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RESEARCH REPORT

"They don't realise how hard he has to try every day": The rewards and challenges of parenting a child with developmental language disorder

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Abstract

Background: An emerging body of literature explores the impact of living with developmental language disorder (DLD) on children, individuals and families. This work has identified a range of challenges and strengths. However, there is limited evidence from the DLD community about the impacts of living with DLD in relation to parenting.

Aims: We explored the perspectives of caregivers in response to an open-text survey question: "*What is most rewarding and challenging about being a parent to a child with DLD?*"

Methods & Procedures: Respondents were caregivers of children with DLD who had signed up to Engage with Developmental Language Disorder. Qualitative content analysis was used to explore the open-ended responses from 112 parents who completed the yearly survey (child average age = 9.6 years; SD = 3.5 years, 46.9% female). Most caregivers lived in the United Kingdom, but we also had responses from around the world.

Outcomes & Results: For 'rewards', 52 codes and seven higher-order categories were identified. These comprised the many rewards experienced from caring for a child with DLD, including seeing and celebrating progress, celebrating their child's personality and being proud to be their child's parent. Caregivers mentioned the positives gained from learning about DLD and working together with their child to help them achieve their potential. They reflected on the supportive nature of the 'right' environment, in particular the school context and social connectedness. For 'challenges', 84 codes and 11 higher-order categories were identified. Caregivers often noted the lack of awareness of DLD amongst the community and professionals in general, within the school system and amongst teachers. Caregivers reported support and information about DLD were difficult

to find and were impacted by a constant need for advocacy. They reflected on the increased time needed to support their child and worried about their child's social and community participation. Many commented on the impact of DLD on the family and the mental health and well-being of both them and their children.
Conclusions & Implications: Hearing the views of caregivers of children with DLD is key because shared decision-making is central to client-centred care. Furthermore, 'client perspectives' are a cornerstone of evidence-based practice. There is much to take from the responses and for professionals to reflect on and use. Collaboration with children, young people and families is needed for effective advocacy, and to develop awareness of DLD.

KEYWORDS
developmental language disorder (DLD), parent perspectives, rewards and challenges

WHAT THIS PAPER ADDS

What is already known on the subject

- An emerging body of literature has explored the impact of living with developmental language disorder (DLD) on the child, the individual and the family. This work has identified a range of challenges and strengths. These are important considerations to support the evidence-based practice of those working with the DLD community from planning treatment goals to designing and providing services.

What this paper adds to existing knowledge

- Caregivers highlighted a range of rewards in parenting a child with DLD. They also identified a wide range of challenges, including a lack of awareness and support from professionals, the constant need for advocacy and the impact on the family as well as the impact on the mental health of their child and themselves as parents.

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

- Shared decision-making is central to client-centred and family-centred care, and client perspectives are a key aspect of evidence-based practice. There is much for clinicians and practitioners to take from this data set of parent perspectives. The findings from this study will guide researchers and clinicians to reflect on how to work in collaboration with individuals with DLD and their families, including in their design and delivery of services and advocacy to continually raise awareness of DLD.

INTRODUCTION

Approximately 7.6% of children, about two in every classroom of 30 children, have developmental language disorder (DLD; Calder et al., 2022; Norbury et al., 2016). DLD is a neurodevelopmental condition characterised by difficulties in learning, expressing and/or comprehending language (Bishop et al., 2016). These difficulties persist into adulthood and are not explained by the presence of a primary biomedical condition, such as autism spectrum disorder, intellectual disability or hearing loss. At a group level, DLD is associated with poorer social, academic and mental health outcomes (Burnley, St Clair, Bedford, et al., 2023; Burnley, St Clair, Dack, et al., 2024; Gibson & Toseeb, 2024; Ziegenfusz et al., 2022). In contrast, at an individual level, there is considerable variability in outcomes (Gibson & Toseeb, 2024; Ziegenfusz et al., 2022). This highlights the need to better understand the implications of DLD for children as they grow up, as well as their perspectives and those of their families on living with DLD.

Parenting a child with a DLD

Researchers have found young people with DLD to be at significantly elevated risk of experiencing internalising difficulties (e.g., anxiety and emotional problems) and externalising difficulties (e.g., behavioural problems; see Gibson & Toseeb, 2024 for an overview). A small but emerging body of literature has begun to explore the impact of living with DLD on the child and their family. This work has identified a range of challenges and strengths.

To date, there are few studies reported in the literature which describe the perspectives and experiences of children with DLD. Lyons and Roulstone (2018) interviewed 11 children with language disorders aged 9–12 years (two of whom also had a speech disorder). The children's narratives highlighted potential risks to their well-being, such as concern about academic achievement, as well as protective strategies, including hope and positive relationships. A recent study presented an account from an adult with DLD, describing her journey from diagnosis as a child, through treatment and into adulthood (Orrego et al., 2023). In this paper, the apparent impact of DLD on her socioemotional well-being, academic outcomes, as well as family and social relationships, highlighted the need to consider the impact of DLD on broad aspects of the individual's life, rather than just their language deficits.

Turning to the perspectives of family members, Ash et al. (2020) explored the thoughts of mothers about their experiences of the first presentation of a diagnosis by a clinician and subsequent discussions with their speech-language therapist (SLT) about their child's language disorder. The researchers interviewed 12 mothers and developed four themes from the data. These included reports of receiving confusing or irrelevant diagnostic terms for language disorders. They also experienced distress about their child's language problems and did not always trust or understand their child's SLT. Despite this, the fourth theme was that the mothers appeared satisfied with the SLT intervention their child received. They also raised concerns about their child's current education and their future. Ash et al. (2020) concluded that supporting children with DLD can be compromised when parents do not understand the nature of their child's difficulties or the options for intervention, nor trust the professionals.

McGregor et al. (2023) interviewed the caregivers of 35 children aged 6–8 years with DLD regarding their child's strengths and challenges and explored the relationship between disability and impairment, risk and receipt of services. The caregivers identified several strengths amongst their children, including socialisation skills and the recent emergence of coping skills. Parents were also proud of their children's independence in their domestic and personal aspects of daily life. In contrast, parents identified challenges in communication, academic skills and interpersonal relationships in wider circles (e.g., lack of friendships and peer rejection; McGregor et al., 2023).

There is a small but emerging evidence base that explores such socioemotional challenges from the perspective of parents. For instance, Burnley et al. (2024) conducted qualitative interviews with 11 mothers of children (aged 6–12) with DLD and five adults with DLD. They identified that the experience of anxiety was common and was characterised in a range of ways (e.g., 'intolerance of uncertainty', 'rumination' and 'negative interpretation bias'). Other themes related to the children and adults with DLD experiencing social frustration. Factors that maintained experiences of anxiety and frustration were also noted, including difficulties with emotion regulation and exhaustion. Importantly, however, parents also described a range of strengths in their child with DLD, including creativity, empathy and kindness. Burnley et al. (2024) described the impact of living with DLD on parents, noting that parents reported feeling isolated due to a lack of awareness and support, leading to stress and feelings of uncertainty for their child's future. These challenges associated with DLD, including the potential impact on parents and families, are important considerations for working with those in the DLD community—whether planning individual goals or when working at the service level—which can be informed by a better understanding of the impact and implications of living with DLD.

Kwok et al. (2022) conducted a scoping review of existing qualitative research studies to identify and describe the perspectives of parents regarding speech, language and communication interventions for children more generally. The findings highlighted a broad recognition of the importance of parental perspectives on intervention across a range of different clinical populations and practice contexts. Little, however, is known about the views and experiences of parents and caregivers who parent children with DLD (Bruinsma et al., 2024). It is important to understand their views given that shared decision-making is central to client-centred and family-centred care, and ‘client perspectives’ is one of the cornerstones of evidence-based practice (Hoffman et al., 2023).

Study aims

We report here on data collected as part of Engage with Developmental Language Disorder (E-DLD), which aims to connect individuals and families experiencing DLD with academic research and does so via an international database of children and adults with DLD (St. Clair et al., 2023). Members receive regular communication about DLD, including a newsletter, plain language summaries of DLD research and online events. Researchers with ethical approval can advertise their studies to members of the E-DLD database according to member preferences. Upon initial sign-up to the E-DLD database, members complete a comprehensive survey about their (or their child’s) diagnosis, family structure, current language difficulties and impact of DLD on wider psychosocial difficulties. Members are also invited to complete a yearly survey, which contains questions about well-being and impact, strengths and challenges and developmental history (for younger children). The current study focuses on qualitative data obtained from caregivers[1] in their first year of filling out the yearly survey. Specifically, we aimed to explore caregiver perceptions of the rewards and challenges of being a caregiver to a child 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. The current study reports on the child data (i.e., information provided by caregivers) from the E-DLD database as of July 2024. We report an analysis of responses from 112 caregivers of children with an average age of 9 years, and 6 months (SD = 3;5, range 3;6–16;8). The average age of the caregivers was 42.43 years (SD = 6.37). Caregivers were mostly mothers (96% female), and the children were approximately equally balanced across genders (46.9% female). For this sample, 49.07% are younger siblings, and 50.93% are only children or the eldest sibling. 106 of the 112 caregivers reported a diagnosis of DLD or LD for their child. Regarding socioeconomic status, 24.8% of the sample had a monthly take-home income of less than £2000 (or the equivalent in their home currency), 33.3% of the sample had a monthly take-home income between £2000 and £4000, 22.8% of the sample had monthly take-home income between £4000 and £6000 and 19.0% of the same had monthly take-home income exceeding £6000. For respondents residing in the United Kingdom ($N = 75$), 17.3% lived in a quintile 1 Indices of Multiple Deprivation (IMD) area, indicating the most deprived areas of the United Kingdom, whereas 5.33% lived in quintile 2, 24% in quintile 3, 28% in quintile 4 and 25.3% in quintile 5, the most affluent areas of the United Kingdom. IMD statistics are compiled separately for the UK countries (England, Wales, Scotland and Northern Ireland). The quintiles were combined for this analysis.

The sample was predominantly White/Caucasian (89.2% for the children, 92.7% for the parents) with mixed ethnicity being the second most common ethnicity for the children (4.5%). Most responses were from parents based in the United Kingdom, but we also had responses from parents based in the Netherlands (1), Sweden (1), Switzerland (1), United States (9), Canada (1), Ireland (2), Australia (7), New Zealand (2) and Indonesia (1).

Materials

One year after initially signing up to the E-DLD database, caregivers of children with DLD are sent an invitation to complete a survey (the ‘yearly survey’). This survey asks caregivers a range of questions, including school progress and sleep habits. Additionally, caregivers are asked open-ended questions about how they feel about their child’s development. In the current paper, we report on the findings from the open-ended question about caregiver perceptions, which asks: “*What is most rewarding and challenging about being a parent to a child with DLD?*”

Procedure

Caregivers of children under 18 and adults and young people over 16 first sign up via the E-DLD website. Those who complete the initial consent and contact information are added to the E-DLD database. All data collected as part of the initial survey sign up and subsequent surveys and information are collected on the Research Electronic Data Capture (REDCap) data system (Harris et al., 2009). E-DLD members are sent a yearly survey to complete, the first one approximately 2 weeks after signing up and subsequently each year after either their initial sign up or their previous year’s survey completion date. The data used in this study are from the caregiver’s first completion of their yearly survey, which could have been 2 weeks after signing up or in subsequent years. Thus, data analysed here encompass responses from 2020 to 2024.

Data analysis

Qualitative content analysis was used to explore caregivers' open-ended responses to the survey question regarding the most rewarding and challenging parts of being a caregiver to a child with DLD. An inductive approach was chosen as this allows the derivation of ideas from the data rather than analysis based on previously determined theories or models as is used in a deductive approach (Elo and Kyngäs, 2008).

The first author (S.L.) immersed herself in the data by reading all the written responses several times, and then split the data into responses that clearly addressed the 'rewards' and 'challenges' aspects of the question. She then re-read the data sheets and conducted open coding using notes throughout the written responses to describe all components of the content. This resulted in 52 codes (rewards) and 84 codes (challenges). These codes were then entered into coding sheets, and initial categories were freely generated. At this early stage, eight initial categories were generated for rewards and 13 for challenges.

For the abstraction process in qualitative content analysis, codes and subcategories are grouped together where appropriate, and these categories are then grouped as main categories. The abstraction process continues until all the data have been classified as belonging together (Elo and Kyngäs, 2008). To prepare for reporting, the categories are then discussed, and subcategories are identified and grouped under higher-order headings to facilitate clear and concise reporting of the concepts identified from the data.

Two authors (S.L., E.J.) discussed and grouped the codes. Following discussion, in the final set of rewards, two categories initially identified ('learning together' and 'understanding diagnosis') were merged into one ('My own learning helps support my child'). For challenges, in the final set, two categories initially identified ('advocacy is hard' and 'support is hard to find') were merged into one ('Advocacy and finding resources is ongoing and often exhausting'), and the single code 'behaviour can be a challenge' was merged with 'child mental health'. This resulted in the identification of a final seven higher-order categories for rewards, some of which contained subcategories (see Figure 1). For challenges, 11 higher-order categories were identified, some of which contained subcategories (see Figure 2). There was a high level of agreement in the grouping of codes. The wording of the categories was discussed in depth to check the adequacy of the analysis and to ensure clarity of reporting (Kyngäs et al., 2011). The categories were reviewed by the remaining core members of the team (M.S.C., N.B., J.G.) and discussed to establish face validity (i.e., they were presented with the identified categories and asked to evaluate whether this matched reality; Cavanagh, 1997).

RESULTS

The results of the qualitative content analysis are presented descriptively according to the subcategories and higher-order category groupings. The results are discussed separately for 'rewards' and 'challenges'. Each category contains illustrative quotes from the data set.

Rewards

In response to part of the question: "What is most rewarding about having a child with DLD?", 52 codes were identified, which were organised into seven higher-order categories (Figure 1).

Celebrating progress

Caregivers reflected on appreciating the progress and improvements made by their child, however small: "*It is amazing to see how well he is progressing despite all his challenges with language*". Caregivers reflected on the importance of celebrating achievements, especially when they were 'against the odds' ("*all the achievements that he manages to achieve given how much harder he has to work*"). Caregivers also described finding reward in observing their child feeling proud of their achievements in reaching goals: "*The pride in herself when she achieves at her own level*".

My child's personality (is rewarding)

Three subcategories of ideas were identified within this higher-order category. Amongst caregiver responses was the strong sense of finding reward in their child's bravery ('My child is brave'), exemplified by the following quote: "*his determination, resilience, and courage is an inspiration*". 'My child is thoughtful and creative': caregivers reflected here on their sense of their child's strengths in how they carefully think situations through and apply problem-solving skills when needed. For example, "*seeing how innovative she can be in her communication and problem solving*". Finally, many caregivers described 'My child is loving and happy' and reflected on how their child

FIGURE 1 What is rewarding?
Abbreviations: DLD, developmental language disorder; SLT, speech-language therapist.

demonstrated positive feelings and care towards others (for example, one caregiver stated, "*he is loving, kind and caring*").

I am proud to be their parent

There were no subcategories in this higher-order category. Common amongst caregiver responses was the idea of being there for their child no matter what, and a sense of pride in being the child's parent: "*She tries so hard, and it makes me proud*", "*I'm utterly proud to be his mum*".

The right (school) environment is supportive

The notion of the right environment being supportive was linked to school in most cases, and often to a specialist placement. For instance, one caregiver reported that they felt "*hugely fortunate to have a placement in a specialist school which is having a hugely positive impact*". Across many responses was mention of the 'right' school being key to supporting their child to reach their potential, build confidence and support participation. In particular, having teachers who are in their child's 'corner', and being in a stable school environment, were noted as being important: "*It is rewarding knowing that he can do reasonably well when he has a stable environment year on year, and believes his educators have his back*".

My child is socially connected

Caregivers reflected on their sense of reward of having a child who was developing socially and felt socially connected. Key responses demonstrating this idea included,

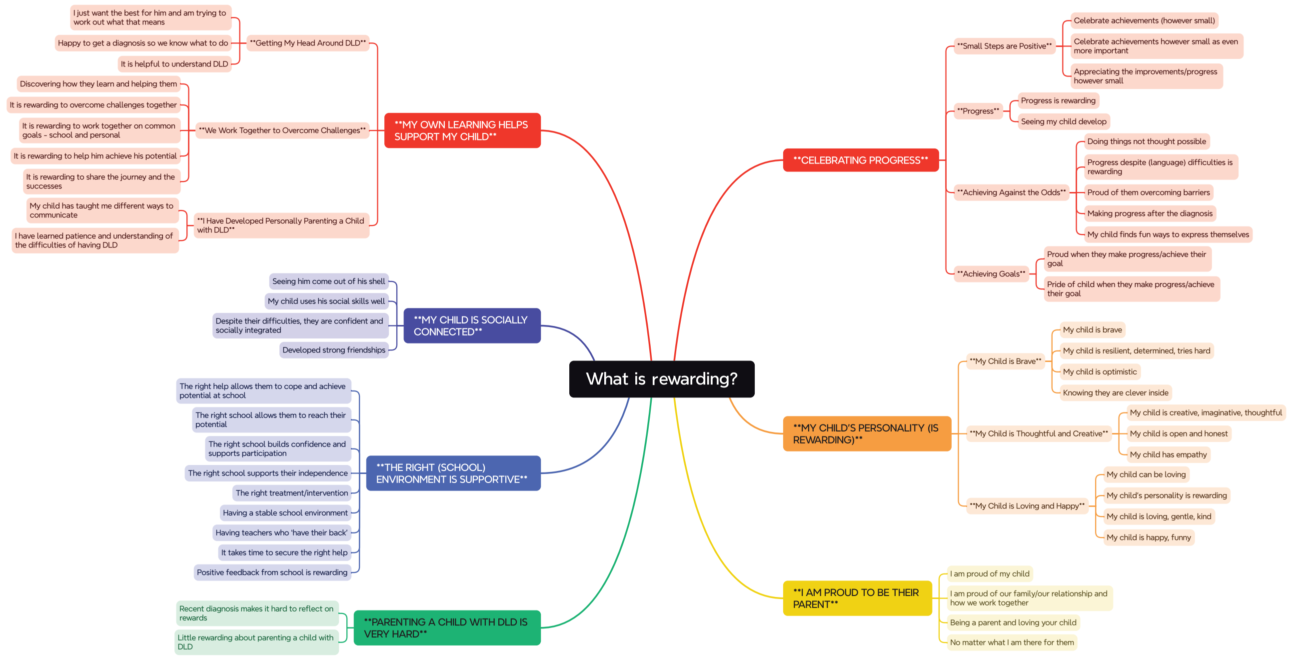

FIGURE 2 What is challenging?
Abbreviation: DLD, developmental language disorder.

"*Seeing the strong friendships he has created and maintained*", and "*Despite her difficulties, she is a very confident child and socially well integrated*".

My own learning helps support my child

Caregivers felt building their own knowledge and skills was instrumental in supporting their child: 'Getting my head around DLD', 'We work together to overcome challenges', and 'I have developed personally parenting a child with DLD'. The common thread was the caregiver's journey in terms of learning about DLD, learning what to do, working together with their child and learning from them: "*It ultimately brings us closer together as a family as we try to understand how to help him best. We are all learning and growing from this experience*". These sub-categories were classified into a higher order category: 'My own learning helps support my child', "*It has made me patient and understanding of the difficulties that children and adults can have*".

Parenting a child with DLD is very hard

Whilst this yearly survey question asked caregivers to describe the rewards of caring for a child with DLD, a few caregivers responded with the comment that it was hard to reflect on rewards and to find much rewarding about parenting a child with DLD. One related this to the recency of the diagnosis, but others simply commented, "*I honestly don't think there is anything rewarding*".

Challenges

Across caregiver responses to the part of the question "What is most challenging about having a child with DLD?", 84 codes and 11 higher-order categories were identified (Figure 2).

The communication difficulties associated with DLD impact my child's social and mental well-being

Common across caregiver responses about challenges associated with caring for a child with DLD was the impact of the child's communication difficulties on their social and emotional well-being. The data were organised into five subcategories, the first relating to 'My child hides/masks their DLD'. Caregivers reflected how "*the most challenging is that she can often be struggling with something for ages, and we haven't got a clue because she hides it so well.*" Caregivers also raised concerns about how 'DLD impacts my child's expression and regulation of emotion'. This included a description of their child having 'meltdowns', which tend to occur frequently (for example, "*[he] often meltdowns when he comes home*"). Some identified that these meltdowns were associated with feeling overwhelmed and frustrated, especially when unable to communicate needs or feelings. This was exemplified by the quote: "*Most challenging is seeing him when he is overwhelmed by a situation or unable to communicate or regulate his emotions*."

The subcategory 'The communication difficulties associated with DLD impact my child's social interaction and mental health' can be illustrated by the following quotes: "*She has big feels and because of her DLD it is really hard for her to express them in a constructive way*", and "*because of his anxiety around his language needs he misses out on things that he would otherwise love*". Overall, within the challenges of the impacts on the children's mental health, caregivers commented on the "*significant worries around (their) mental health*."

Communication difficulties can be frustrating and challenging

This higher-order category addressed the frustration and upset experienced by caregivers in relation to their child's communication difficulties. Caregiver responses were often broad, for example: "*Most challenging is the miscommunication that occurs and the frustration*". They also mentioned specific communication contexts in which frustration occurred: "*It can be very frustrating for us both when she is trying to tell me a story and she and I both don't know what she is talking about*."

Diagnosis can be challenging (and take a long time)

Many responses mentioned the challenges around the diagnosis of DLD. These included the process taking a long time ("*absurdly long waiting list for an assessment*"), not being taken seriously ("*it took 6 years until we were taken seriously, had always been dismissed before*"), the expense involved ("*we were not prepared to wait so got a diagnosis privately… we were scared of the further implications to our child's education*") and at times, the mismatch among different family members' beliefs about the diagnosis.

Professionals lack awareness, understanding and support (DLD is unknown and misunderstood)

A number of caregivers mentioned the challenges of health professionals (including SLTs) not recognising DLD and the lack of awareness and support they had encountered:

"*The frustration with professionals who do not recognise my child's challenges. This has even included some SLTs and special ed* [education] *teachers. Some seem poorly equipped to identify and treat communication disorders*."

Caregivers reflected on their perception that DLD was seen as unknown and misunderstood amongst professionals. For example, one stated, "*It being so unknown and misunderstood as a diagnosis is challenging*", and another reported their feeling that "*It's a constant battle*". Caregivers also mentioned others judging their child—people who did not know about nor understand DLD: "*Sadly to most adults who have little knowledge of the disorder, such children come across as lazy and underachieving*". These were grouped under the single higher-order category of professionals overall lacking awareness, understanding and support.

Schools and teachers lack awareness, understanding and support of (my child with) DLD

Many caregivers specifically commented on their experiences with the education system as a challenge: "*Finding teachers and support in the school that are aware of or understand DLD has been overwhelmingly challenging*", categorised as 'Schools and teachers don't understand DLD' and 'It's an ongoing battle with schools'. They often used the term 'battle' as well as qualifiers such as 'constant' and 'ongoing'. For example, "*The ongoing battle with school to ensure his DLD doesn't affect his true abilities academically*", and "*The sheer battle to access support… and then make sure it happens, is horrendous*".

DLD impacts the whole family

The caregivers highlighted the impact that DLD has on family decisions, for example, "*how much it impacts massive things like where we can live because there needs to be an appropriate school nearby*". Caregivers also described how DLD increases the family workload: "*Challenging parts would definitely be all of the appointments, emails, meetings with therapists, teachers etc*.". These were grouped together reflecting the impact DLD has on the whole family, "*Everything needs to be considered with her in mind*".

We worry about the future and the long-term impact of DLD

Caregivers were concerned about the future of their child and the long-term nature of DLD. This is highlighted by the following example: "*The most challenging is how much* *worrying we do about the future, how uncertain it is*". Many caregivers reflected on their concerns about the transition to adulthood and independence: "*I worry about my child in the future and being able to live on his own and earn enough money to do this*." Another example of these worries is "*The worry that they are vulnerable and there seems little support for them transitioning into adulthood*".

Advocacy and finding resources are ongoing and often exhausting

A strong sense of exhaustion amongst caregivers was a key challenge. In particular, a common idea expressed by caregivers was related to their role as advocates for their child with DLD, and that they found it to be ongoing and often exhausting. As stated by one parent, "*Advocacy fatigue is exhausting*". Another caregiver highlighted that they found it "*challenging: to continuously be advocating for them as a parent at school and in the wider community due to the low level of awareness regarding DLD and the needs of these children*". The sense of tiredness amongst parents was also present when they spoke of ongoing challenges associated with finding support and information. For example, one caregiver stated, "*It is so difficult to get help and support*". As in other categories, parents used the metaphor of 'battling', mentioning "*fighting to access support*".

My child needs more time (from me and school) and personalised support

Another challenge raised by caregivers was their child's reliance on them. In particular, they mentioned their child demanding more time and support from their caregiver to help them understand language. This was exemplified by caregiver responses such as, "*She needs extra support to understand and follow things*", and "*he does rely a lot on us*". Caregivers also spoke of needing to spend a great deal of time helping their child to engage with language for learning at school, stating that "*schoolwork takes a very long time*". Because of the perceived demands on their time, caregivers also commented that they found it challenging to "*really listen and have patience*".

I worry about my child's social and community participation

Another key challenge described by caregivers was in relation to their child's difficulties with friendships and social development. They expressed concern about their child not fitting in, with one caregiver describing that they felt "*Sadness listening to him trying to join in with his peers' conversations and missing out socially*". Another described how "*It is challenging as he doesn't fit with his peer group*." Common across the responses relating to this category was the impact on caregiver emotions, with one stating, "*It is also really upsetting when other children who she considers friends leave her out or ignore her*". Caregivers also mentioned their concerns that their child had difficulties making and keeping friends, with one stating that this "*is the constant worry about how her DLD impacts her now, in terms of social confidence and wider friendships*."

Parenting a child with DLD has an impact on my mental health

Relatedly, there was a strong sense that parents found it challenging to parent a child with DLD because of the impact it had on their own mental health, such as, "*It is having a detrimental effect on everything, including my mental health*." Caregivers also commented on the impact that their own negative emotions had on their interactions with, and ability to support, their child, stating that they find it "*hard to stay calm when I am so frustrated*". Others focused on the worry about their child being bullied, sad or depressed, and that caregivers felt similar emotions experienced by their child. For example, one caregiver stated that it "*makes me sad and upset as a mum to hear this coming from my boy who is not mature enough to deal with all these pains*". As caregivers, there was also the sense that they carried the burden of knowing how challenging DLD was for their child, even if the children themselves were not fully aware of the extent of their challenges: "*Feeling sad that they (others) don't realise how hard he has to try every day*."

DISCUSSION

In this paper, we aimed to explore caregiver perceptions of the rewards and challenges of parenting a child with DLD. We applied qualitative content analysis to responses to an open-ended question in our yearly survey. It is encouraging to hear from caregivers about the many rewards they experienced from parenting a child with DLD. Caregivers found rewards in seeing and celebrating progress and experiencing joy in their child's personality, and they talked about being proud to be their parent. They commented on the rewards gained from learning about DLD and working together with their child to help them achieve their potential. They reflected on the supportive nature of the 'right' environment, especially having their child attend a supportive and consistent school context. Caregivers also found it rewarding to observe their child's social connectedness.

It is concerning, however, to read about the lack of awareness of DLD within the community, despite advocacy efforts (e.g., https://radld.org/, https://thedldproject.com/, DLDandMe.org). Caregivers described their concerns about a lack of understanding and awareness amongst professionals in general (including health professionals), but this was also seen as a significant issue within the school system and amongst teachers. Caregivers found it hard to find support and information about DLD and often experienced exhaustion as a result of their constant need to engage in advocacy for their child. It seems there is still a way to go with raising awareness when some caregivers feel that even SLTs have difficulties in recognising and supporting children and families with DLD. Caregivers mentioned the increased time needed to support their child, and worried about their child's social and community participation. It is also concerning to read about the impact on the family and the mental health and well-being of both the children and the parents.

The Pathway to DLD

The diagnosis was raised as a process that could be challenging and take a long time. Newbury and Eagle (2023) reported on the experiences of 14 caregivers of children with language and literacy difficulties in having their child's needs identified in New Zealand. Whilst the mothers in this study were knowledgeable about their child's difficulties and mostly supported the need for a diagnosis, they mentioned the fight to have their child's needs recognised due to a perceived lack of knowledge of some professionals, a reluctance to identify a child as having difficulties, and difficulties accessing the (often costly) assessment services. Similar to our current findings, the parents also identified a lack of knowledge available at the local schools (Newbury & Eagle, 2023).

Living with DLD

Celebrating progress and achieving against the odds was seen as positive, along with pride in their child. It was heartening to read the many comments where caregivers celebrated their child's personality—their loving and kind natures and their empathy and creativity. Many also commented on how brave and resilient their child was. This is important, given the responses to the 'challenges' that are grouped under the impact of DLD on a child's mental well-being (discussed in a later section).

Caregivers valued social connectedness and the right environment—especially the right school. The codes around the impact of 'the right school' in building a child's confidence, supporting participation and being rewarding, contrast with the many responses to the challenges aspect of the question. Here, caregivers mentioned the lack of understanding, awareness and support more broadly from schools as well as their child's teacher. They used the term 'battles' when trying to get support from schools and teachers. They also worried about their child's social and community participation. This aligns with the findings of previous research, with Renneke et al. (2020) finding that children with DLD (compared to those without) experience higher risk of bullying involvement (as victims and perpetrators). These concerns were felt by the mothers of children with DLD, who demonstrated higher levels of burden.

McGregor (2020) reminds us that DLD is often a 'hidden' impairment and in a recent online survey, less than 20% of Australian respondents had heard of DLD, in contrast to more than 95% who had heard of Autism Spectrum Disorder (ASD) and dyslexia (Kim et al., 2023). Teacher ratings of children's language skills were found to have poor sensitivity and specificity compared to a screening test (Antoniazzi et al., 2010). Teachers lacked knowledge about DLD, did not recognise its persistence and had difficulty selecting appropriate adjustments in scenarios based on classroom contexts (Glasby, 2021). Without this awareness of the educational impact of DLD, teachers and schools are not able to consider the language needs and make adjustments for children, "*Teachers don't understand him or his needs*". Reasonable adjustments (steps to enable a student to participate in education on the same basis as a student without a disability) are required in many countries internationally, for example, the 1992 Disability Discrimination Act (Australia), the Equality Act, 2010 (England and Wales), the Special Educational Needs and Disability Code of Practice (England) and the Individuals with Disabilities Act (United States).

This lack of awareness, understanding and support went beyond schools and teachers, including, "*the lack of support from speech and language therapy services*". Caregivers also mentioned the constant battle for a child's diagnosis and difficulties in being recognised and supported by professionals, "*Having a child with DLD is only made more difficult by the lack of support from so-called professionals. They make us doubt our parenting, we get gaslit and treated like we don't know best*".

Many mentioned the frustration and challenges of the communication difficulties experienced by their child. This finding of significant communicative challenges is mirrored in the survey data from 60 parents of children with DLD who reported limitations in their child expressing themselves and being understood as core difficulties (Bruinsma et al., 2024).

The impact of DLD on the family

DLD does not just impact the child; the responses from our cohort of caregivers remind us that DLD impacts the whole family—from decisions such as where the family lives (to access the right school and services) to caregivers who had to leave their jobs to provide extra support. This echoes the observations of parents of young children with language difficulties, with Nes et al. (2015) finding that mothers of 5-year-old children with language difficulties are less likely to be employed and have a higher risk of taking long-term sick leave. Notably, co-occurring problems (e.g., with behaviour) further increased these risks.

DLD also increases the workload of the family. Caregivers noted the need to provide extra support for their child, as well as the time taken up by appointments and paperwork. Logistics, navigation and resources have all been identified as influential factors in access to services (Wells et al., 2024). Many caregivers commented on the constant need to explain to others about DLD and the impact on their child, how they were often let down by services and the exhaustion associated with their role as advocates, "*getting people to understand his difficulties is hard*".

Caregivers worry about the future and acknowledge the long-term nature of DLD. Concerns ranged from the lack of support in the transition to adulthood and independence, to worry that others would not understand, support or accommodate their child as they grow up. The most commonly reported concern in a sample of mothers of adolescents with a history of DLD was the future and social concerns (Pratt et al., 2006). Similar concerns were identified by parents of adolescents with a history of DLD in Conti-Ramsden et al. (2008), notably in relation to "more negative expectations in the areas of future/adult life, socialisation and community resources" (p. 84). Amongst the caregiver responses in our data, it was acknowledged that they felt a sense of reward in learning about DLD, learning together with their child and learning from their child. This substantiates a finding from Conti-Ramsden et al. (2008), who identified that despite the negative expectations amongst parents, their sense of positive family relationships was a source of reward for them. These are important factors for clinicians to consider in working together with a family.

DLD and mental health

Caregivers talked about the impact of DLD on their child's mental health. They specifically mentioned masking/camouflage (also discussed in Hobson & Lee, 2023), internalising symptoms such as anxiety and externalising symptoms such as meltdowns and tantrums. Similar findings were identified by Hobson et al. (2022), who interviewed nine parents of children with DLD aged 7 to 17 years. Their study focused on parental experiences in accessing mental health support, and they developed five themes. One key theme related to parents noting that their child's language difficulties impacted how they were able to communicate distress and that not realising the extent of their child's difficulties was distressing for parents as well. Some mentioned their concerns that their child would be vulnerable, worrying about the future for them. The school environment was pivotal to the experiences of many of the families, who reflected on the caring and supportive nature of some professionals and how positive this was. In contrast, some noted less positive experiences and the impact of this. Parents talked about the role of professionals in general, reflecting on it often being their task to link these together. Similar to our data set, parents talked about being made to feel they were making a fuss and used phrases such as the need to 'keep fighting'. The final theme described by Hobson et al. (2022) was around the impact on parents, who took on many roles including advocate and liaison. Although the focus of the study by Hobson et al (2022) was specific to mental health, the patterns in the themes developed from the interview data are mirrored in our survey responses about caregiver challenges—that is, parental concerns being downplayed by professionals ('we were not taken seriously', 'lack of support from professionals', 'ongoing battle with schools'), the impact of communication difficulties on the child's mental well-being, the parent's mental health and the impact on the whole family, as well as advocacy being ongoing and exhausting. This important area of research warrants further investigation.

Little is known about the impact of parenting a child with DLD on a parent's well-being. The caregivers mentioned worrying about their child and also the impact of DLD on their own mental health. A small number of responses reflected on how hard it is to parent a child with DLD. Parents of children with speech and language disorders have also reported that they perceive both their child and themselves to be faced with stigmatisation related to their child's communication difficulty and that such stigmatisation comes from other children, adults and family members (Macharey & von Suchodoletz, 2008). Craig et al. (2016) explored parenting stress amongst 239 parents of children and adolescents with and without neurodevelopmental disorders (including ASD, specific learning disorders, attention-deficit/hyperactivity disorder and 34 with language disorders). Overall, parents of children and adolescents with language disorders reported higher parental stress than those of children without neurodevelopmental disorders (Craig et al., 2016). The authors recommended that parents be provided with support to empower them with knowledge and skills to tackle stress and improve their quality of life.

Limitations and future directions

The data set described in the current study comprises written responses to a single question on the first yearly survey completed within the E-DLD database. It would be useful to follow up on the themes in semistructured interviews or focus groups to allow a deeper exploration of the experiences of the caregivers. However, the survey responses were rich and often detailed, and the categories that were developed are consistent with much of the emerging literature. It would also be useful to confirm the findings we report here by discussing them with caregivers of children with DLD. Additionally, whilst our 112 caregivers came from across the world, the data set is predominantly English-speaking and from the United Kingdom. Future research should explore the question in a multicultural context.

CONCLUSION

It is heartening to hear from caregivers about the many rewards they experienced from parenting a child with DLD. These are strengths that we should nurture. It is concerning, however, to read about the continued lack of awareness of DLD amongst the community and professionals in general, but also within the school system and amongst teachers in particular. Parenting a child with DLD was often described as difficult, worrying and frustrating. The impact on the children, the caregivers and the whole family came through clearly, especially the impact on their mental health and well-being.

There is much to take from this data set, and for us to reflect on and use when we offer services. We need to increasingly work in collaboration with our DLD children, young people and families and continue our advocacy work to raise awareness of DLD. We may need to re-think our approaches and consider developing and supporting services that target the parents themselves directly. Listening to the experiences of caregivers of children with DLD should play an important and powerful role in developing and providing collaborative and evidence-base services, and we are grateful to our E-DLD community who contribute annually to our database and allow us to hear their voices.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. Data are available on request through https://researchdata.bath.ac.uk/1458/

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ENDNOTE

[1] 89.7% of our respondents in this study were biological mothers and 93% legal guardians. We chose to use the term ‘caregiver’ as the label throughout our study to acknowledge the inclusion of parents and other caregivers, and the term ‘parenting’ as the verb to denote the lived experience of our participants.

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