACES MEET OUR NEEDS

- **People with DLD want: ‘schools to all know about DLD, what it is, how to help’ and that ‘methods of teaching are understood, such as visuals and mind maps’.**

Young people reported spending lessons being overwhelmed by the amount of language used in the classroom. They report teachers regularly using complex sentences and advanced vocabulary that young people with DLD could not

understand. Families described having more knowledge about DLD than the school staff. Adults with DLD regularly struggle in the workplace as managers and colleagues are unaware of DLD. When brave enough to talk about their DLD managers did not know what to do or where to access further information and advice.

The changes required to support people with DLD in the classroom and the workplace are often simple and low cost. Such as increasing the use of visual information such as symbols, diagrams, images and objects, or making job application processes more inclusive. Widely available technology can often be useful too. Schools and workplaces need to build sustainable systems, with support strategies embedded in daily practice.

Increased awareness of what DLD is and what strategies help would improve communication and create more inclusive school and work environments. More people with DLD would be able to thrive.

5. WE ARE INDEPENDENT

- **People with DLD want to be able to lead independent lives full of opportunity. They want:**
 - **the life skills needed to be ready for adulthood.**
 - **DLD to no longer be associated with mental health concerns in adulthood because they have had all the support they needed growing up.**

Currently DLD is associated with poorer educational outcomes and in adulthood, lower rates of employment and pay, and higher mental health needs. In many cases this is because diagnosis has not been made, made late and/or inadequate support has been provided. A diagnosis of DLD can in many cases be transformative, and with support people with DLD can succeed. Services need to reflect DLD as a lifelong condition and be available not just in childhood and adolescence but periodically throughout adulthood also. Support services such as social care and psychological therapies need to be aware of DLD and make adjustments.

If a robust system of awareness, diagnosis and support was available nationally people with DLD would be able to lead full independent lives; 'they could live their best lives.'

What happens next?

Afasic, NAPLIC, RCSLT and Speech and Language UK are committed to working together on a UK wide plan to achieve the vision.

This is a long-term process but the first steps are listed below. It also includes simple steps in how you can get involved and help to make change.

	Action this group will be taking	How others can get involved
1. Everyone knows about DLD	Develop a joint strategic DLD awareness plan for the UK.	Everyone: Get involved with DLD day. Go to RADLD.org, but also follow each organisation's social media accounts
2. We access support easily	Achieving consensus among Speech and Language Therapists about provision, defining what 'good' looks like, what should be available and a good practice example library. Including adult services.	Share your experiences as a person with DLD, family and professional. What is working, what are the barriers? Contact any of the organisations. We want to hear your experiences.
3. We are diagnosed early	Joint statement on the importance of diagnosis. Sharing good practice, developing clinical pathways and supporting the development of NICE guidelines. Facilitating the development of adult services	For Speech and Language Therapists: use the NAPLIC DLD online learning resources. naplic.org.uk/dld
4. All schools and workplaces meet our needs	Simple guides for older age group: FE Colleges, universities and employers including transitions	For SENCOs: use the Speech and Language UK webinars and resources speechandlanguage.org.uk/dld-educational-support/
5. We are independent	Listening to people with DLD to understand what will make the biggest difference to their lives	People with DLD and families: what actions would help you on the way to becoming independent? Contact any of the organisations. We want to hear your experiences.

Appendix - more about Developmental Language Disorder

What is DLD?

Developmental language disorder (DLD) is a form of neurodiversity in which children do not acquire language as expected. People with DLD may have challenges with understanding what others say to them, and producing language that accurately articulates their thoughts, feelings and experiences. They describe DLD as 'experiencing everything on catch-up, a recipe for isolation and loneliness.'

DLD affects approximately 7.5% of the school-aged population, or 2 children in every classroom (Norbury et al. 2016). DLD is a persistent, life-long condition that impacts every aspect of a person's life.

DLD is a biological condition, in which genetic variations interact with each other and environmental factors to affect brain development (Mountford et al. 2022). These differences appear to affect connections in the brain (Krishnan et al. 2022) in ways that make learning language from the usual adult input challenging.

Why do we need a vision and a national strategy for action?

Language is a uniquely human accomplishment that is central to social participation. DLD, therefore, increases risk of a number of adverse outcomes including:

Academic outcomes: Young people with DLD as a group have lower levels of academic attainment, fewer academic qualifications and examinations, and are more likely to leave formal education early (Dubois et al. 2020). Literacy is a particular barrier to academic (and employment) success, with 50% of young people with DLD unable to read simple texts, and more than 80% struggle to comprehend what they read.

Employment: Adults with DLD experience higher rates of unemployment and part-time working relative to peers and more than 25% of those in work on low-incomes (see Dubois et al. 2020). At the age of 19, young people with DLD are twice as likely as peers to be NEET (not in employment, education or training) (Conti-Ramsden and Durkin, 2012).

Mental health: Young people with DLD are 1.5 to 2 more likely to experience internalizing and externalizing disorders by adolescence (Yew & O'Kearney, 2013; Donolato et al. 2022). Young people diagnosed with a mental health condition are five times more likely than peers to have primary language deficits (NHS Digital, 2018) and at least 50% of adolescents referred to tertiary mental health services are found to have language deficits on assessment (Cohen et al., 2013; Hollo et al., 2014).

Quality of life: Young people with DLD have reported challenges with social relationships, emotions, classroom participation and school achievement, independence, and a lack of appropriate support, all of which impact on overall quality of life (Le et al., 2020). Young people with DLD are more likely to be bullied and/or victimized by peers (van dem Badeem et al. 2018), and in extreme cases, to experience maltreatment and sexual abuse (Brownlie et al. 2017).

Youth offending: Young people with DLD are over-represented in the youth justice system (Snow, 2019). In 2019-2020, 71% of young people sentenced in youth courts had language disorders (MoJ 2021).

Despite the costs to both individuals and society, there is a paucity of research concerning DLD. Relative to other conditions with similar prevalence and severity (e.g. ADHD), DLD is under-researched and affected young people are under-served.

A national strategy, underpinned by a vision for the future driven by people with and affected by DLD, is urgently needed to reduce these risks and improve outcomes for all people with DLD, which in turn will benefit society as a whole.