City Research Online

City, University of London Institutional Repository

Citation: St Clair, M. C., Horsham, J., Lloyd-Esenkaya, V., Jackson, E., Gibson, J., Leitão, S. & Botting, N. (2023). The Engage with Developmental Language Disorder (E-DLD) project: Cohort profile. International Journal of Language & Communication Disorders, 58(3), pp. 929-943. doi: 10.1111/1460-6984.12835

Permanent repository link: https://openaccess.city.ac.uk/id/eprint/29580/

Link to published version: https://doi.org/10.1111/1460-6984.12835

Received: 24 August 2022 | Accepted: 30 November 2022

DOI: 10.1111/1460-6984.12835

International Journal of Language & Communication Disorders

RESEARCH REPORT

The Engage with Developmental Language Disorder (E-DLD) project: Cohort profile

Michelle C. St Clair[1] | **Jasmine Horsham**[1] | **Vanessa Lloyd-Esenkaya**[2] | **Emily Jackson**[3] | **Jenny Gibson**[4] | **Suze Leitão**[3] | **Nicola Botting**[2]

[1]University of Bath, Bath, UK
[2]City, University of London, London, UK
[3]Curtin University, Perth, Australia
[4]University of Cambridge, Cambridge, UK

Correspondence
Michelle C. St Clair, Department of Psychology, University of Bath, Claverton Down, Bath BA2 7AY, UK.
Email: mcsc21@bath.ac.uk

Funding information
QR-Strategic Priorities Fund

Abstract

Background: Public awareness of Developmental Language Disorder (DLD) is lower than other neurodevelopmental disorders, despite its high prevalence of 7.6%. This lower awareness means recruitment for DLD research studies is difficult. DLD is both underfunded and under-researched, resulting in relatively limited research investigating individuals with DLD. Engage with Developmental Language Disorder (E-DLD) is a response to these considerations. E-DLD is the first international participant database of those affected by DLD. Parents of children with DLD under 16 and young people and adults over 16 from anywhere in the world can sign up to be a part of the E-DLD.

Aims: This paper aims to describe the families of children with DLD and adults with DLD in the database thus far.

Methods & Procedures: E-DLD members sign up via our website, reporting demographic characteristics as part of this procedure. We request all E-DLD members subsequently fill in a yearly survey. The content of the yearly survey changes dependent on the age of the child, while the yearly survey for adults remains consistent. We measure a wide range of domains, such as speech and language therapy (SLT) support, school support, socialisation skills, and early developmental milestones for our youngest members, and health care support and mental well-being measurements for our adults. We also collect parent and self-reported reflections on strengths and challenges for the person with DLD using open-ended questions and the Strengths and Difficulties Questionnaire.

Outcomes & Results: The database currently consists of 196 parents of children with DLD and 20 individuals over the age of 16 with DLD or suspected DLD across a range of socioeconomic status (SES) backgrounds. Our initial results confirm that E-DLD members meet the linguistic profile of DLD in relation to self- or parent-rated language difficulties. Both children and adults show increased rates of psychosocial difficulties compared to established norms, consistent with past research on clinical samples of people with DLD.

Conclusions & Implications: The findings indicate that a participant database for DLD research is feasible and useful. The rates of emotional, behavioural and sleep difficulties among the child probands are higher than reported rates amongst typically developing children. Initial data indicate that adults with DLD have poorer well-being than their peers. The E-DLD is a useful collection of data on those affected by DLD and is a promising method for connecting people with DLD with academic researchers.

KEYWORDS
database, research facilitation, developmental language impairment, cohort, specific language impairment (SLI)

What This Paper Adds

What is already known on this subject

- Developmental Language Disorder (DLD) is characterised by expressive and/or receptive language difficulties in the absence of another biomedical condition that could explain these difficulties. It is critically under-researched and underfunded. As such, there is a lack of public awareness and difficulty recruiting sufficient sample sizes for DLD research studies.

What this paper adds to existing knowledge

- Engage with Developmental Language Disorder (E-DLD) is the first international participant database of individuals with DLD. This paper provides a preliminary report on the profile of linguistic and psychosocial skills among the individuals on the database, adding to current understanding of DLD across age groups.

What are the potential or actual clinical implications of this work?

- Our aim is that the E-DLD will provide much-needed facilitation of research into DLD. E-DLD will enable those with DLD and their families more readily to shape research agendas and to participate in studies that interest them. Families may be recruited into research that could directly translate to better clinical treatment of DLD. We also believe that the E-DLD yearly survey holds potential to provide key information on the development and longitudinal experience of children and adults with DLD.

INTRODUCTION

Approximately 7.6% of children, or two in every classroom, have Developmental Language Disorder (DLD; Norbury et al., 2016). Previously termed Specific Language Impairment, DLD is a neurodevelopmental disorder characterised by difficulties in expressive and/or receptive language (Bishop et al., 2016). These difficulties persist across development and cannot be explained by the presence of a primary biomedical condition, such as Autism Spectrum Disorder (ASD) or hearing loss. Whilst there is limited understanding of DLD aetiology, several neuroanatomical and neurofunctional correlates are starting to be identified (Krishnan et al., 2021) and research discusses potential polygenic and environmental risk factors (Mountford et al., 2022). DLD is associated with poorer social, academic and mental health outcomes. Children with DLD are more likely to have higher levels of peer problems (Lloyd-Esenkaya et al., 2020) and smaller peer networks (Chen et al., 2020) compared to typically developing (TD) children. DLD is also associated with academic difficulties throughout development (Young et al., 2002) and lower academic qualifications in young adults compared to age-matched peers without DLD (Conti-Ramsden et al., 2018). Additionally, those with DLD are at increased risk of mental health problems, like anxiety and depression, compared to their TD peers (Botting et al., 2016b). There is a high rate of individuals with undiagnosed DLD within the youth justice system (Winstanley et al., 2021). Individuals with undiagnosed DLD also often have emotional and behavioural difficulties (Hollo et al., 2014).

Despite the prevalence of DLD, the number of research publications on this subject is disproportionate to both the prevalence and severity of the disorder (Bishop, 2010; McGregor, 2020). For example, the prevalence and severity of DLD are greater than for attention deficit hyperactivity disorder (ADHD), yet between 2010 and 2019, the number of total publications addressing ADHD was 14 times greater than those for DLD (McGregor, 2020). Similarly, there is discrepancy in the amount of research funding allocated to DLD in comparison to other disorders, with Bishop (2010) documenting only US$28 611 000 in National Institutes of Health (NIH) funding for DLD research compared to US$532 800 000 in NIH funding for ADHD research in 2008–2009. Given the associated outcomes with both diagnosed and undiagnosed DLD and the relatively limited research funding and publications, it is crucial that researchers and funders prioritise DLD to further our understanding of this pervasive disorder.

Awareness and identification of DLD

This lack of scientific papers and grant funding is compounded by poor awareness of the disorder; only 60% of people across European countries have heard of Childhood Language Impairment (the term used for DLD; Thordardottir et al., 2021). Comparatively, at least 90% have heard of ASD and over 80% have heard of ADHD. Awareness across countries for ASD ranges between 83% and 100% and awareness for ADHD ranges between 59% and 100%, whereas awareness of DLD ranges from 13% to 93% (Thordardottir et al., 2021). Similarly, in a study of workplace managers, all reported awareness of autism, ADHD and dyslexia, whilst only 38% had heard of DLD or Specific Language Impairment (Lemos et al., 2022). Moreover, parents and teachers are not always good at identifying DLD. Only 60% of parents whose children met criteria for DLD report concerns regarding language difficulties (Hendricks et al., 2019). This figure drops to 40% when the child does not exhibit word reading difficulties. Furthermore, compared to parents and early intervention educators, identification rates by teachers in identifying children with a language impairment when making referrals to special education are much lower than prevalence expectations (35% identification accuracy; (Christopulos & Kean, 2020). Teachers have also been found to overidentify language impairments in students aged 5 to 6, in comparison to results from formal language testing (Antoniazzi et al., 2010). These findings indicate that both caregivers and teachers may struggle to identify DLD in children, suggesting a high number of individuals have undiagnosed DLD. While it is difficult to estimate the rate of under-diagnosis in the general population, we do know that only 39% of those identified as having DLD at age 5 had a referral to a speech and language therapist (SLT) (Norbury et al., 2016). In addition, Winstanley et al. (2019) showed that around 60% of young offenders have DLD, none of whom had previously received a diagnosis. It is, however, worth stating that youth offending is not more common in those with identified DLD (Winstanley et al., 2018), suggesting earlier identification of DLD is associated with lower likelihood of maladaptive outcomes.

One factor that has hampered research into DLD in the past was the diagnostic label. The term “Developmental Language Disorder (DLD)” has recently been agreed by an international consensus of researchers, SLTs, and other professionals (Bishop et al., 2017). Prior to this consensus, children with DLD were diagnosed using a range of different terms, including specific language impairment, dysphasia, and mixed receptive/expressive language disorder. Currently, SLTs around the world are adopting the new diagnostic label and criteria, and rates of diagnosing DLD have been increasing, at least anecdotally.

However, other issues also affect research in this area. Partly due to the lack of awareness and identification of DLD, many research studies struggle to recruit enough participants with DLD for the findings to be generalisable and representative, which, in turn, influences the reach and impact of the findings. Moreover, it may be difficult for those affected by DLD to engage with, and access the findings of, research. Few studies are open access and many use complex scientific language that cannot be easily understood.

The Engage with Developmental Language Disorder project

In response to the issue of recruiting participants, the lack of large-scale data, and the limited access to research experienced by families experiencing DLD, Engage with Developmental Language Disorder (E-DLD) was established in October 2020. Our primary aim was to create a research database of individuals affected by DLD to whom we could advertise research participation and co-design opportunities, from whom we could collect yearly data, and with whom we could share the latest research. With ethical approval, researchers can apply to recruit participants through the database. Internationally, caregivers of children with DLD, and individuals with DLD over the age of 16, can sign up to be an E-DLD member via the project website (https://www.engage-dld.com/). Members are contacted monthly or quarterly (according to their preference) about DLD research opportunities and invitations to E-DLD events. They are also sent quarterly E-DLD newsletters. Members are asked to fill in our survey, which contains several well-being and social measures, every 12 months. Easy-to-read summaries of DLD research are regularly uploaded to the E-DLD website and highlighted on the E-DLD Twitter account. Full details of our wider activities can be found in the supplementary materials.

E-DLD does not aim to raise awareness of DLD per se. Other projects have been set up to raise awareness and provide support for those affected by the disorder and professionals working with individuals with DLD. In particular, Raising Awareness of DLD (RADLD; https://radld.org/), DLD and Me (https://dldandme.org/), and The DLD Project (https://thedldproject.com/) are key projects making a difference in the DLD field. However, none of these organisations aims to build research capacity in the DLD space, which is the primary objective of E-DLD. Specifically, the aims of E-DLD are to (1) help engage people affected by DLD in research, (2) collect large-scale longitudinal data from families with DLD; and (3) help make DLD research more accessible to those affected by the disorder. Since establishing the initiative, we have identified additional needs and responded by (4) creating opportunities for those affected by DLD to connect with one another, and (5) building partnerships with other DLD projects across the world.

The current paper aims to present and discuss data from E-DLD from the initial 21 months of data collection. In addition to collecting data regarding the types of language difficulties, SLT support and support within schools, we also measure other domains of long-standing and more recent research interest. For instance, we measure sleep habits in children, which we hope will contribute to recent literature documenting differences in subjective and objective sleep differences in children with and without DLD. We also change what we measure as children develop, for instance, measuring early developmental milestones for the youngest children and measuring adolescent self-reported social competence. We also measure general psychosocial difficulties throughout childhood and adolescence and continue to measure mental health symptoms as well as alexithymia in adulthood. In this paper, we evaluate whether the reported language and psychosocial difficulties in the children and adults in the E-DLD database substantiate what we already know about DLD, thereby supporting our assertion that our recruited sample is primarily a sample of individuals with DLD. We also provide an overview of current demographics and socioeconomic status (SES) data of the current database and present preliminary associations of interest. We plan to report on the data set in future papers as it grows, and envisage the information can be drawn upon widely to advocate for services for people with DLD.

METHOD

Ethical approval was obtained from the Department of Psychology Research Ethics Committee at the University of Bath (Refs: 20–207 and 20–208).

Participants

The E-DLD cohort comprises caregivers of children with DLD, and individuals with DLD who are over the age of 16, from across the world. As of 28 June 2022, the cohort consisted of 216 families and adults with DLD or language difficulty. Of these, 196 are caregivers of children with DLD, registered on behalf of their child (*the proband*). Twenty are individuals with DLD over the age of 16. Demographics of the E-DLD database are generated monthly based on the sign-up data from participants. See Table 1 for the demographics of the child probands and Table 2 for the demographics of our adult probands (current as of 28 June 2022).

In line with the diagnostic criteria recommended by Bishop et al. (2017) and the International Classification of Diseases, 11th Revision (World Health Organisation, 2019) that language disorder associated with autism is a separate but related diagnosis to DLD (Bishop et al., 2016), E-DLD members who report a diagnosis of only ASD ($N = 3$ currently) are not sent research opportunities nor included in the E-DLD research database[i]. These members are provided suggestions of other appropriate organisations (e.g., autism research databases) that circulate research opportunities to their members. They remain as a “newsletter-only” E-DLD member.

If caregivers/adults report a primary diagnosis of DLD (or equivalent) but also report an autism diagnosis, we retain these individuals as full members. This is due to the current variability in the diagnosis of DLD and autism: some children are given both diagnostic labels, and some children are diagnosed with DLD and autism by separate practitioners. We realise that this may lead us to include some children who could be described as having a

TABLE 1 Summary demographics of the child probands and caregivers in the E-DLD database

Measure	Child probands ($N = 196$)	Caregivers ($N = 196$)
Gender – Female	40.2% ($N = 78$)	92.3% ($N = 179$)
Mean age (SD; range)	8.6 (3.1; 3–15)	41.7 (5.8; 29–61)
English monolingual	80.1% ($N = 157$)	77.0% ($N = 151$)
UK residents	71.9% ($N = 141$; 90.1% England)	
Diagnosis of DLD[a]	83.3%	
Diagnosis of DLD or equivalent (e.g., SLI)*	93.4%	
Diagnosis of language delay[a]	4.8%	
LD associated with another condition	0.6%	

[a] Total $N = 167$, $N = 29$ left this section blank or have no diagnosis yet.

Abbreviations: DLD, Developmental Language Disorder; E-DLD, Engage with Developmental Language Disorder; SLI, specific language impairment.

TABLE 2 Summary demographics for the adult probands in the E-DLD database

Measure	Adult probands ($N = 20$)
Gender – Female	75.0% ($N = 15$)
Mean age (SD; range)	36.8 (12.7; 18–58)
English monolingual	66.7% ($N = 12$)
UK resident	75% ($N = 15$, 86.7% England)
Diagnosis of DLD[a]	35% ($N = 7$)

[a] The remaining sample screened positive on our screening tool for adults with undiagnosed DLD.

Abbreviations: DLD, Developmental Language Disorder; E-DLD, Engage with Developmental Language Disorder.

language disorder associated with ASD (Bishop et al., 2016). However, we feel that as the caregivers have sought out and decided to actively participate in this DLD-specific project, the main difficulties the child faces are likely to be language based. Furthermore, some children with a history of not meeting the criteria for autism later show more autism-like behaviours (Conti-Ramsden et al., 2006). Until the clinical field comes to a better consensus on DLD and autism, we will accept reports of a primary diagnosis of DLD with autism as a secondary descriptor and note this in the database for future analysis. There are only three cases meeting this criterion (i.e., 1.4% of our database).

Adults who do not have a diagnosis of DLD, but who experience language difficulties, are also able to sign up to the database. Adults who indicate that they do not have a DLD diagnosis complete a screening tool that assesses their language difficulties in terms of both current and lifelong difficulties (e.g., *Did you start speaking at a later age than most children normally start speaking? Do you often have difficulty understanding when people tell you things? If yes, have you always had this problem?*). We also ask about exclusionary criteria relating to hearing loss, diagnosis of aphasia and traumatic head injury, which may indicate an acquired language disorder. If the screening tool indicates presence of language difficulties consistent with a DLD diagnosis, they can sign up as an E-DLD member. This is in acknowledgement that obtaining a DLD diagnosis in adulthood is a difficult process, and the growing evidence that many children and adolescents go undiagnosed for their entire development to adulthood (Barry et al., 2007; Plante et al., 1996; Winstanley et al., 2019). This screening measure was created by the E-DLD team, who are in the process of validating the tool, which will be made freely available to the research community once validated.

Materials

Initial sign-up survey

The initial sign-up survey collects information about the individual with DLD and their family. This includes contact information and the probands' sex, age, nationality, multilingual status and residency, as well as details of their siblings. Also recorded are the living arrangements of the child and adult probands. For our UK residents, we collect postcode data, which we translate into Indices of Multiple Deprivation (IMD) data (for England: https://www.gov.uk/government/collections/english-indices-of-deprivation). From this, measures of deprivation are generated, including the Index of Multiple Deprivation (IMD) as well as the Income Deprivation Affecting Children Index (IDACI) for England residents. IMD measurements are also available separately for Wales, Scotland and Northern Ireland. High values indicate the least deprived areas of the UK, with lower values indicating higher economic deprivation.

The survey also includes child diagnosis, areas of language difficulty, comorbid conditions, and medication. The question about language difficulties asks members to select (tick) options from a list (e.g., 'understanding others [receptive language]', 'expressing themselves through language [expressive language]', 'learning new words', etc.) and then to describe any additional difficulties or conditions. Members also report whether they have any formalised and mandated support at school (UK only) and details of any standardised testing they have had, such as SLT assessments. SLT assessment results can be reported within text or uploaded directly to our secure servers.

Yearly survey

Within the yearly survey, caregivers report on a variety of measures. Please see Table 3 for the full domains measured at each age. Highlighted here are the measures discussed in this paper.

The **Strengths and Difficulties Questionnaire** (**SDQ**; Goodman, 1997) consists of two versions, one for 2- to 4-year-olds and one for 4- to 16-year-olds. It has 25 items: 10 regarding 'strengths', 14 on 'difficulties', and one that is neutral. Each item is rated on a three-point scale (*not true, somewhat true and certainly true*). These items comprise five subscales: hyperactivity, emotional symptoms, conduct problems, peer problems and prosocial skills. The four difficulty subscales are summed to create a total difficulties score. Higher subscale and total scores indicate more problems, except for the prosocial score, where lower score indicate lower prosociality. Five items are reverse scored. For example, in the peer problems subscale, the question 'generally liked by other children' is reversed scored. The 4–16 SDQ has an internal consistency of 0.73 and a test–retest reliability of 0.62 (Goodman, 2001).

The **Children's Sleep Health Questionnaire** (**CSHQ**; Owens et al., 2000) is a 45-item questionnaire composed of eight subscales assessing sleep problems in school-aged children (aged 4–10). This includes sleep duration and bedtime resistance, amongst other items. Most questions are rated on a three-point frequency scale (*rarely* [0–1 times per week], *sometimes* [2–4 times per week], *usually* [5–7 times per week]), although two questions about sleepiness watching TV and riding in a car are measured on a different three-point scale (*not sleepy, very sleepy, falls asleep*). Six items are reverse scored, such as 'child sleeps the right amount'. It has an internal consistency of 0.68 in a community sample and a test–retest reliability ranging between 0.62 and 0.79. A total score is created by summing all items and a higher score indicates more sleep problems. A cut-off score of 41 for sleep problems yields a sensitivity of 0.80 and a specificity of 0.72. We report on data only within the 4–10 age range for this study.

Adult E-DLD members complete a number of measures within the yearly survey. This includes the 9-item depression subscale of the **Patient Health Questionnaire** (**PHQ-9**; Kroenke et al., 2001). The PHQ-9 assesses depression severity and is measured on a four-point frequency scale reflecting on feelings over the previous 2 weeks (not at all, several days, more than half the days, nearly every day). The items are summed to create a total score and a higher score indicates more depressive symptoms. It has an internal reliability of 0.89 and a test–retest reliability of 0.84 (Kroenke et al., 2001). Kroenke and colleagues proposed cut-offs which have been generally accepted; scores of 5–9 is mild, 10–14 is moderate, 15–19 is moderately severe and 20–27 is severe. A cut-off of 10 had a sensitivity of 88% and a specificity of 88% for major depression.

The **Generalised Anxiety Disorder Assessment** (**GAD-7**; Spitzer et al., 2006) assesses anxiety symptom severity and is measured in the same manner as the PHQ-9. The items are summed to create a total score and a higher score indicates more anxiety symptoms. It has an internal consistency of 0.92 and a test–retest reliability of 0.83. Cut-offs are generally accepted as 5, 10 and 15 for mild, moderate and severe anxiety, respectively. A cut-off of 10 yields a sensitivity of 0.89 and a specificity of 0.82 for generalised anxiety disorder.

The **Toronto Alexithymia Scale-20** (**TAS-20**; Bagby et al., 1994) measures alexithymia, the ability to identify one's emotions. The 20 items are measured on a five-point agreement scale, ranging from strongly disagree to strongly agree. Five items are reverse scored, for example 'I am able to describe my feelings easily'. The scores are summed, and high scores indicate higher alexithymia. The scale has an internal consistency of at least 0.80 in different samples and a test–retest reliability of 0.77. A cut-off of 61 is generally adopted as indicative of alexithymia (Bagby & Taylor, 1997).

The **Rosenberg Self-Esteem** (**RSE;** Schmitt & Allik, 2005) scale is a measure of an individual's self-esteem. The 10 items are measured on a four-point agreement scale, ranging from *strongly disagree* to *strongly agree*. It has a test–retest reliability of 0.87 (Torrey et al., 2000) as well as an internal consistency of 0.81. Five items are reverse coded, for example 'At times I think I am no good at all'. The scores are summed, and higher scores indicate a higher self-esteem. Isomaa and colleagues (2013 et al. (2013) propose a score of below 25 to indicate low self-esteem; this cut-off yields a sensitivity ranging between 0.59 and 0.78 and a specificity ranging between 0.87 and 0.95. These ranges encapsulate both boys and girls when discriminating between adolescents with and without depression and social anxiety.

The **New General Self-Efficacy** (**NGSE**; Chen et al., 2001) scale is an eight-item measure of self-efficacy, which is measured on a five-point agreement scale ranging from strongly agree to strongly disagree. All items are summed to create a total score and a higher score denotes higher self-efficacy. It has an internal consistency of 0.86 and 0.90

TABLE 3 Content of the E-DLD yearly survey for different age groups

	Child probands (responses given by caregivers)						Individuals with DLD	
Measure or domain	**3–4**	**5–7**	**8–10**	**11–13**	**14–15**	**16–17**	**16—17**	**18+**
Demographic information	✓	✓	✓	✓	✓	✓	✓	✓
General Development Questionnaire (GDQ)[a]	✓							
Caregiver–child and social activities	✓	✓						
Social clubs (e.g., scouting, sports clubs)		✓	✓	✓	✓			
Peer relationships		✓	✓	✓	✓			
Friends and family relationships								✓
Children's Sleep Habits Questionnaire (CSHQ)	✓	✓	✓	✓				
Strengths and Difficulties Questionnaire (SDQ)	✓	✓	✓	✓	✓	✓	✓	
If and how frequently proband sees an SLT	✓	✓	✓	✓	✓	✓		
School progress including recent qualifications and national tests	✓	✓	✓	✓	✓	✓	✓	
Specialised school support including EHCP	✓	✓	✓	✓	✓	✓		
Employment					✓	✓	✓	✓
Patient Health Questionnaire depression subscale (PHQ-9)							✓	✓
Generalized Anxiety Disorder scale (GAD-7)							✓	✓
Toronto Alexithymia Scale (TAS-20)							✓	✓
Rosenberg Self-Esteem Scale (RSE)							✓	✓
New General Self-Efficacy scale (NGSE)								✓
Experiences of health care							✓	✓
Experiences of mental health support							✓	✓
Child and Adolescent Social Support Scale (CASSS)[b]							✓	
Proband's strengths and respondent's concerns about proband's language difficulties	✓	✓	✓	✓	✓	✓	✓	✓

[a] The GDQ assesses several aspects of development like motor skills, attention, hyperactivity and memory (Kadesjö et al., 2017). An abbreviated version of subscales most relevant to DLD is used.

[b] The CASSS measures children's and adolescents' perceived social support (Kerres Malecki & Kilpatrick Demary, 2002).

DLD, Developmental Language Disorder; E-DLD, Engage with Developmental Language Disorder; EHCP, education, health and care plan; SLT, speech and language therapist.

at two different time points, and a test–retest reliability of 0.67.

We also ask about monthly household take-home pay (with a currency conversion link provided for our non-UK members), which allows a measure of SES for all participants. Additionally, we ask questions relating to support in schools, SLT engagement and social clubs. Formalised support in schools was asked only of UK E-DLD members and was tailored to each UK country. Education, health and care plans were asked of England residents, whereas Welsh and Northern Ireland residents were asked about statements of special education needs. Scottish E-DLD members were asked about additional support for learning or coordinated support plans. All E-DLD members were asked whether their child was receiving SLT support. If the answer was yes, we followed up by asking about the frequency of SLT support. We also asked whether the children attending a formalised social group, such as Girlguiding or Scouting. All these questions were a yes/no response, with the SLT question being followed up by a frequency question. Finally, caregivers were asked about what aspect of the child's development they are most worried about, about their child's strengths and about the most rewarding and challenging part of being a caregiver to a child with DLD. These final questions were free text responses.

Procedure

Initial sign-up survey

Caregivers of children under 18 and adults and young people over 16 can sign up via the website (https://www.engage-dld.com/). Those who complete the initial consent and contact information are added to the E-DLD database. Participants can withdraw at any time or update the database with new information, using links provided on the website and in our regular communications, or by emailing the E-DLD project. All data collected as part of the initial survey sign up and subsequent information are collected on the REDCap data system (Harris et al., 2009). All data are stored in secure servers hosted by the University of Bath. No identifying data are shared with anyone beyond the immediate research team at E-DLD.

Yearly survey

E-DLD members are sent a yearly survey to complete, the first one approximately 2 weeks after signing up. This survey is completed via the survey and database software REDCap. Each year after signing up, members are sent the survey again to monitor their development over time. Each E-DLD member receives an email invitation to complete the survey at the appropriate time. Two email reminders are sent on a weekly basis after the initial invitation. A monthly prize draw of a £20 voucher (or local currency equivalent) has been offered since May 2021 for survey completion.

Data security

All data collected as part of the E-DLD project are collected through the REDCap data capture software system (Harris et al., 2009). This centralised system developed by Vanderbilt University has been installed at the University of Bath and allows E-DLD members to share sensitive information in the knowledge that the data are stored securely within University of Bath servers. This has benefits for data security, as many other online survey platforms store data in external servers which the research institutions do not have direct control over. All procedures are strictly General Data Protection Regulation compliant with no shared access to data for anyone external to the research team at E-DLD. Instead, families are invited to respond to research opportunities and surveys.

Free text response analysis

To analyse the free text responses, each item mentioned by caregivers was recorded and often put into a broader theme, for example, mathematics achievement was categorised as academic ability. The frequency of each theme was recorded as a tally. These tallies were then converted into a percentage denoting how many caregivers had reported this item. The most frequently mentioned items are reported here.

Results

We now present findings reporting descriptive analyses that allow us to characterise the E-DLD cohort and compare it to known profiles for individuals with DLD. Where relevant, and if we have sufficient data, we present inferential statistics to enable investigate the cohort in relation to known clinical cut-offs (e.g., mood disorder)

Comorbid and language difficulties

The initial sign-up survey asks respondents to tick the areas of language that the child proband/adult struggles with as well as any comorbid conditions that they have.

TABLE 4 Summary of the language and comorbid difficulties experienced by the child and adult probands

	Child Probands ($N = 186$[a])	Adult Probands ($N = 19$[a])
Language		
Expressive language	95.7%	84.2%
Word finding	88.7%	89.5%
Receptive language	76.9%	73.7%
Learning new words	69.4%	73.7%
Pragmatic language	64.0%	47.4%
Speech sound	53.2%	31.6%
Other language difficulties	19.4%	15.8%
Comorbid difficulty		
Anxiety	31.7%	52.6%
ADHD	14.0%	26.3%
Dyscalculia	12.4%	10.5%
Developmental Co-ordination Disorder (DCD)/dyspraxia	11.8%	5.3%
Dyslexia	9.1%	36.8%
ASD (not their primary diagnosis)	8.6%	5.3%
Conduct disorder	4.3%	0%
Depression	1.6%	31.6%
None	28.5%	10.5%

[a] *Note*. Not everyone signed up to E-DLD has completed this section of the questionnaire.
Abbreviations: ASD, Autism Spectrum Disorder; E-DLD, Engage with Developmental Language Disorder.

See Table 4 for a summary of the difficulties experienced by the child probands, as reported by their caregivers, as well as data self-reported by adults with DLD.

Socioeconomic status

The total range in England (English Indices of Deprivation 2019) is 1–32 844, for Scotland (Scottish IMD 2020) the total range is 1–6976 and for Wales (Wales IMD 2019) the total range is 1–1909. We do not yet have any E-DLD members from Northern Ireland. The mean IMD ranks and quintiles for the UK are reported in Table 5. The table indicates that E-DLD is not just attracting mid-high SES families but has representation across the IMD range.

TABLE 5 Mean IMD ranks and quintiles for the UK ($N = 145$)

Country	*N*	Mean IMD rank (*SD*)/% in IMD quintile
England	143	19350(*9322*)
**Quintile 1	21	14.7%
Quintile 2	16	11.2%
Quintile 3	32	22.4%
Quintile 4	34	23.7%
*Quintile 5	40	28.0%
Scotland	10	4736(*1834*)
**Quintile 1	1	10.0%
Quintile 2	0	0%
Quintile 3	2	20%
Quintile 4	4	40%
*Quintile 5	3	30%
Wales	5	1292(*315*)
**Quintile 1	0	
Quintile 2	0	
Quintile 3	2	40.0%
Quintile 4	1	20.0%
*Quintile 5	2	40.0%

**Most deprived *Least deprived.
Abbreviation: IMD, Indices of Multiple Deprivation.

Yearly survey

We have 76 caregivers of children aged 3–15, and ten young people and adults who have filled in the first year of the yearly survey. The caregiver survey completion rate for the first year is currently 40.8%. For the adult probands, survey completion rate for the first year is 60%. The average time taken to complete the yearly survey is 23 min for caregivers and 29 min for adults with DLD. In this section,

TABLE 6 Average household monthly take-home pay for caregivers and adults completing the yearly survey (Year 1 only)

	N	%
Caregivers	69	
Under £1000	7	10.1%
£1001–£2000	11	15.9%
£2001–£3000	13	18.8%
£3001–£4000	17	24.6%
£4001–£5000	9	13.0%
£5001–£6000	4	5.8%
£6001–£7000	2	2.9%
£7001–£8000	1	1.5%
£8001–£9000	–	–
£9001–£10000	1	1.5%
Over £10000	4	5.8%
Adults	10	
Under £1000	3	30%
£1001–£2000	4	40%
£2001–£3000	–	–
£3001–£4000	3	30%

TABLE 7 Table of outcomes for child probands

Measure	*N*	Mean(*SD*)	% above cut-off
SDQ total difficulties	64	15.3(*6.6*)	44.4%[a]***
SDQ emotional subscale	69	5.4(*2.3*)	60.3%***
SDQ peer problems subscale	72	3.1(*2.2*)	42.3%***
SDQ prosocial subscale	72	7.7(*1.9*)	29.6%**
SDQ hyperactivity subscale	68	6.3(*2.7*)	37.3%***
SDQ conduct subscale	71	2.2(*2.0*)	25.7%*
Sleep habits (CSHQ) total	40	45.9(*10.4*)	59.0%[b]***

[a] Percentage 'high' or 'very high', from https://sdqinfo.org; normative rates above cut-offs are 10% for all SDQ scales. Cut-offs for the 4–16 SDQ only. One 3-year old excluded.

[b] 23.3% is the rate above cut-off of 41 expected in the general population (Owens et al., 2000). CSHQ data evaluated only for 4—10-year olds.

$*p < 0.05$; $**p < 0.01$; $***p < 0.001$.

we report only the first yearly survey completed for each E-DLD member.

Socio-economic status

Within the yearly survey, we asked about average monthly take-home pay (see Table 6).

Child outcomes

We report in Table 7 the summarised SDQ scores and sleep habits for child probands, as reported by caregivers. We compared the percentage above clinical cut-offs to the expected percentage that should be found in the general public. We found elevated rates of total difficulties in the SDQ, in addition to elevated levels of emotional, hyperactivity, conduct and peer problems as well as more prosocial difficulties. The results also indicated increased clinical level sleep problems in children with DLD aged 4–10 years old.

The yearly survey also recorded that 59.6% ($N = 31$) of the probands living in the UK have an education, health and care plan (England), statement of special education needs (Wales) or support for additional needs (Scotland). In total, 72.2% ($N = 52$) of our sample reported seeing an SLT, with 54.9% seeing the SLT at least on a weekly basis. Additionally, 23.8% ($N = 15$) attend a social club, such as Girlguiding or Scouting.

Abbreviations: CSHQ, Children's Sleep Habits Questionnaire; SDQ, Strengths and Difficulties Questionnaire; SLT, speech and language therapist.

Caregiver's viewpoints

Caregivers also reported their child's strengths and weaknesses, rewards and challenges, and concerns for the future, via free-text responses (see Table 8).

Frequently occurring strengths are kindness to others, such as being helpful, sharing and empathetic. Also noted by 25.4% of caregivers were school and academic abilities, such as being good at maths. Many caregivers reported that their child was creative, good with younger children and has a good sense of humour. Another strength commonly mentioned was engagement in sports, like football, swimming and horse-riding. The determination and resilience of their child was also often mentioned, including working hard.

In terms of rewards and challenges of being a caregiver of a child with DLD, a substantial number reported concerns regarding poor awareness and understanding of their child's DLD. These concerns included frustration with schools and professionals for not sufficiently supporting these children, as well as in general with others not understanding. Caregivers also reported struggling with a lack of support and knowing how to access support. Moreover, many caregivers expressed fear over how the child's future would be affected by their language difficulties.

There was considerable variability in the types of rewards mentioned by caregivers about being a caregiver of a child with DLD. However, a considerable number reported that it was rewarding to see their child progress despite their language challenges. Some caregivers also found it rewarding to see their child's determination and resilience. Some also reported that it was rewarding to see

TABLE 8 Percentage of caregivers reporting their child's strengths, what they find rewarding and challenging, and their worries

Item	% reporting this
What are your child's strengths?	
Kindness to others	43.3%
Creativity	28.4%
Academic abilities	25.4%
Determination	22.4%
Sense of humour	20.9%
Engagement in sports	19.4%
Good with younger children	16.4%
What is most rewarding and challenging about being a caregiver to a child with DLD?	
Rewards: Seeing their child progress	21.2%
Rewards: Their child's determination and resilience	12.1%
Rewards: Seeing their child happy	9.1%
Challenges: Accessing support	22.7%
Challenges: Frustration with schools and professionals	21.2%
Challenges: Lack of understanding	16.7%
Challenges: Worrying about child's future	15.2%
What aspects of proband's development are you most worried about?	
Academic learning	35.8%
Socialising	34.3%
Well-being	19.4%
Language development	16.4%

Abbreviation: DLD, Developmental Language Disorder

their child happy, particularly when they had achieved something.

Caregivers were most worried about their child's ability to socialise and form or maintain friendships. Many also reported specific areas of language development as concerns – particularly receptive language. Caregivers were also concerned about their child's academic learning, such as worrying that their child will fall behind or will not meet their potential. Additionally, several caregivers expressed concern over their child's well-being and emotional development.

Adult outcomes

In Table 9, we report the summary scores for a range of outcomes for our E-DLD members who are over 16, taken from published scales of emotional and personal well-being. Although this is a very small sample, it is important to present information on this underreported group. This group reported elevated levels of clinical symptoms of depression, GAD, higher rates of self-esteem problems and more alexithymia issues than expected in the general population.

DISCUSSION

The establishment of E-DLD is an important step forward in building a more sustainable infrastructure to support research into DLD. We have recruited over 200 E-DLD members to our research database at the time of writing. The initial findings confirm that the majority of those who sign up report a diagnosis of DLD (and had a caregiver-reported or self-reported clinical profile clearly indicating DLD), suggesting that this participant database method is a feasible way to increase research capacity. Similarly, the findings we highlight in relation to our yearly survey are in line with previous research profiles of children with DLD (Botting & Baraka, 2018; Chen et al., 2020; Lloyd-Esenkaya et al., 2020). The results from our smaller cohort of adults with DLD are also in line with both our child data as well as expectations from previous literature (Botting et al., 2016a, 2016b), in that they experience persisting difficulties with both expressive and receptive language, reading, and co-occurring mental health issues. However, we note that the research regarding adult outcomes is less well established. All in all, our results indicate that we are meeting our aim and attracting and recruiting caregivers of children with DLD and young people/adults with DLD into our

TABLE 9 Summary of mental health outcomes for members over the age of 16 ($N = 9$)

Scale	Mean (*SD*)	% above cut-off/ notes
Depressive Symptoms (PHQ-9)	12.8 (*6.9*)	66.7%[a]***
Generalised Anxiety (GAD-7)	11.4 (*6.4*)	66.7%[a]***
Self-esteem (RSE)	25.4 (*5.7*)	44.4%[b]**
Self-efficacy (NGSE)	27.3 (*5.0*)	Higher score = higher self-efficacy
Alexithymia (TAS-20)	64.3 (*6.7*)	66.7%***

[a] Percentage above cut-off for 'moderate' depression/anxiety.

[b] Scoring above the cut-off here indicates scoring below 25.

Due to the low numbers in this sample, exact tests rather than chi-square analysis was used to compare the general population expected cut-offs to our distribution.

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.

database, with few respondents who do not seem to fit the profile.

Most caregivers report that their children experience a range of language difficulties, the most common being with expressive and receptive language, and word finding difficulties. These are consistent with a diagnosis of DLD (Bishop et al., 2016). The comorbid difficulties reported by the caregivers indicate that a significant proportion of child probands experience anxiety. Adolescents and adults with DLD or a history of childhood language difficulties experience significantly more anxiety than their TD peers (Brownlie et al., 2016; Wadman et al., 2011). The findings of the current study suggest that anxiety is also prevalent in childhood for those with DLD and are in keeping with the meta-analysis by Yew and O'Kearney (2013).

These caregiver-reported difficulties within our initial sign-up survey are further supported by our yearly survey results, which indicate that children with DLD struggle with well-being more than TD peers, as indicated by SDQ total and subscale scores. The child probands had increased levels of clinical difficulties compared to the general population as reported by caregivers. This aligns with current literature which indicates that children with DLD have more socioemotional and behavioural difficulties (e.g., Yew & O'Kearney, 2013).

The literature indicates that children with language difficulties may have more sleep difficulties (Botting & Baraka, 2018). We have replicated previous research showing increased rates of caregiver reported sleep problems in children with DLD (Botting & Baraka, 2018; Knowland et al., 2021). However, research objectively measuring sleep behaviour in children with DLD has not found worse sleep outcomes or sleep efficiency (Knowland et al., 2021). Further research is needed to disentangle whether children with DLD do in fact suffer more from sleep issues, or whether this is a caregiver perception driven by fatigue in their children (Burnley et al., in preparation).

In terms of those over 16, the initial findings indicate poorer emotional health, with our sample showing a significantly higher proportion scoring above thresholds for depression, generalised anxiety, self-esteem and alexithymia. A larger sample is needed to confirm these findings, but these preliminary results align with current literature that young adults with DLD comorbidly experience mental health conditions such as depression and anxiety (Botting et al., 2016a). It should be noted that only about 37% of our adult cohort report an official DLD diagnosis. Nevertheless, the rates of adults reporting language difficulties were high, supporting our assertion that adults without an official diagnosis, but with substantial language difficulties, are suitable to be included within the E-DLD database.

Interestingly, there may be different patterns of language and of comorbid difficulties in adult probands. When our adult sample increases, objectively testing the language of our adult cohort and comparing this with self-reported difficulties, as well as comparing profiles of difficulties with those of the child cohort, will be important next steps.

Limitations and future directions

A challenge for the E-DLD project may be attracting a global audience. It is possible that some individuals internationally have heard of E-DLD but have not signed up, believing the project was only for those in the UK. Therefore, the international nature of E-DLD is now emphasised to improve sign-ups from other English-speaking countries and individuals. Additionally, we aim to keep rate of recruitment steady. To both these ends, we have recently launched collaborations with other DLD organisations – The DLD Project (https://thedldproject.com/) and DLD and Me (https://dldandme.org/) – which has resulted in a continued recruitment drive via a social media campaign to boost UK and international recruitment. In the future, we aim to develop translated versions of the sign-up and yearly surveys so that the E-DLD database is accessible to people whose primary language is not English.

Another limitation is potential bias in families recruited. However, we are encouraged that we have a wide range of participants across the socioeconomic range, as shown by our IMD data. Indeed, the income data from the yearly survey is even more promising, as this indicates that many of our yearly survey respondents are from lower SES brackets. Nonetheless, we may be recruiting families who have a good knowledge and understanding of DLD, perhaps due to higher support from their SLT and/or school. We hope that with increasing recruitment and the word spreading about E-DLD we will be able to expand our recruitment of individuals and families who perhaps have less knowledge and support. To help facilitate the recruitment of individuals with language difficulties themselves (either individuals with DLD or caregivers with language or literacy difficulties themselves) we have created an optional video information sheet. From August 2022, anyone signing up to E-DLD can choose to read the written information sheet or watch the video information sheet video. We hope this will help increase the size of our adult cohort and will help to diversify our recruitment profile.

CONCLUSION

The E-DLD project has created the first ever international database of families and individuals affected by DLD. This database can be used by all researchers studying DLD, as any researcher with an ethically approved study can apply to advertise to the E-DLD cohort. Similarly, the data we collect will be open access and freely available to the DLD research community in time, which will allow future research to be conducted on this cohort. Initial results presented here verify that the child and adult probands we are recruiting are similar to clinically identified samples in terms of types of language difficulties and comorbid psychosocial difficulties. In summary, the E-DLD project has made an immediate impact on the DLD research community, and we hope this project will continue to make an impact in facilitating research into the causes, treatment and consequences of DLD.

Research Integrity Statement

The data are not yet openly available but will be made available in due course through the UK Data Service. This project was partially supported by 2020–21 QR-Strategic Priorities Fund ‘Engaging Policy Makers with Developmental Language Disorders: E-DLD Database’. This funding was awarded to Professor Botting at City, University of London. The authors disclose no conflicts of interest. This project was approved by the Departmental of Psychology Research Ethics Committee at the University of Bath (REFs: 20–207 and 20–208).

DATA AVAILABILITY STATEMENT

The data from the project described in this paper will be made publicly available from the UK Data Service or a similar data repository at a later date. cd_value_code=text

ORCID

Jenny Gibson https://orcid.org/0000-0002-6172-6265
Nicola Botting https://orcid.org/0000-0003-1082-9501

NOTE

[i] This is also the case if members have another neurodevelopmental or neurological condition that can explain their language difficulties, meaning DLD is not the suitable diagnosis. However, we are yet to encounter a sign-up with another exclusionary condition besides ASD.

REFERENCES

Antoniazzi, D., Snow, P. & Dickson-swift, V. (2010) Teacher identification of children at risk for language impairment in the first year of school. *International Journal of Speech-Language Pathology*, 12, 244–252.

Bagby, M. & Taylor, G. (1997) Measurement and validation of the alexithymia construct. *In:* Taylor, G., Bagby, R., Parker, J. & Grotstein, J. (eds.) *Disorders of affect regulation: alexithymia in medical and psychiatric illness*, Cambridge University Press.

Bagby, R.M., Parker, J.D.A. & Taylor, G.J. (1994) The 20-Item Toronto-Alexithymia-Scale .1. Item Selection and Cross-Validation of the Factor Structure. *Journal of Psychosomatic Research*, 38, 23–32.

Barry, J.G., Yasin, I. & Bishop, D.V.M. (2007) Heritable risk factors associated with language impairments. *Genes, Brain and Behavior*, 6, 66–76.

Bishop, D.V.M. (2010) Which neurodevelopmental disorders get researched and why? *PLoS ONE*, 5(11), e15112, 1–9.

Bishop, D.V.M., Snowling, M.J., Thompson, P.A., Greenhalgh, T. & Consortium, C. (2017) Phase 2 of CATALISE: a multinational and multidisciplinary Delphi consensus study of problems with language development: terminology. *Journal of Child Psychology and Psychiatry*, 58, 1068–1080.

Bishop, D.V.M., Snowling, M.J., Thompson, P.A., Greenhalgh, T. & Consortium, C. (2016) CATALISE: a Multinational and Multidisciplinary Delphi Consensus Study. Identifying Language Impairments in Children. *PLoS ONE*, 11(7), e0158783, 1–26.

Botting, N. & Baraka, N. (2018) Sleep behaviour relates to language skills in children with and without communication disorders. *International Journal of Developmental Disabilities*, 64, 225–230.

Botting, N., Durkin, K., Toseeb, U., Pickles, A. & Conti-ramsden, G. (2016a) Emotional health, support, and self-efficacy in young adults with a history of language impairment. *British Journal of Developmental Psychology*, 34, 538–554.

Botting, N., Toseeb, U., Pickles, A., Durkin, K. & Conti-ramsden, G. (2016b) Depression and anxiety change from adolescence to adulthood in individuals with and without language impairment. *PLoS ONE*, 11(7), e0156678, 1–13.

Brownlie, E.B., Bao, L. & Beitchman, J. (2016) Childhood language disorder and social anxiety in early adulthood. *Journal of Abnormal Child Psychology*, 44, 1061–1070.

Burnley, A., Dack, C., Wren, Y. & St Clair, M.C. In preparation. Exploring the experiences of parents raising a child with Developmental Language Disorder: a qualitative study.

Chen, G., Gully, S.M. & Eden, D. (2001) Validation of a new general self-efficacy scale. *Organizational Research Methods*, 4, 62–83.

Chen, J., Justice, L.M., Rhoad-drogalis, A., Lin, T.J. & Sawyer, B. (2020) Social networks of children with developmental language disorder in inclusive preschool programs. *Child Development*, 91, 471–487.

Christopulos, T. & Kean, J. (2020) General education teachers' contribution to the identification of children with language disorders. *Perspectives of the ASHA Special Interest Groups*, 5, 770–777.

Conti-ramsden, G., Durkin, K., Toseeb, U., Botting, N. & Pickles, A. (2018) Education and employment outcomes of young adults with a history of developmental language disorder. *International Journal of Language & Communication Disorders*, 53, 237–255.

Conti-ramsden, G., Simkin, Z. & Botting, N. (2006) The prevalence of autistic spectrum disorders in adolescents with a history of specific language impairment (SLI). *Journal of Child Psychology and Psychiatry*, 47, 621–628.

Goodman, R. (1997) The strengths and difficulties questionnaire: a research note. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 38, 581–586.

Goodman, R. (2001) Psychometric properties of the strengths and difficulties questionnaire. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, 1337–1345.

Harris, P.A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N. & Conde, J.G. (2009) Research electronic data capture (REDCap)-A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, 42, 377–381.

Hendricks, A.E., Adlof, S.M., Alonzo, C.N., Fox, A.B. & Hogan, T.P. (2019) Identifying children at risk for developmental language disorder using a brief, whole-classroom screen. *Journal of Speech Language and Hearing Research*, 62, 896–908.

Hollo, A., Wehby, J.H. & Oliver, R.M. (2014) Unidentified language deficits in children with emotional and behavioral disorders: a meta-analysis. *Exceptional Children*, 80, 169–186.

Isomaa, R., Vaananen, J.M., Frojd, S., Kaltiala-heino, R. & Marttunen, M. (2013) How low is low? Low self-esteem as an indicator of internalizing psychopathology in adolescence. *Health Education & Behavior*, 40, 392–399.

Kadesjö, B., Janols, L.-O., Korkman, M., Mickelsson, K., Strand, G., Trillingsgaard, A., et al. (2017) *General Development Questionnaire Five-To-Fifteen-Revised (5-15R)* [Online]. Available: www.5-15.org [Accessed].

Kerres malecki, C. & Kilpatrick demary, M. (2002) Measuring perceived social support: development of the child and adolescent social support scale (CASSS). *Psychology in the Schools*, 39, 1–18.

Knowland, V.R., Gaskell, M.G., Walker, S., Van rijn, E., Norbury, C. & Henderson, L. (2021) Sleep behaviour in children with developmental language disorder. *Language Development Research*, 1, 283–318.

Krishnan, S., Asaridou, S.S., Cler, G.J., Smith, H.J., Willis, H.E., Healy, M.P., et al. (2021) Functional organisation for verb generation in children with developmental language disorder. *Neuroimage*, 226.

Kroenke, K., Spitzer, R.L. & Williams, J.B.W. (2001) The PHQ-9 - Validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16, 606–613.

Lemos, C.D., Kranios, A., Beauchamp-whitworth, R., Chandwani, A., Gilbert, N., Holmes, A., et al. (2022) Awareness of developmental language disorder amongst workplace managers. *Journal of Communication Disorders*, 95, 106165.

Lloyd-Esenkaya, V., Russell, A.J. & St Clair, M.C. (2020) What are the peer interaction strengths and difficulties in children with developmental language disorder? A systematic review. *International Journal of Environmental Research and Public Health*, 17, 3140, 1–27.

Mcgregor, K.K. (2020) How we fail children with developmental language disorder. *Language Speech and Hearing Services in Schools*, 51, 981–992.

Mountford, H.S., Braden, R., Newbury, D.F. & Morgan, A.T. (2022) The genetic and molecular basis of developmental language disorder: a review. *Children-Basel*, 9, 586, 1–17.

Norbury, C.F., Gooch, D., Wray, C., Baird, G., Charman, T., Simonoff, E., et al. (2016) The impact of nonverbal ability on prevalence and clinical presentation of language disorder: evidence from a population study. *Journal of Child Psychology and Psychiatry*, 57, 1247–1257.

Owens, J.A., Spirito, A. & Mcguinn, M. (2000) The Children's Sleep Habits Questionnaire (CSHQ): psychometric properties of a survey instrument for school-aged children. *Sleep*, 23, 1043–1051.

Plante, E., Shenkman, K. & Clark, M.M. (1996) Classification of adults for family studies of developmental language disorders. *Journal of Speech and Hearing Research*, 39, 661–667.

Schmitt, D.P. & Allik, J. (2005) Simultaneous administration of the Rosenberg Self-Esteem Scale in 53 nations: exploring the universal and culture-specific features of global self-esteem. *Journal of Personality and Social Psychology*, 89, 623–642.

Spitzer, R.L., Kroenke, K., Williams, J.B.W. & Lowe, B. (2006) A brief measure for assessing generalized anxiety disorder - The GAD-7. *Archives of Internal Medicine*, 166, 1092–1097.

Thordardottir, E. & Topbas, S. & Working Group 3 Cost Action IS1406 (2021) How aware is the public of the existence, characteristics and causes of language impairment in childhood and where have they heard about it? A European survey. *Journal of Communication Disorders*, 89, 1–17.

Torrey, W.C., Mueser, K.T., Mchugo, G.H. & Drake, R.E. (2000) Self-esteem as an outcome measure in studies of vocational rehabilitation for adults with severe mental illness. *Psychiatric Services*, 51, 229–233.

Wadman, R., Durkin, K. & Conti-ramsden, G. (2011) Social stress in young people with specific language impairment. *Journal of Adolescence*, 34, 421–431.

Winstanley, M., Webb, R.T. & Conti-ramsden, G. (2018) More or less likely to offend? Young adults with a history of identified developmental language disorders. *International Journal of Language & Communication Disorders*, 53, 256–270.

Winstanley, M., Webb, R.T. & Conti-ramsden, G. (2019) Psycholinguistic and socioemotional characteristics of young offenders: do language abilities and gender matter? *Legal and Criminological Psychology*, 24, 195–214.

Winstanley, M., Webb, R.T. & Conti-ramsden, G. (2021) Developmental language disorders and risk of recidivism among young offenders. *Journal of Child Psychology and Psychiatry*, 62, 396–403.

WORLD HEALTH ORGANISATION (2019) ICD-11: International Classification of Diseases

Yew, S.G.K. & O'kearney, R. (2013) Emotional and behavioural outcomes later in childhood and adolescence for children with specific language impairments: meta-analyses of controlled prospective studies. *Journal of Child Psychology and Psychiatry*, 54, 516–524.

Young, A.R., Beitchman, J.H., Johnson, C., Douglas, L., Atkinson, L., Escobar, M., et al. (2002) Young adult academic outcomes in a longitudinal sample of early identified language impaired and control children. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 43, 635–645.

How to cite this article: C, M., Horsham, J., Lloyd-Esenkaya, V., Jackson, E., Gibson, J., Leitão, S. et al. (2022) The Engage with Developmental Language Disorder (E-DLD) project: Cohort profile. *International Journal of Language & Communication Disorders*, 1–15. https://doi.org/10.1111/1460-6984.12835