

## RESEARCH ARTICLE

WILEY

# A Delphi study exploring the barriers to dyslexia diagnosis and support: A parent's perspective

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The Rose Report (Rose, *Independent review of the primary curriculum (England)*; 2009) outlined a set of recommendations for the management of dyslexia in the United Kingdom after a range of issues were found. Despite these recommendations, recent reports indicate that issues are still prevalent in the diagnosis process and support offered for dyslexic children. The Delphi method was employed to gain parental consensus as to the most significant barriers to diagnosis and delivery of support for children with dyslexia, as well as solutions to overcoming these barriers. Parents of primary school children with dyslexia were recruited for the study and were presented with a three round iterative questionnaire surrounding their experience of their child's dyslexia management. Parents' experiences of their child's diagnosis were explored to provide a first-hand account of the diagnosis procedure. Two overarching issues were identified: parents perceive that teachers have a lack of training around dyslexia, both initially and from continued professional development, and parents believe there is insufficient funding for dyslexia in schools and local authorities. Overall, the study indicated that better guidance is needed to ensure that reform and spending leads to tangible change in the identification of

Emily Oxley and Sophie Harding were formerly at the University of Leeds. We would like to thank the families who took part in our survey.

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dyslexia and provision of support for children with dyslexia in primary education in the United Kingdom.

#### KEYWORDS

Delphi survey, diagnosis, dyslexia, parents, support

## 1 | INTRODUCTION

Dyslexia is a neurodevelopmental disorder, with a biological origin, that manifests in learning difficulties characterised by problems with accurate or fluent word recognition, poor spelling and decoding ability (American Psychiatric Association [APA], 2013). It is estimated that around 10% of the population have dyslexia, making it the most common specific learning difficulty in the United Kingdom, affecting around 1 million young people in education (British Dyslexia Association [BDA], 2019a).

The impact of dyslexia goes much further than reading and writing, affecting academic attainment, self-esteem and quality of life as well as a myriad of later life outcomes (Livingston et al., 2018). Individuals diagnosed with dyslexia have been found to achieve lower pay rates to non-dyslexic counterparts (de Beer et al., 2014) and slower career progression (Morris & Turnbull, 2007). It is therefore crucial that children receive a timely diagnosis and appropriate support to limit the negative cascading effects of dyslexia.

Dyslexia has been found to have a profound emotional impact on the individual and their family. Research has found an association between dyslexia and a variety of mental health difficulties as well as impaired psychosocial functioning (Livingston et al., 2018; Parhiala et al., 2015). Dyslexia has been linked to negative self-concept and lower self-esteem as well as those with dyslexia being more likely to exhibit symptoms of anxiety and depression (Doikou-Avlidou, 2015; Eissa, 2010). Protective factors that encourage high self-esteem and self-efficacy, such as emotional support from family members (Terras et al., 2009) and early-diagnosis (Battistutta et al., 2018) should therefore inform the structure and approach to supporting children with dyslexia. The negative impact dyslexia can have on mental health and wellbeing is heavily influenced by the environment in which dyslexia is identified and managed.

Despite government policy in England requiring all teachers to have the capacity to meet the needs of children (Department for Education, 2015) provision of targeted, appropriate and one-on-one support has found to be lacking for children with dyslexia (Knight, 2018). The Rose Report (Rose, 2009) was an independent review of the management of dyslexia, commissioned by the UK government. This in-depth report highlighted issues with the diagnosis and support for dyslexia and formulated recommendations for future educational policy and the classroom environment. These included better training to improve mainstream teacher knowledge and provision of more in-depth training for 'dyslexia specialists'. However, more recent reports on dyslexia in the United Kingdom have highlighted similar issues (BDA, 2019a, 2019b); indicating that the recommendations made by the Rose Report (Rose, 2009) have not been acted upon. The Dyslexia Screening Bill (Dyslexia Screening, 2021) proposes that all children are screened for dyslexia before leaving primary school and argues for better assessment and improved training for teachers. Issues regarding identification and support for children with dyslexia and other special educational needs or disability (SEND) are laid out in the recent SEND review (HM Government, 2022). Parents of children with SEND report their experiences of the current system as bureaucratic and adversarial, encompassing difficulties and delays. The current system is not equally accessible, with those who have access to better financial and social resources better able to navigate the system and get support for their child (HM Government, 2022). The review identifies greater national consistency, early and accurate identification and prompt access to support as key targets for reform.

The Morton and Frith (1995) causal model explains dyslexia as a multi-level disorder, with biological, cognitive and behavioural levels all relevant to informing effective interventions. Interventions targeting phonological

processing in children with dyslexia have been shown to be most effective (McArthur et al., 2018). However, the majority of teachers surveyed by (Washburn et al., 2014) attributed dyslexia to visual difficulties. Bell et al. (2011) also found that less than half of teachers surveyed mentioned the cognitive aspect of dyslexia and even fewer acknowledged the biological component. These findings highlight a lack of in-depth knowledge from teachers on dyslexia and the processes relevant to effective interventions. The Specialist Dyslexia Training for Teachers Programme was developed in response to the Rose Report (Rose, 2009) with the aim of strengthening multisensory teaching methods, an approach that has been found to be effective for all children, including those with dyslexia (Joshi et al., 2002). The programme also focused on developing teacher knowledge of the theory that underpins effective intervention for dyslexia (Boardman, 2020). While this programme has found to be effective in increasing teacher knowledge and confidence in teaching children with dyslexia (Boardman, 2020), teachers in the UK report that access to continued professional development focused on dyslexia is poor (Knight, 2018).

While there is still debate over the use of the label of dyslexia (Knight & Crick, 2021) identifying and diagnosing dyslexia is typically necessary to access specialist support and intervention. Delays in identification and diagnosis of dyslexia can feed into poorer outcomes (Livingston et al., 2018), with the frustration of not being able to perform at the same level of peers causing behavioural issues, impeding learning further (Lisle & Wade, 2013). Early identification and diagnosis are therefore important for effectively managing and supporting children with dyslexia, and helping to improve self-image (Colenbrander et al., 2018).

The process of diagnosis in the United Kingdom remains in the hands of the local authority, meaning the system varies nationally and most of the time the parent/carer has to pay for a private diagnostic assessment, which can range from £500–£700 (BDA, 2019b). Socioeconomic status (SES) has been found to be a mediating factor in access to a dyslexia assessment. Children from lower SES backgrounds are significantly less likely to be assessed and diagnosed with dyslexia compared to children of higher-earners (Knight & Crick, 2021; Macdonald & Deacon, 2019). These findings show that the dyslexia label is not evenly distributed in England, which means that resources for support are also not likely to be fairly distributed. Once reading difficulties are identified, children from all SES backgrounds should be able to access a formal diagnosis that is free and within the educational system (Macdonald & Deacon, 2019). Removing the financial and social barriers to a formal diagnosis is critical as diagnosis acts as a gateway to access specialist resources (Ross, 2019).

The Rose Report (Rose, 2009) provided recommendations to improve the care and management of children with dyslexia. However, recent reports have shown that these recommendations have not been acted upon. Both the Educational Cost of Dyslexia Report (BDA, 2019b) and the Human Cost of Dyslexia Report (BDA, 2019a) explored the impact of dyslexia in the United Kingdom more recently. The Human Cost of Dyslexia report (BDA, 2019a) found that 76% of parents felt the school was not doing a good job in supporting their child's dyslexia and 82% of parents stated that they sometimes felt angry with their child's school. The Educational Cost of Dyslexia report (BDA, 2019b) outlined significant issues in access to support and the financial pressures of dyslexia for the family, as well as the longer lasting impact on educational attainment for individuals with dyslexia.

These reports, along with the more recent SEND review (HM Government, 2022) offer recommendations that echo those from the Rose Report (Rose, 2009). Providing appropriate and specific dyslexia training for both specialist and mainstream teachers was identified as key (BDA, 2019a, 2019b). The reports also highlight the need for adequate and consistent support with national standards and frameworks to improve the identification and support of dyslexia in the United Kingdom (BDA, 2019a, 2019b; HM Government, 2022).

## 2 | THE CURRENT STUDY

The current system for identifying and supporting children with dyslexia requires improvement and evidence from major reports suggests that little has changed for families and children with dyslexia. The current study used the Delphi method (Dalkey & Helmer, 1963) to arrive at a consensus as to the most significant barriers to diagnosis and

support for dyslexic children and recommendations for solutions and improvements to help remove barriers. The Delphi method was selected because it is suitable for research where the goal is to improve understanding of problems and solutions, as it allows a collective voice from a specific community without the difficulties and downfalls of typical group survey methods (Kezar & Maxey, 2016).

Participants were parents of primary school children diagnosed with dyslexia and were considered to be experts by experience. While we acknowledge that the parents in this study are not dyslexia experts in the traditional sense, the study is focused on their lived experience of the diagnosis procedure, including potential barriers to diagnosis and support they faced, as well as possible solutions for their removal for future parents facing the same diagnosis procedures. The perspective of people with direct experience, such as parents, offer a valuable and important insight into processes and systems and areas where change may be needed (CFE Research Report, 2020). The barriers and solutions identified in this research will be generated solely from parental responses and not from published literature with the aim of providing new insights into the management of dyslexia in UK primary education.

### 3 | METHOD

#### 3.1 | Study design

The study conducted a three-round Delphi to identify the barriers and solutions to diagnosis and support for children with dyslexia. The Delphi method is an iterative questionnaire technique to enable a panel of experts by experience to reach a consensus on an issue (Borg & Gall, 1983). The different iterations allow members to change and elaborate on their opinion throughout the survey (Rowe et al., 1991). The 'controlled feedback' at each round allows group opinion to be seen by panel members without removing the anonymised format that encourages more in-depth expression of opinion (Rowe et al., 1991).

The first round of the Delphi focuses on the generation of ideas, through qualitative open-ended questions via online survey format (Keil et al., 2002). In this study panel members were asked about how they would define dyslexia, the process of diagnosis and their thoughts on the label of dyslexia. Parents were asked about the barriers they have faced with diagnosis and support for their children and what could be done to remove these barriers. They were also asked about the type of support their child received and who provided that support.

Panel members provided information about their relation to the child, their postcode, their child's age and if their child had any siblings. Panellists were also asked to provide any details about family history of reading difficulties, or if their child had been formally diagnosed with any other developmental disorders (other than dyslexia).

The qualitative responses from the first round were then collated, with themes generated and presented back in the second round, where parents were asked to rank the different themes (Keil et al., 2002). The third round aimed to establish consensus, with panellists being asked to look at their own rankings and the average group rankings from the previous round to consider whether they would like to amend their rank order (Hsu & Sandford, 2007).

#### 3.2 | Data analysis and consensus

The open-ended questions from the first round were analysed using Thematic Analysis (Braun & Clarke, 2006, 2021). This six-stage data driven inductive analysis was used to identify, analyse and report common themes from the open questions (Braun & Clarke, 2006, 2021). Consensus was measured through group agreement with rankings, alongside the descriptive analysis of standard deviations. Consensus was considered to be reached when  $\geq 70\%$  of the panel agreed on ranking in this study, in line with previous Delphi studies (Okoli & Pawlowski, 2004).

### 3.3 | Panel formation

As the focus of this survey was the identification of barriers and solutions to diagnosis and support for children with dyslexia, panel members were parents of children who had recently received a formal diagnosis of dyslexia. Parents were required to be UK based and for their child to have received a formal diagnosis of dyslexia while in primary school and to still be in primary school (11 years or younger), in order that experiences of the process were as recent and relevant as possible.

While there is no standard for panel size in a Delphi study, the minimum panel size has been suggested to be between 10 and 18 (Okoli & Pawlowski, 2004). Attrition between rounds is common in Delphi studies, so a larger group of parents was initially targeted to account for this. Recruitment took place via social media on sites relevant to the target group. Consenting participants were sent a link using Qualtrics online survey software (<https://www.qualtrics.com>). Ethical approval was granted by the University of Leeds School of Psychology research ethics committee.

## 4 | RESULTS

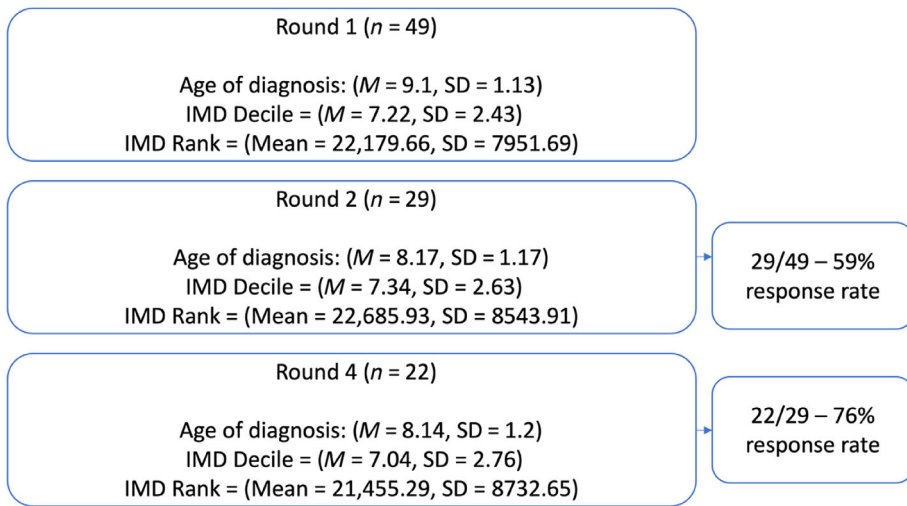
### 4.1 | Panel characteristics

Seventy-six responses were collected in the first round, however, due to failure to meet inclusion criteria or incomplete survey response, 49 responses were analysed. The panel was made up of 48 mothers and 1 stepmother, 53% of whom had a history of reading difficulties in their family. Forty-six of the panel members lived in England, with two based in Scotland and one panel member located in Wales. Twenty-nine percent of panellists' children at Round 1 had been formally diagnosed with another developmental disorder alongside dyslexia (most commonly Autism Spectrum Disorder, Dyspraxia and Irlen's Syndrome).

Figure 1 outlines the panel size, average age of dyslexia diagnosis of panellists' children, English Indices of Multiple Deprivation (IMD) rank and decile and retention at each round. The IMD data considers sociodemographic factors such as average income, employment rate and education to form a ranking (1–32,844) and decile (1–10) for each postcode in England from most to least deprived. The average decile from the first round of data shows that the panel was leaning towards a higher SES (mean 7.22; SD = 2.43). The composition of the SES remained stable throughout rounds, with the range of IMD decile (2–10) and rank maintaining consistent throughout.

### 4.2 | Round 1

Overall, the results indicated that parents noticed their child's reading difficulties earlier than school. Age where dyslexia was first noticed by parents ranged from 2 to 7 years old ( $M = 5.1$ ,  $SD = 1.16$ ), whereas age first noticed by school ranged from 5 to 11 years old ( $M = 6.75$ ,  $SD = 1.52$ ). It should be noted that children start school (and begin formal literacy instruction) at age four in England and Wales, and between the ages of four and five and a half in Scotland, therefore school cannot identify difficulties before this. However, 13 parents (27%) reported that school had never noticed their child's reading difficulties. Sixty-seven percent of parents stated that they were the ones to raise concerns and a further 22% said it was a joint process, raising concern with the school. Only four members of the panel stated that school raised concerns without initial parental input. Eighty-six percent of parents stated that they initiated the diagnostic process, and a further 82% of the panel secured a diagnosis themselves, paying for a private assessment. The length of the diagnostic process varied (range = 1 month to 7 years), however, a longer process was more common (>2 years = 61%).



**FIGURE 1** Number of panel members, average of dyslexia diagnosis and average English Indices of Multiple Deprivation (IMD) Data at each round of the Delphi survey. Forty-six of 49 parents' data was suitable for computing English indices of deprivation at Round 1. Twenty-seven of 29 parent's data was suitable for computing English indices of deprivation at Round 2. Twenty-one of 22 parent's data was suitable for computing English indices of deprivation at Round 3.

A diverse range of answers resulted from asking parents to define dyslexia, with some describing dyslexia as a 'difficulty with learning and reading' and others describing it as 'different way of learning'. A lot of parents spoke about the different aspects of learning that dyslexia can cause issues with, such as information retrieval, phonological processing and reading comprehension.

When asked about the label of 'dyslexia' many panel members highlighted how the dyslexia label gave their child, the school and themselves a greater understanding as to how and why their child was struggling; 'I think it gives an understanding to people, an awareness is always helpful'. The label and diagnosis also gave parents a sense of relief 'Glad we've finally got to the bottom of what is holding him back'. It was also considered important by parents as a label meant their children were able to access support 'The diagnosis helped get the right support in school ...' or were hopeful that it would enable future support 'Hope it helps him get more time and input with the school'. However, some parents did still worry about negative connotations around intelligence and being different, 'I don't mind [about the label] providing people don't think she lacks intelligence'.

Parents were then asked six open questions regarding barriers and support to dyslexia diagnosis:

1. What barriers, if any, did you experience with your child's dyslexia diagnosis?

Eight different themes were generated from caregiver responses to question one, many barriers focused on management of dyslexia within school, such as lack of appropriate knowledge and resources available 'Teachers in the mainstream are not adequately equipped'. The financial aspect of dyslexia management and support was also mentioned. Insufficient funding within school, as well as the cost of private assessment for the family were both identified as barriers. Further themes focused on school's failure to recognise their child's difficulties, with parents stating that school waited too long before recognising that there was an issue. Both the child's age and out-of-school support masking difficulties were also identified 'School couldn't do much until they reached Key Stage 2'. Schools' failure to recognise dyslexia altogether was another barrier, with some schools reluctant to use the diagnosis for further support 'School did not believe a diagnosis was necessary'. Finally, a lack of good quality communication with school was identified.

## 2. What do you feel could be done to help remove these barriers?

Eight themes were developed from caregiver responses to question two. School remained a focus, with better training, *'the school requires more training on dyslexia in order to remove these barriers'*, and funding, *'better funding and access to support'*, identified as potential solutions. Parents highlighted how schools could better recognise a diagnosis of dyslexia and utilise this to provide support for children. Early screening for children as well as a more standardised process for diagnosis were two further themes generated from panel responses that focused on the diagnostic process *'Reintroduce the formal dyslexia assessment and diagnosis [of dyslexia]'*. Parents discussed the need for dyslexia to be more widely understood and discussed, beyond the school and home *'greater awareness to remove any stigma and show positive side'*.

## 3. What support or treatment, if any, is provided for your child?

A range of different treatments and types of support were identified from response to question three, including specialist technology; coloured overlays, lenses and rulers; differentiated class work and additional time in assessments. Other in school support was highlighted by panel members, including additional one-to-one or small group literacy support, dyslexia specific interventions as well as an Individual Education Plan in place.<sup>1</sup> Out-of-school interventions were also cited by parents, such as private tuition and speech and language therapy.

## 4. Who provides this?

Parents, teachers, teaching assistants, SENDCOs<sup>2</sup> and parents themselves were all identified as providers of support. Further providers were private tutors and speech and language therapists. Many responses stated that parents were the only or main provider of support for their child *'We have provided most of the support'*.

## 5. Is there any support you would like for you child that is not currently made available to them?

The use of technology, one-to-one support and extra time were all themes identified when parents were asked about the support they desired. Additional teaching resources, support from a teacher with specialist training, and emotional support were prominent themes identified in analysis.

## 6. What are the barriers, if any, to receiving this support?

Lack of access to specialist dyslexia support as well as a general lack of teacher knowledge, lack of funding in schools and pressure on school to meet curriculum targets were all themes identified when parents were asked about barriers to receiving support.

## 4.3 | Round 2

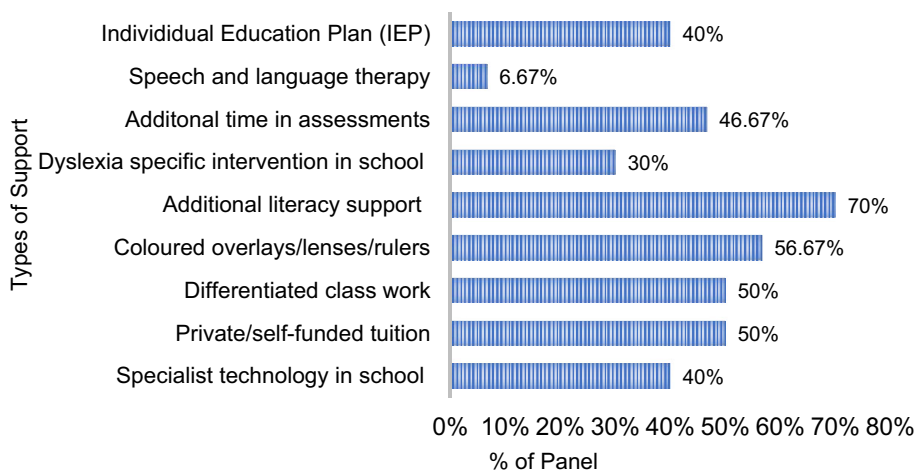
Parents were asked to rank the themes developed from Round 1 responses around barriers to diagnosis. A lack of knowledge and resources in schools were ranked as the greatest barriers to diagnosis, closely followed by schools' reluctance to recognise dyslexia. Factors ranked lower by the panel were additional support at home masking difficulties and poor communication between school and home. Financially related barriers were, on average, ranked around the middle alongside the child's age. However, consensus for the rankings at the second round remained relatively low, with only the lowest ranking for *'Additional support masking difficulties'* approaching consensus at 68%.

When asked to identify the most important solutions for removing the aforementioned barriers, better training for teachers in order to ensure recognition of dyslexia was ranked top (37% agreement). Better training and funding for schools were ranked second and third, but again there were lower levels of agreement. Early screening for all children and a more standardised diagnostic process were ranked in the middle, followed by improving communication between schools and parents. Greater awareness and understanding of dyslexia in the general population and schools' ability to use private diagnoses to prompt further support were ranked as the least important solutions to barrier in the second round. All solutions were carried on to the third round as consensus for ranking was not reached.

Panelists gave varied answers when asked about the types of support their child received. Seventy percent of panel members listed additional one-to-one or small group support as an intervention their child received, making it the most common form of support. Coloured overlays and lenses were also widely offered with over half of the panel's children (56.67%) receiving these. Speech and Language therapy was the least common (6.67%). Dyslexia specific intervention in school was also less widely offered, with only 30% of parents having indicated it as a support their child currently received. This question was very individualised, as outlined in Figure 2, and therefore it was not appropriate to ask for consensus and answers were not carried on to the third round.

Panel members also were asked to indicate the frequency of support from the sources identified in Round 1. Parents were the greatest providers of support for their children, as all panel members said they always (72.41%) or frequently (27.59%) provided support for their children. Teaching staff followed, 48% of parents listed teachers as 'always' or 'frequently' providing support, however a higher amount (62%) listed teaching assistants as 'always' or 'frequently' providing support. Over half of the parents (55.1%) stated that their child received private tuition, always or frequently. In line with the small number of parents who cited speech and language therapy as a support their child received, 79.31% of panel members stated their child had never received support from speech and language therapists (Figure 3).

Panelists were asked to identify the means of support they believed to be most helpful, from the support they currently received and the support they desired for their child identified in the first round. Support from a teacher or teaching assistant, with specialist training, was ranked as the most helpful. One-to-one support with literacy closely followed and emotional support for their child came third. Technological support and additional teaching resources were ranked towards the bottom for helpfulness according to group rankings. Extra time to complete assessments and tasks in class was ranked as the least helpful means of support for dyslexia by the panel.



**FIGURE 2** The different types of support the children of the panel receive.



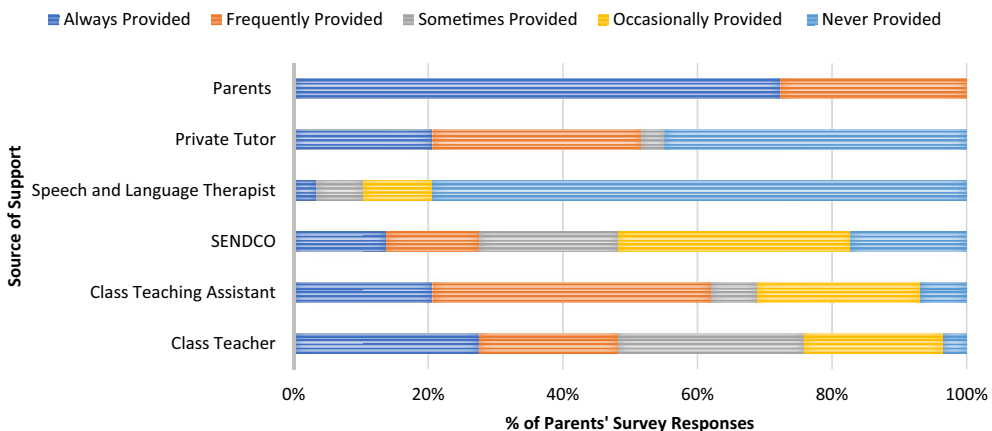
Finally, parents ranked potential barriers to the support they most desired for their child from the themes developed in round one. Lack of funding within school was the greatest barrier to support, followed by lack of access to a dyslexia specialist. While lack of initial teacher training came third in group rankings, the mean and median rankings were very similar to lack of funding and lack of access; suggesting these three were similarly ranked. Pressure on school to meet targets was ranked as the least important potential barrier.

#### 4.4 | Round 3

In the final round, parents were sent individualised surveys comprising 27 statements for ranking, for the four different questions from round two. Panel members were presented with their own individual rankings as well as the average group rankings. The parents were asked to reconsider their own ranking from the previous round in light of the group response and were reminded that the aim of research was to gain a consensus. Consensus was considered to be reached when  $\geq 70\%$  of the panel agreed on ranking, in line with previous Delphi studies (Okoli & Pawlowski, 2004). Consensus levels significantly improved from round two.

Table 1 outlines rankings of barriers to diagnosis in round three. Insufficient funding within schools was the greatest barrier to diagnosis, approaching consensus at 68%. Adopting a 'wait and see' approach was ranked the second greatest barrier, although this failed to reach accepted levels of consensus (57% agreement). A lack of knowledge around dyslexia in schools and schools' reluctance to recognise the importance of a diagnosis were the next greatest barriers. Both barriers were near to reaching consensus with 65% and 68% group agreement. Cost of paying for a private assessment was ranked fifth, which reached consensus at 73%. Lack of appropriate resources for a dyslexic learner followed, approaching consensus at 68% group agreement. Additional support masking difficulties (95%) and poor communication between the family and schools (90%) reached very high levels of group agreement as the least important barriers to diagnosis.

Consensus was reached for all but one ranking position for the importance of solutions for removing barriers to diagnosis as shown in Table 2. Better training for teachers was ranked as the most important approach to removing barriers to diagnosis (81% agreement), closely followed by better training for schools (86% agreement). Additional funding for school and early screening followed, both reaching consensus at 73% agreement. The middle ranking for 'a more standardised diagnostic process' was the only solution that had a ranking agreement below 70%. However, the closely aligned mean and median suggest most panellists were ranking this in the middle of the table and were also reaching agreement at 64% group consensus. The three least important solutions; better communication



**FIGURE 3** The frequency of provision from different sources of support.

**TABLE 1** Group ranking of barriers to diagnosis, from greatest to smallest, for Round 3.

Ranking	Barriers to diagnosis	Mean	Median	Consensus on ranking (%)
1	Insufficient funding within school to fund an assessment	1.5	1	68
2	Childs age, school adopting a 'wait and see' approach	1.95	2	57
3	A lack of knowledge in schools about dyslexia	2.82	3	65
4	School reluctant to recognise, believing a diagnosis is not necessary for support	4.36	4	68
5	Cost of paying for a private assessment	4.77	5	73
6	A lack of resources appropriate for a dyslexic learner	5.77	6	68
7	Poor communication between school and family	6.86	7	90
8	Additional support masking difficulties	7.95	8	95

Note: 1 = greatest/8 = smallest.

**TABLE 2** Group rankings of solutions to the removal of barriers to diagnosis, from most to least important, for Round 3.

Ranking	Solutions to removal of barriers	Mean	Median	Consensus on ranking (%)
1	Better training for teachers so they can recognise dyslexia	1.27	1	81
2	Better training for schools in the early signs of dyslexia, to avoid 'waiting and seeing'	1.95	2	86
3	Additional funding for schools	3.45	3	73
4	Early screening for children	3.91	4	73
5	More standardised diagnostic process	5.09	5	64
6	Better communication between school and parents	5.73	6	77
7	Schools using private diagnoses to prompt further assessment or provision of support	6.95	7	82
8	Greater awareness and understanding of dyslexia in the general population	7.64	8	86

Note: 1 = most important/8 = least important.

between school and parent; use of private diagnosis by schools and greater public awareness of dyslexia all reached consensus.

A strong level of consensus for the top and bottom rankings was found for the helpfulness of different types of support (Table 3). Support from a teacher with relevant training was ranked as the most helpful (91% agreement), ahead of one-to-one support (73% consensus). Emotional support, ranked third most helpful, was approaching consensus at 68%. Technology and additional teaching resources were ranked in the middle but failed to reach consensus, both at 59% agreement. Extra time in class and assessments was ranked as the least helpful method of support with a strong level of consensus (77%).

All four barriers to support achieved high levels of group agreement as shown in Table 4. Lack of sufficient funding in schools (91% agreement) was considered to be the greatest barrier to support, followed by a lack of access to a dyslexia specialist within school (91% agreement). Lack of initial training and development in dyslexia and pressure on schools to meet targets were ranked third and fourth, both achieving consensus.

**TABLE 3** Group rankings of the means of support offered to children, from most to least helpful, for Round 3.

Ranking	Means of support	Mean	Median	Consensus on ranking (%)
1	Support from teacher with specialist dyslexia training	1.09	1	91
2	One-to-one support with literacy	2.23	2	73
3	Emotional support for child	3.5	3	68
4	Technology—laptop or software	3.77	4	59
5	Additional teaching resources	4.73	5	59
6	Extra time to complete tasks in class and assessments	5.68	6	77

Note: 1 = most helpful/6 = least helpful.

**TABLE 4** Group rankings for the barriers to support, from the greatest to the smallest, for Round 3.

Ranking	Barriers to support	Mean	Median	Consensus on ranking (%)
1	Lack of funding in school	1.18	1	91
2	Lack of access to a dyslexia specialist	2	2	91
3	Lack of initial training and continued professional development in dyslexia	3.04	3	86
4	Pressure on school to meet targets	3.77	4	86

Note: 1 = greatest/8 = smallest.

## 5 | DISCUSSION

It is clear the current system for identifying and supporting children with dyslexia requires improvement and that little progress has been made between major reports exploring dyslexia management. This study aimed to use the Delphi method to arrive at a consensus as to the most significant barriers to diagnosis and support experienced by parents of UK children with a diagnosis of dyslexia. A further aim was to identify potential for removing these barriers, from the perspective of parents who have been through the process in recent years.

In the final round of the Delphi survey, 22 parents ranked different barriers and solutions to the diagnosis of dyslexia and access to support. Parents identified significant school-based barriers to diagnosis including funding for an assessment, their child's age combined with the use of a 'wait and see' approach, and lack of knowledge around dyslexia. The panel was also asked to rank the most important solutions to remove these barriers. Parents ranked better training for teachers as most important, followed by better training for schools to avoid the aforementioned 'wait and see' approach. Better funding for schools then followed, ranked as the third most important solution.

When asked what means of support was most helpful for their child, support from a teacher with sufficient dyslexia training was ranked most helpful. One-to-one support with literacy and emotional support for their child were ranked as second and third most helpful by parents. Panel members identified lack of funding in schools as the greatest barrier to accessing these means of support. Lack of access to a dyslexia specialist and lack of sufficient training for teachers on dyslexia were also ranked as important barriers by parents, to their child getting support.

Funding, or lack thereof, remained a consistent theme throughout parental responses. Lack of funding was ranked as the greatest barrier both for obtaining a diagnosis and for access to appropriate and helpful support. School leaders and staff have identified children with SEND as those most negatively affected by financial pressures within schools (Ofsted, 2020). The government are attempting to address concerns of underfunding in education, with commitment to a £7.1 billion increase in 2019 (HM Treasury, 2019) and another recent pledge of a further £1 billion investment in SEN in 2022–2023 (HM Government, 2022). However, as previous reports highlighted,

increased spending does not necessarily solve the issues children with dyslexia face and needs to be paired with appropriate spending and provision (Education Committee, 2019; Ofsted, 2020). Government spending appears to be both inadequate and unsustainable for supporting children with additional needs and the gap between provision and need is widening (Education Committee, 2019). Recent findings confirm these concerns, with a lack of cohesiveness and consistency in SEND provision resulting in little change in outcomes for young people despite unprecedented spending (HM Government, 2022).

Lack of sufficient training for teachers and lack of knowledge around dyslexia in schools were both highlighted as significant barriers to both diagnosis and support. Better teacher training was considered the greatest solution to overcoming barriers to diagnosis, and support from a teacher with specialist dyslexia training was identified as the most helpful means of support for children by parents in the study. In a survey of teachers, Knight (2018) found poor coverage of dyslexia in initial training as well as a lack of opportunity for continued professional development in specialist dyslexia training. A national survey with newly qualified teachers also found only 40% felt prepared to assess progress in SEND pupils (Ginnis et al., 2018).

Despite the DfE commitment to invest in professional development in dyslexia for teachers in 2016 (DfE, 2016), there still seems to be a lack of improvement. The Driver Youth Trust (Driver Youth Trust [DYT], 2020) report looked at Rose's recommendations (Rose, 2009) and sought to explore what specialist support was available in the United Kingdom. It found that while the number of specialist teachers had increased, the system remained unclear and confusing with specialists rarely employed in state schools and frequently underutilised (DYT, 2020).

The interventions and support provided by school post diagnosis were also viewed by parents as sub-par in this study. Visual-based interventions were much more commonly provided, with over half of parents (56.67%) identifying this as a form of support their child received. This raises additional concern about school and teacher knowledge as there is a relatively small evidence base for the effectiveness of coloured overlays and lenses (P. G. Griffiths et al., 2016). It is important to note that we did not ask whether such support materials were provided by school or parents themselves. While parents agreed they would like teachers to have a better understanding of dyslexia, the range of misinformation which still dominates the field could lead to parents having inaccurate information about support their child may benefit from. Many companies exist in the United Kingdom selling coloured overlays and lenses to parents of dyslexic children, despite the limited evidence base. It is therefore important to interpret parents' perceptions of teacher knowledge with caution, as parents themselves may indeed hold some misinformation about dyslexia as fact. Though there may still be a need for evidence based training around dyslexia, evidence suggests teachers have a lack of knowledge on the phonological basis when asked about interventions for dyslexia (Knight, 2018).

The diagnostic process was found to be a challenge for many of the families in this study, as 86% of parents in the panel initiated the process of diagnosis and 82% paid for a diagnosis to be done privately. These findings mirror that of the Educational Cost of Dyslexia Report (BDA, 2019b), which found that 80% of young people with dyslexia are not identified in school. With a lack of funding and opportunity for diagnosis in schools, parents are having to outsource and personally fund diagnoses, feeding into additional barriers and further inequalities. Parents in this study were more economically advantaged than the average population, which may account for the high rate of private diagnoses. For families who cannot afford this privately funded route, a dyslexia diagnosis may be further delayed or not realised. This inequity in diagnosis was highlighted by Knight and Crick's (2021) findings that higher income and SES predicted dyslexia diagnosis.

Another barrier to diagnosis was a child's age, ranked as the second most important barrier because of the 'wait and see' approach many schools take. There was wide variation in the length of diagnosis reported by parents (1 month to 6 years), but a longer (>2 years) and more arduous process was more commonly experienced. Better training in schools around dyslexia, to avoid this approach, was ranked as the second most important solution to removing barriers to diagnosis. Again this finding mirrored the BDA report, which found a major barrier to diagnosis identified by parents was that their child had to be 'at least two years behind their peers' (BDA, 2019b). Early

identification is key as evidence has found that earlier intervention helps to facilitate more successful outcomes (Y. Griffiths & Stuart, 2013; Snowling & Hulme, 2011).

Ross (2019) suggests that schools act as a gateway to support and therefore need to communicate with parents to facilitate a cohesive team between school and parents. However, all parents in this study 'always' (72.41%) or 'frequently' provided support to their child, whereas only 30% of the panel said that teachers 'always' provided support. This highlights the lack of cohesiveness between school and home and the increased burden on parents to provide support that schools are failing to offer. The Human Cost of Dyslexia Report (BDA, 2019a) found that 95% of parents felt they lacked the skills and knowledge to support their children and 77% stated they felt exhausted with dealing with their child's dyslexia. This pressure, which can be found from feeling unequipped or overloaded among many reasons, has been found to lead to increased tensions and worries within families (Knight, 2018).

The parents in our study were also concerned about the emotional toll of dyslexia for their children, highlighting emotional support as important for their child. This echoes previous literature on parents' dissatisfaction with school provision and worries about how this may negatively affect their child's confidence (BDA, 2019a). Recent literature highlights the importance of considering the mental health of young people with dyslexia and how support and the label of dyslexia is framed (Reid & Mackay, 2022). Young people with undiagnosed dyslexia may be particularly vulnerable to unhelpful coping responses, negative self-talk and increased distress (Morgan & Sideridis, 2013), underlining the need for a systematic diagnosis process and proficient support.

'Dyslexia Friendly' schools is an initiative developed by the BDA to give accreditation to schools that made significant efforts to facilitate the learning of children with dyslexia (BDA, 2017). To gain this accreditation schools must demonstrate evidence of teacher education as well as the provision of evidence-based interventions and inclusive classrooms (Maxwell, 2019). The Rose Report (2009) found that a fifth of authorities had gained this accreditation, but this survey along with subsequent reports (BDA, 2019a; DYT, 2020) seems to signal that major tenants of this scheme are still found to be lacking in many schools. The Human Cost of Dyslexia Report (BDA, 2019a) also recommends that schools should invest in resources and training to meet this Dyslexia Friendly standard. An important focus for future educational policy is the enforcement of this accreditation across schools in the United Kingdom as it encapsulates many of the areas highlighted by parents as in need of improvement, from training to communication.

## 5.1 | Study strength and limitations

High group agreement was achieved on solutions to removing barriers to diagnosis, with only one of the eight statements not achieving group consensus. When parents were asked to rate the helpfulness of the support offered to children, there was group consensus on the most and least helpful factors. Identifying the greatest barriers to support was an area with high levels of consensus for all four generated themes. The speed of analysis and distribution of iterations also meant that little time elapsed between each round, which encouraged participation and resulted in good size sample at the final round.

A limitation of this study is the potential lack of representativeness of the parents who took part. While there was a variation in social economic background maintained throughout the study (our panel included families representing the bottom 20% of the deprivation index), the average IMD decile score of the panel for each round remained around 7. This score indicates, on average, that the panel was more economically advantaged than the general population, which should be considered when applying the findings to a variety of contexts. This was, however, difficult to avoid due to the inequity prevalent in the diagnosis of dyslexia in the United Kingdom (Knight & Crick, 2021). Increased equity in access to diagnosis and support for dyslexia should be a focus in future policy. Future research should also ensure representativeness in the perspectives of families going through the diagnostic process, with efforts to ensure seldom-heard voices are represented, particularly due to the amplified impact dyslexia can have on more disadvantaged children (Macdonald & Deacon, 2019).

The survey also failed to reach consensus on the rankings for a items, as a fourth round could have enabled more clarification on rankings, but this was beyond the scope of the current study due to time constraints. Of the 27 themes generated, 16 reached consensus, with a further 4 approaching consensus (68% group agreement). Barriers to diagnosis received the lowest level of consensus, with only the barriers deemed the least significant gaining consensus. This could be explained by the large variation in the experience of diagnosis. The diagnosis process ranged from a month to several years and therefore the barriers faced, and those that parents found the most substantial, are potentially extremely varied.

## 6 | CONCLUSION

This research employed a well-established methodology to gain an in-depth insight into the issues faced by families with the management of dyslexia and the ways they could be overcome. The consensus reached on the most important factors in dyslexia management signifies those most urgently in need of reform from the perspective of parents in the panel, facilitating recommendations for educational policy most important to the families affected.

This Delphi study identified that, from the panel's perspective, the current system for identifying and supporting children with dyslexia requires major improvement. While these findings cannot be generalised to all parent's experience of the dyslexia diagnosis procedure, they offer a valuable insight into the lived experience of the process. The Rose Report (Rose, 2009) and other major subsequent reports (BDA, 2019a, 2019b) identified overarching issues with dyslexia management in the United Kingdom. These reports recommended improving overall knowledge of dyslexia in mainstream teaching, access to a dyslexia specialist and the development of a system that can help identify and subsequently provide quality provision for children with dyslexia (British Dyslexia Association [BDA], 2019a, 2019b; Rose, 2009).

Despite efforts to address systemic issues, with SEN reforms (Children and Families Act, 2014) and further pledges for increasing funding for schools and training (HM Government, 2022) parents in this study still highlighted lack of funding as a major barrier to dyslexia diagnosis and support. Furthermore, the issues around teacher training and school support highlighted by the parents in this report support previous findings that insufficient training is an ongoing issue. The funding and reforms into SEN and dyslexia particularly, while well-intentioned, have not yet led to better outcomes for children with dyslexia. The lack of cohesiveness and consistency in the system and the lack of guidance provided to local authorities means that the system is still disjointed.

The panel of parents in this study highlight that the experience of gaining a diagnosis and accessing further support for their child's dyslexia is still very challenging. Parental voices add an important dimension to inform changes that need to be made. Their experiences, along with expert opinion and the experience of educational providers, are needed to help inform the development of a clear and structured framework for local authorities to use government funding sustainably and effectively. In turn, this should help to create diagnostic systems and support that are easier to access, for both families and schools, and consistently provided.

### CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study may be available on request but due to the personal nature of data they not publicly available.

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## ENDNOTES

- <sup>1</sup> Individual Education Plan is a school-based document that outlines a teaching and learning plan, outlining and identifying areas a child need support. It acts to inform teachers and anyone working with a child of their specific learning needs.
- <sup>2</sup> SENDCO (Special Educational Needs and Disabilities Coordinator) is a qualified teacher who has received extra training around SEND. Their job is to arrange extra support for children and young people with SEND in school.

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**How to cite this article:** Harding, S., Chauhan-Sims, M., Oxley, E., & Nash, H. M. (2023). A Delphi study exploring the barriers to dyslexia diagnosis and support: A parent's perspective. *Dyslexia*, 1–17. <https://doi.org/10.1002/dys.1743>