



# “I struggle at times to see her struggle”: Mothers' perspectives on dyslexia-related school struggles and the inter-connected nature of mother and child well-being

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## Funding information

National Health and Medical Research Council, Grant/Award Number: Investigator Grant 1173043

**Introduction:** Parents of children with dyslexia may be at elevated risk for parenting stress and mental health concerns. Our aim was to explore the emotional experience of growing up with dyslexia in Australia from parents' perspectives. In so doing, we also developed an understanding of parents' own mental health and support needs informed by their lived experience.

**Methodology:** Seventeen interviews with mothers of children (9–14 years; 16 with a diagnosis of dyslexia) were analysed using Braun and Clarke's reflexive thematic analysis approach.

**Analysis:** Five themes were developed to address our aim: Theme 1: Years in the wilderness: Life before diagnosis; 2: “I struggle at times to see her struggle”; 3. School struggles: Advocating for our children and managing distress; 4. “It's a full-time job” and a “long slog”; 5: Care for the carer: Social support and coping strategies.

**Conclusions:** Our analysis suggests that mothers of children with dyslexia may be at elevated risk for mental health concerns. Specifically, chronic worry and stress, secondary distress, challenges to parenting self-efficacy, and lack of

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support and understanding (feeling isolated) were highlighted as plausible risk factors. Mothers described coping strategies at the community level (e.g., school connectedness) and at the individual level (e.g., “acceptance”) as protective.

#### KEYWORDS

dyslexia, mental health, parent support, parenting stress

#### Practitioner points

- The language of neurodiversity and a strengths-based approach is a useful framework and reflects parents' own perspectives
- The emotional support needs of parents are important to consider in addition to those of the children
- Schools and teachers can promote family-school connection

Dyslexia is “characterised by difficulties with accurate and fluent word reading, poor spelling and decoding abilities that do not progress as expected with the provision of well-intentioned and targeted intervention” (Dyslexia SPELD Foundation, 2022). The dominant aetiological account of dyslexia is that it is associated with difficulties with the ability to represent, store or retrieve speech sounds, which can present challenges when learning to associate those sounds with their corresponding letters (Castles, McLean, & McArthur, 2010). These difficulties are based on neurocognitive differences that are highly heritable (Brimo et al., 2021); persistent across the lifespan (Maughan, Rutter, & Yule, 2020); and frequently associated with language processing (Snowling & Melby-Lervåg, 2016); as well as executive functioning (Loneragan et al., 2019) and sensory processing differences/difficulties consistent with other forms of neurodevelopmental difference (Brimo et al., 2021). The Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-5) has a category for dyslexia within the Specific Learning Disorders (SLDs), which also includes dysgraphia (difficulties with writing) and dyscalculia (difficulties with maths), all of which appear under the umbrella of Neurodevelopmental Disorders (American Psychiatric Association, 2013).

If diagnosed, Australian children with dyslexia can receive educational accommodations such as extra time to complete tests (Dyslexia SPELD Foundation, 2022). However, many children with dyslexia remain unidentified. It may be that they employ compensatory cognitive mechanisms to read, reading at what teachers/parents consider to be age-appropriate levels albeit with more cognitive effort invisible to an outside observer (Livingston & Happé, 2017). Furthermore, families in Australia face barriers to diagnosis, such as financial cost, and needing to demonstrate diagnostic exclusionary criteria such as whether their child has received adequate educational opportunity to learn to read. For these and other reasons, it is difficult to accurately assess prevalence rates for dyslexia. Nevertheless, it is estimated that up to 10% of children experience severe and persistent word-reading difficulties consistent with dyslexia (Brimo et al., 2021; Hulme & Snowling, 2013).

Australian researchers using longitudinal designs and large population-based samples find that early reading difficulties are a unique risk factor for long-term educational and occupational outcomes, such as secondary school completion (Smart et al., 2017), consistent with findings from other parts of the world (see for example, Maughan et al., 2020). Researchers also find that children with reading difficulties, including dyslexia, are at elevated risk for

mental health concerns, both internalizing (e.g., anxiety) and externalizing (e.g., aggression) symptoms (Francis, Caruana, Hudson, & McArthur, 2019; Russell, Ryder, Norwich, & Ford, 2015). These concerns appear (at least in terms of anxiety) to have environmental rather than genetic causes (Whitehouse, Spector, & Cherkas, 2009), and an onset in the early years of schooling (Jordan & Dyer, 2017).

Indeed, children with dyslexia often struggle at school and many report feeling stressed, sad, and frustrated (Leitão et al., 2017; Morgan, 2012). School-related stressors have been linked to poor self-esteem, anxiety, and school refusal among children with reading difficulties (Claessen et al., 2020; Riddick, 2010). In terms of parenting, cumulative evidence suggests that parents of children with dyslexia may be at elevated risk of experiencing parenting stress and distress (isolation and unhappiness in the parenting role; Antshel & Joseph, 2006; Bonifacci, Montuschi, Lami, & Snowling, 2013; Carotenuto et al., 2017; Delaney, 2017; Matteucci, Scalone, Tomasetto, Cavrini, & Selleri, 2019; Woodcock, 2020). However, there are mixed results in this field, especially in terms of the nature and source of parenting stress (i.e., child and/or parent factors) and risk for mental health concerns such as anxiety (see, for example, Bonifacci, Massi, Pignataro, Zocco, & Chiodo, 2019; Bonifacci et al., 2013; Matteucci et al., 2019). Mixed results such as these highlight the likelihood of risk and protective factors influencing parents' well-being in the context of dyslexia.

## 1 | RATIONALE AND AIM FOR THE CURRENT STUDY

Given the identified links between parents' mental health and children's well-being broadly (Reupert & Maybery, 2016), and the particular importance that parental support appears to have for the self-esteem and mental health of children with dyslexia specifically (Singer, 2007; Terras, Thomson, & Minnis, 2009), further research exploring the emotional experience of parenting children with dyslexia is needed. With few notable exceptions (Delaney, 2017; Earey, 2013; Woodcock, 2020), qualitative research in this field has focused on the well-being of children rather than parents (see for example, Leitão et al., 2017). Furthermore, interventions to support the mental health of children with dyslexia (see, for example, Boyes et al., 2020) have focused on within-child rather than whole family factors and may therefore need to be complemented with parenting support/intervention. Our aim was to explore the emotional experience of growing up with dyslexia in Australia from parents' perspectives. In so doing, we also developed an understanding of parents' own mental health and support needs informed by their lived experience.

## 2 | METHODOLOGY

Braun and Clarke's (2006, 2013, 2022) reflexive thematic analysis approach guided our analysis. Employing this approach, researchers develop themes from patterned responses across the dataset. We selected this approach as it is theoretically flexible, well-suited to exploring people's lived experiences, and promotes an in-depth and interpretative analysis of data allowing semantic and latent (underlying meanings) coding (Braun & Clarke, 2019, 2022). We anticipated that parents may speak indirectly rather than directly about their mental health. Therefore, an approach that encourages latent-level coding and an interpretive analysis would be needed to address our research aim. Our analysis was situated within a critical realism/contextualism framework, which acknowledges the reality of mothers' experiences as perspectives, framed by their own sociocultural context (Braun & Clarke, 2022).

## 3 | RESEARCHER POSITIONALITY

Our research team includes people with lived experience of neurodiversity and clinical experience working with families of children with a range of neuro-developmental differences. The first author situates her research within the

neurodiversity paradigm that conceptualizes neurodevelopmental “disorders” such as dyslexia and autism as brain-based “differences” to be accepted rather than “disorders” to be “cured” or “fixed” (Baron-Cohen, 2017; den Houting, 2019; Singer, 1998). Taking this perspective would suggest that children with dyslexia have a right to be given opportunities to learn in ways that match their strengths (environmental changes) in addition to being provided with evidence-based reading intervention to improve their reading if desired (within-child changes). Although used in scientific and popular literature in the autism field (for a review see, Pellicano & den Houting, 2021), to the best of our knowledge, our research (see also, Wilmot, Pizzey, Leitão, Hasking, & Boyes, *in press*) is the first to take a neurodiversity lens to a study of the mental health and well-being of parents and children with dyslexia.

## 4 | MATERIALS

Interviews were guided by a semi-structured interview protocol consisting of open-ended questions (see Data S1 for a list of questions included in the interview guide). This approach empowered participants to shape the focus and direction of their interview whilst staying within the parameters of the research topic. In addition to the interview, parents completed a survey that provided background (e.g., child diagnosis) information. We also interviewed the children in a separate interview (see the companion article, Wilmot et al., *in press*).

Interview questions focused on child and parent well-being (i.e., emotional experience, coping, support) and included a question about mothers' (and child) feelings about the transition from primary to secondary school. The protocol was piloted on one mother of a child with dyslexia, an acquaintance of the first author, before recruitment for the study commenced. The pilot went well and so the protocol remained unchanged and the data from the pilot interview were retained.

## 5 | PARTICIPANTS

The study was open to all parents or carers of children with recognized reading difficulties aged 10–13 years. Only mothers volunteered. We chose this age range as we were interested in exploring the experiences of families during the transition from primary to secondary school. In Western Australia, the last year of primary school is generally year 6, when children are approximately 11 years old. We later extended the age range to 9–14 years to accommodate interested families.

Seventeen mothers of children (aged 9–14 years, 7 girls and 10 boys) with a reading difficulties diagnosis participated. Nine children had at least one other diagnosis (see Table 1). All children were attending mainstream schools and the majority (15 children) were in primary school. Three mothers lived in single-parent households. Most families had between 2 and 4 children and some siblings also had learning and/or attentional difficulties. Of the 17 participating families, 16 lived in Perth, West Australia and 1 in Sydney, New South Wales.

## 6 | PROCEDURE

The study was approved by Curtin Human Research Ethics Committee (HRE2021-0084) in early 2021. Interviews were conducted between May and December 2021. Participants were recruited through speech pathologists, a tutoring service, social media and word of mouth. Interviews took approximately 45 min and were audio-recorded. Two interviews occurred online due to distance or Coronavirus safety requirements. The remainder took place face to face at Curtin University or in participants' own homes, depending on participant preference. Participants were fully informed about the aims and nature of the study before providing written consent. All participants received a \$15 gift voucher to thank them for their participation.

**TABLE 1** Child diagnostic details.

Background variable	Number of children	Frequency (%)
Reading difficulties diagnosis		
Dyslexia	16	94.1
Other: "Phonological processing difficulties"	1	5.9
When was dyslexia diagnosed (school year)?		
No dyslexia diagnosis	1	5.9
Year 2	5	29.4
Year 3	5	29.4
Year 4	1	5.9
Year 5	2	11.8
Year 6	3	17.6
Additional diagnosis		
No additional diagnosis	8	47.1
ADHD/ADD	5	29.4
ASD	1	5.9
Additional SLD (dysgraphia and/or dyscalculia)	4	23.5
Auditory processing difficulties	1	5.9
Processing and working memory difficulties	1	5.9

Abbreviations: ADHD, attention deficit hyperactivity disorder; ADD, attention deficit disorder; ASD, autism spectrum disorder; SLD, specific learning disorder.

Reflexivity during the 8-month interview process was promoted through reflexive journaling and regular discussions between the first and second authors. Familiarization with the data (Phase 1 of Braun and Clarke's (2022) 6-phase approach) began during transcription and coding. All interviews were transcribed by the first author, checked against audio files by the second author, and returned to the first author for finalizing. A pseudonym was used to de-identify the transcripts. Furthermore, details that could cumulatively identify a participant were replaced with a generic descriptor or the pseudonym removed.

Our analysis was explorative, so coding was inductive and occurred at both a semantic (surface meaning) and latent (underlying meaning) level (Phase 2). The first author led this process, reading and re-reading the transcripts, applying code labels, and developing an initial set of themes (Phase 3). Input from the whole research team was sought during a recursive process of reviewing, refining, defining, naming themes (Phases 4 and 5) and report-writing (Phase 6). We provided mothers with a research summary and an invitation to provide feedback before finalizing the report.

## 7 | ANALYSIS

Our analysis developed five themes to address the research aim. Theme 1: Years in the wilderness: Life before diagnosis explores mothers' doubts and stress (and later regret) during the years before their child's diagnosis when gut feelings about something being "different" about their child were often assuaged by teachers in addition to responses to diagnosis. Theme 2: "I struggle at times to see her struggle" explores mothers' worries (about their child's future and present situation) and secondary distress (e.g., "heartbreak") in relation to their child's school-related struggles. Theme 3: School struggles: Advocating for our children and managing distress explores mothers' advocacy

role and stress/distress in response to their child's school struggles (e.g., homework conflicts). Theme 4: "It's a full-time job" and a "long slog" explores workload issues and family dynamics in the context of providing support. Theme 5: Care for the carer: Social support and coping strategies explores mothers' perspectives on social support, coping and views about dyslexia as misunderstood.

Each theme was illustrated with data extracts. Editing of the data consisted of adding punctuation and removing some utterances (e.g., um) to improve readability. Further editing such as the removal of irrelevant details, or providing context, interviewer comments, or combining data from the same participant from different time points is indicated by [].

## 7.1 | Theme 1: Years in the wilderness: Life before diagnosis

Several parents described the long journey to receiving a dyslexia diagnosis (Martha: "it took a couple of years it was a bit of a process"). Mothers discussed barriers to diagnosis, such as cost, long waiting lists and teachers/others who assured them that all was well, or told them just to wait, despite their gut feeling that something was different about their child. This pre-diagnosis stage appeared to be a period of stress and self-doubt for many mothers. For instance:

Tess: [describing the years before diagnosis] It seems to be like never ending stress or concern about "have we got it right" "what is it?" you know[] it's gone down the road of testing and more things and then they have realised at last he's dyslexic.

Relatedly, several parents expressed regret that they had not pursued an earlier diagnosis for their child and, in retrospect, a sense of misplaced trust and/or anger and frustration at early childhood teachers who had disbelieved them or put them off course. For instance, Mary described a difficult journey to her son's (Year 6) dyslexia diagnosis:

I wish I'd trusted my instincts a bit earlier and got him diagnosed a bit earlier, not that I think it would have had a different outcome, but I think he might have understood some of his frustrations in school earlier than year 6 because I was thinking about it in 3 and 4 and talking to the teachers and they were saying, "yeah he's fine he's fine" and being ignorant at that point I kind of believed them [then later talking about getting the diagnosis] I did it myself, I went and got some information from the [service provider] and I went and got a literacy profile done with them and then went to see a psych and yeah got it all done but the teachers were still saying, "yeah, there's nothing wrong with him."

There was a sense that parents needed to persevere to get their child diagnosed. Generally speaking, receiving the diagnosis helped mothers to understand and support their child better and was frequently described as a relief. Nevertheless, even after diagnosis, some expressed periods of doubt and worry about whether they were making the right choices for their child. Several discussed how difficult it is to find information about how best to support children with dyslexia and how they have mostly done this information gathering alone and unsupported. Relatedly, most expressed how even after diagnosis they still face ignorance and misunderstanding from others about what dyslexia entails. For example, Grace expressed frustration that she needed to educate her child's teachers about dyslexia, which she did not perceive to be her "job."

## 7.2 | Theme 2: "I struggle at times to see her struggle"

Rose: If I could just wave my magic wand that [referring to her daughter's dyslexia] would be what I'd fix, cos it's the world, if you can't read you can't do anything, you cannot apply for a job, you can't, you know it's hard, it's hard.

The mothers we spoke to varied in the extent to which they perceived society to exclude people with learning challenges such as dyslexia. Some, like Rose above, expressed a belief that there are many restrictions (“if you can’t read you can’t do anything”) whereas others expressed more optimism about inclusivity in the world beyond school. Nevertheless, most, but not all, acknowledged a degree of permanence about their child’s dyslexia. For Cherie, this meant preparing her son for an adult life in a society that is not always accommodating. When asked about how her son’s reading difficulties affected her and her son emotionally, she responded:

I do feel like sorry for him sometimes that he has to go through these struggles and things like that so that’s an emotional thing for us that I do feel, we try our best but he also needs to do his own thing cos he’s got to deal with this for the rest of his life even when we get older, he’s going to have to find that resilience to keep going.

Whilst many mothers expressed concern for their child’s future, as above, many also worried about more immediate concerns such as the impact of everyday classroom experiences on their child’s self-esteem and mental health. For instance, Cassie remarked: “It absolutely keeps me up at night, worried most of all about his self-confidence.” Similarly, Grace, who has more than one child with dyslexia, expressed worry for the future and present situation:

I think worry, worry for them in the future. Even simple things like you think about, you think about them getting their licence, are they going to be able to read the tests enough to [] and also, I worry about I guess at school [] he came home from school the other day and so upset because he heard the child before him read and then he had to read so he can see the gap and then you can see the gap and then obviously we get an IEP [Individual Education Plan] and we can see the gap and so just worry.

Moving to high school was a worry for mothers. Many expressed concerns regarding the impact that the larger environment (seven teachers rather than one) may have on their ability to advocate for their child at school. For instance, Molly, whose daughter had more than one diagnosed learning difficulty (including dyslexia) said:

I struggle at times to see her struggle and so I worry about, you know, how she will progress and how school will be for her particularly that she’s had, primary school has just been one teacher, one classroom, I can talk to the classroom teacher about interventions and accommodations, you know, multiple times go back to them and get support from them, or not, but there’s only one person to deal with.

Some worried about whether their child would be adequately supported, and many expressed concerns about an increase in their child’s workload/homework and the impact that will have on the whole family. For instance:

Cassie: I am terrified for him and I’m terrified for us because so much of the, so much of the dis-organisation or the work that does not get done at school or whatever it may be, comes home and gets dumped on the family table and at the moment I have no idea how big that mountain might be. I do not know what I’m up against, but I know that I’m not going into it [talking about the move from primary to secondary school] feeling especially confident.

In addition to worry, our analysis suggests that mothers experienced secondary distress. As Molly put it, “I struggle sometimes to see her struggle” or as Cheryl, below, described it, “it’s hard for him, it’s hard for us.” In other words, this suggests that the struggles their children face are not theirs alone but the whole family’s struggle. Secondary distress was often expressed as sadness and/or heartbreak, and there was often a sense that this distress prompted parental protectiveness. For instance:

Cheryl: It's hard, it's hard for him, it's hard for us, it's also a bit disheartening, because of, well you can see the frustration in [name of child] especially when he's trying to read and how it has caused him to have downfalls in other areas of his education [] I feel for him because he, he wants to be like everyone else but he just struggles [] it breaks my heart being so young and having these struggles [] it just makes me more involved to not let him ever feel like that because even as an adult there's nothing worse and children should not be suffering like that but they do.

### 7.3 | Theme 3: School struggles: Advocating for our children and managing distress

Like Cheryl, several mothers expressed feeling “heartbroken”, protective of their child, and/or frustrated and angry if their child is not being treated justly (e.g., being made to stay in at lunchtime to finish work). For instance, in response to her son's (and her own) distress, Grace expressed anger towards her son's school: “I was really quite angry and really quite, you know, cos we were dealing with distress when he came home, he was upset when he came, he couldn't do it [referring to unadjusted school-work her son had been given].”

Our analysis suggests that mothers perceived school, with its focus on reading and writing, to be an environment that highlighted their child's difficulties and minimized their strengths. Some, like Rose, had reached the conclusion that systemic issues with the school system (e.g., lack of teacher training) contributed to their children's struggles:

It's very frustrating for me because, you know, most teachers do not get it and they do not have the education to educate children who aren't the cookie cutter and it's very, very difficult, it's, I'd say that it's probably been the hardest part of parenting for me [at another point in the interview] the Australian curriculum it just does not cater to children who might not be average.

Consistent with previous research (see for example, Delaney, 2017; Leitão et al., 2017; Woodcock, 2020), many mothers in our study felt they had to fight, and continue to fight, to have their child's needs recognized and/or met at school; taking on the role of “pushy parent” (Christy) even when they did not really feel comfortable doing so. For instance:

Christy: I've actually got to be my child's advocate. I have to be that parent now that goes “well what are you doing for my child?” “Why is he doing this subject when he can't do that? he should be doing something else” Yeah, and that's a change, that's a hard shift for me, to be that mother [laughs].

There was a sense that mothers needed to maintain their watch regarding the way their children were being treated at school so that things did not get forgotten: “if you don't advocate for your child, advocate meaning being constantly on their back about whatever and I'm not even very good at it, you get nothing, nothing (Rose)”. Several mothers provided examples of negative events occurring when they did not keep up their watch at school, such as missing out on group interventions that may have assisted their child's learning.

Mothers expressed varying degrees of success with their advocacy. For example, Cassie reported feeling like she had to fight to be heard:

It's challenging to go up against a school when, as a parent, I know that something is not right and I'm not going to be able to fix it without their partnership, but they may or may not see it the way I see it or be interested or able to help [later in the conversation] school is driving the process and I am not allowed to be a partner in that, I'm not welcome, I'm generally uninformed, I have to really fight to be heard with things.

Similarly, at her son's school, another mother expressed how she did not feel listened to:

I used to call the meeting, like when we'd do like his IEP [Individual Education Plan] meetings at school, his “I need a drink afterwards” meetings cos I'd just feel like I was banging my head against the wall a lot of the time.



In contrast, some mothers reported having excellent relationships with their children's school based on frequent and open communication and their concerns/recommendations listened to and acted upon. From our analysis, this sense of school connectedness (feeling included, supported and respected at school; Libbey, 2004) was an important protective factor for both mothers' and children's well-being (see also, Wilmot et al., *in press*). For example, Karen had moved her son to a new school that focused on “not just academic” but also “emotional well-being.” She expressed how she could relax her watch a little, trusting her child's new school, because she felt listened to and valued, which lessened her worry:

I've just relaxed, still get worried but he'll get there, he'll get, we'll all get there [] the school, their communications are a lot better than where we were previously and the reassurance as well cos I did also say, “I hope I'm not coming across as annoying by asking 50 million questions all the time” but he said “oh no that's what our job is, if you're happy then the kids are happy.”

When things are not going well at school, when the pace of the learning is too fast, when the workload is building and when children have been embarrassed or not treated fairly, mothers discussed how their children release their emotions at home. Managing meltdowns, school refusal and homework resistance was described by many as a particularly challenging aspect of their parenting; but not one which is the child's “fault” (Pru) but rather was perceived as their child's emotional response to school as a poor “person–environment fit” (Mandy, 2019, p. 1880). For instance, Tess explained how her son's school frustrations spilled out into the home environment and how they manage it as a family:

Mostly his behaviour is one of the things that we have found really difficult as a family to deal with, he's very angry, and then when he went to school he was sort of OK to go to school so that was good but then it started with “I hate school” [] “I don't wanna go to school” [later in the interview] We just try and explain to him that it's ok to feel frustrated but you cannot be mean to other people because he was really like lashing out at his [siblings] and like us and just really screaming and yelling and just quite badly behaved and we just explain like we understand that school is hard for you and it's frustrating but you can't be mean to other people.

Many mothers discussed homework conflicts as a particular cause of stress within families: For instance, Pru, whose child has ADHD in addition to dyslexia, described homework as a “real challenge for the whole house”, which “puts a lot of pressure on us all.” Relatedly, Mary expressed her belief that schools ought to re-think homework for children who have learning difficulties: a change at an environment level (adjusting homework demands) rather than expecting children with dyslexia (and their mothers) to just cope.

Homework conflicts, when they occur, can also contribute to mothers' distress. For instance:

Cheryl: Just the arguments that it would cause because he doesn't want to do it [referring to after school reading homework] it sort of flows into the mood of the rest of the night [] I don't like to shout and I don't like to be like that and nor does his dad but it ends up being like that and it's, it's sad because we don't want it to be like that, and cos that can, that can just ruin the whole evening, so yeah, that's pretty much how it gets to so, with just the arguments of trying to read and I guess for me I just feel disheartened and a bit sad that it is so, it is such a struggle.

## 7.4 | Theme 4: It is a “full-time job” and a “long slog”

Cassie [talking about her journey with her son's reading difficulties]: There has been no silver bullet [] there has not been a specific teaching style or a specific action plan or a specific anything that kind of cracks the nut. It's just a kind of a long slog.

During our conversations, many mothers discussed feeling under pressure, in terms of time, energy and financially, to support their child. For instance, Christy remarked: “it's just finding the time, finding the time to fit his homework in, and courses and stuff, and the expense, the expense of it all, and there's no financial help.” One mother described how she is often up late at night to support her child with homework and organization. Another told us how she had reduced the number of her paid workdays so she had time to manage her child's appointments and supports. One mother who had several children with learning challenges described the cumulative workload and financial consequences (e.g., needing to save money to get other children diagnosed) and another expressed that supporting them all was a “full-time job.”

Parents who had other children without learning difficulties had other concerns, such as managing sibling dynamics. For instance:

Cassie: It's always in the back of my mind and when he needs extra help and extra tutoring and extra driving around, I have to mentally kind of figure out how to keep the equilibrium [laughs] and keep the other kids also engaged and feeling like they are being paid attention to.

Most families reported having accessed out-of-school support for their child's reading difficulties, in particular, tutoring and speech-language therapy. Whilst this was valued by parents, it came at a cost (time and money). Many mothers expressed disappointment and frustration that schools are not funded to provide support for children with dyslexia, leaving them to manage the shortfall. For example, Trudy referred to this as her “main gripe” about raising a child with dyslexia.

We found mothers' perspectives of their child's support at school to be highly variable. For example, one mother reported that her child received daily support with a reading specialist whilst another that support at school was infrequent. Generally, when there is less support at school, parents' workload, in terms of providing academic and organizational support to their children increased, as did the potential for homework conflicts and parental stress and distress. Relatedly, mothers expressed concern for families who were not as well-resourced (time, money and skills) as them. For instance, Michelle, who had received a relatively early dyslexia diagnosis for her child (Year 2) offered her perspective on the value of timely identification and parental involvement to support children's mental health:

I think unless you go out and kind of do your own research and advocate for your kid they can get left behind. So, I think it's quite important for parents if they have got a gut feeling or if their kid is struggling then to get down to the what is actually going on cos the longer you leave it their confidence will not be great and then going into high school if they are still struggling and they can't read, that's probably when the mental health and the difficulties get more extreme []. Lots of parents I speak to don't know where to start to get help or where to look.

## 7.5 | Theme 5: Care for the carer: Social support and coping strategies

Feeling isolated and unsupported, both before and after their child's diagnosis, was a common thread to the conversations we had with mothers. Many mothers expressed that they had limited or no support in their parenting role outside of the family, except perhaps from other parents of children with learning difficulties who “understand”. For instance:

Cassie [when asked about her own support]: That list is very short, possibly non-existent, maybe the mum of this buddy of his [who also has reading difficulties] at school is a nice person to sort of chat

with and vent too, and we are able to be mutually supportive of one another, but otherwise, I can't, I can't say that, that I know where to go for support or encouragement [later in the conversation] I think if you do not have a child who is living through this, it's very hard to understand.

Like Cassie, several mothers linked isolation to their perception of dyslexia as poorly understood by people without lived experience. For instance, Christy expressed her opinion that dyslexia is typically regarded as simply an issue with learning and that the socio-emotional aspect is neither considered nor supported. Similarly, Tess described raising a child with dyslexia as “all encompassing”, more than just reading “that's what people don't really, like friends and people like that, they're he's dyslexic and so he can't really read very well or write very well and I'm like well it's everything that goes with that.” Karen, on the other hand, described feeling isolated due to perceptions of dyslexia-related stigma and living in a society that celebrates ability:

It is quite isolating I think, from a parent, like, from my own support network, because I know it's out there but parents just don't shout it from the rooftops I suppose, that my kids are struggling at school, it's not something that we talk about when we are waiting for school pick up and things like that, so it's more about all the achievements, that the kids are achieving that we talk about, we don't talk about the struggles really, so that's isolating.

Some mothers described certain health professionals and/or teachers as reassuring and supportive of both them and their child; highlighting that parents as well as children benefit from emotional support.

In addition to social support, mothers discussed a range of cognitive and/or behavioural strategies that helped them cope. For instance, Karen described addressing her “heartbreak” by focusing on her son's strengths rather than ruminating on his challenges:

He has said to me “mum how much more can I keep trying and not get anywhere?” and I was like, that was like my “oh this is heartbreaking” and then that's when I thought, you know what, let us not just focus on academic let us try other things and then the [name of sport] and he sees his hard work pay off in a shorter time.

Judy took hope from her perception of a lessening of social stigma related to learning difficulties and her focus on mental health rather than grades: “I'm big on the emotional support [] I'd rather her be happy and fail than be getting As but then be miserable.” Whereas Kate felt optimistic about her daughter's future because of her work ethic and focused on that as well as celebrating how far she has come with her learning:

I've said to her “you'll do well with whatever you choose to do this is not going to hold you back, this is just something you'll just have to work at” and fortunately she is that sort of personality that she just works her little socks off, she really does.

Several mothers discussed the importance of acceptance, both in terms of acknowledging dyslexia as a positive aspect of their child's identity (akin to the definition of “autism acceptance”; Cage, Di Monaco, & Newell, 2017) and in terms of “letting go” by adjusting parental expectations. For instance:

Mary: The other thing as a parent, I've had to learn to let things go, and it's OK [] if he just gets through and he passes, actually, that's fine, that's a good thing, because he's still doing what he's trying to do, he still wants to do it but you just have to accept that trying is enough.

Whereas Michelle identified how staying positive herself and having a non-stigmatizing attitude to dyslexia was crucial for her own and her daughter's mental health:

I think not being embarrassed about it [] that keeps your kid's mental health good as well, cos if you think it's a bad thing and stress about it she will pick that up and be stressed herself yeah, so just try to look on the bright side [laughs] I think [Int: yeah] yeah, and just keep her positive and willing to try.

## 8 | CONCLUDING COMMENTS

Our aim was to explore the emotional experience of growing up with dyslexia in Australia from parents' perspectives. In so doing, we also developed an understanding of parents' own mental health and support needs informed by their lived experience. Our analysis took a neurodiversity perspective and was guided by Braun and Clarke's reflexive thematic analysis approach (2006, 2013, 2022). This article is a companion piece to another, which focused on children's mental health in the context of dyslexia and included both child and parent perspectives (Wilmot et al., *in press*).

Consistent with findings from research in the broader field of neurodevelopmental differences (see for example, Karande, Kumbhare, Kulkarni, & Shah, 2009; Kütük et al., 2021; Matteucci et al., 2019) but in contrast to the findings of Bonifacci et al. (2013), our analysis suggests that mothers of children with dyslexia may be at elevated risk for mental health concerns both before and after diagnosis. Specifically, chronic worry and stress, secondary distress, challenges to parenting self-efficacy, and lack of support and understanding (feeling isolated) were highlighted and warrant further investigation in relation to their association with parental mental health.

In terms of maternal stress (and distress), our analysis is largely consistent with previous research (see for example, Carotenuto et al., 2017), but provides nuance regarding the nature and source of parenting stress in the context of dyslexia. Specifically, our analysis suggests that mother's stress and distress were related to witnessing (and managing) their children's school-related distress (e.g., meltdowns) and compensating (e.g., homework support), or advocating, for any perceived shortfall in their children's education. Importantly, "difficult" child behaviour was perceived as a response to school as poor "person-environment fit" (e.g., inappropriate curriculum/lack of support) (Mandy, 2019, p. 1880) and not the child's "fault". In keeping with findings from Leitão et al. (2017) in our study, mothers' workloads in terms of being tutor, advocate and mother, whilst also managing potentially challenging family dynamics, was highlighted as a factor of concern. Transition to high school seemed to be a particularly worrying time for mothers. Many described how their (and their child's) concerns were assuaged by school transition programmes; however, there was a sense that a staged transition with an earlier start would benefit families. Future researchers are therefore encouraged to investigate mental health in the context of dyslexia over the transition to secondary school using longitudinal design.

As would be expected based on known levels of co-occurring conditions in developmental dyslexia (see for example, Brimo et al., 2021), many of the children in our research had additional diagnoses, which may account for the socio-emotional difficulties described. Additionally, the age at which children were diagnosed, and the way this facilitated self-understanding and support (or not) was touched upon in our analysis but warrants further exploration. Future research, which specifically interviews parents regarding the road to diagnosis, age of diagnosis, the language used to frame diagnosis, and the impact of this on child and parent well-being, would extend our analysis and that of other researchers (see, for example, Brunswick & Bargary, 2022; Leitão et al., 2017).

In terms of protective factors, our analysis suggests that coping strategies at the community level (e.g., parents' perceptions of school connectedness and support from other parents of children with dyslexia), and at the individual level (e.g., having a neurodiversity mindset characterized by: "acceptance", focusing on strengths and non-stigmatizing attitudes to dyslexia) may be especially important. School connectedness has been linked to children's mental health during the transition from primary to secondary school (Lester, Waters, & Cross, 2013), but appears to be under-explored in the dyslexia field. Similarly under-studied, in comparison to the autism field, is the association between "acceptance" of one's (or one's child's) neurodiversity and the well-being/mental health of neurodiverse individuals and their families (Cage et al., 2017; Crane, Jones, Prosser, Taghrizi, & Pellicano, 2019; Weiss, Cappadocia, MacMullin, Viecili, & Lunskey, 2012). Future researchers are encouraged to investigate these factors in association with mental health in the context of dyslexia.

The results of our study are limited in that all participants, except one, resided in one Australian city. Furthermore, the interviews took place during the Coronavirus pandemic in which Australian families experienced periods of home-schooling/online learning, which is another consideration. Given that isolation was identified as a risk factor for parental well-being, future researchers are encouraged to explore parenting experiences among those living in rural locations and/or those isolated for other reasons (e.g., minority groups) in addition to seeking the views of fathers and siblings. Nevertheless, our analysis has implications for the importance of funding public awareness campaigns (and teacher training) about dyslexia; developing peer support programmes for parents of children with dyslexia; and the importance of whole family (parent in addition to child) mental health programmes, which support parents' advocacy and promote school connectedness.

In summary, our analysis highlighted the interconnected nature of mothers' and children's well-being. Specifically, mothers' stress and distress related to witnessing their child's school struggles, advocating and compensating for shortfalls in their child's education. Perceptions of school connectedness, and a neurodiversity mindset characterized by "acceptance", focusing on strengths and having non-stigmatizing attitudes to dyslexia were highlighted as protective of mother and child well-being. These themes suggest that child mental health programmes should consider a parenting component and support parent advocacy and school connectedness. When mothers feel that they (and their children) are understood, respected and treated fairly at school, whole families benefit.

## ACKNOWLEDGMENT

Open access publishing facilitated by Curtin University, as part of the Wiley - Curtin University agreement via the Council of Australian University Librarians.

## FUNDING INFORMATION

Adrienne Wilmot is supported by An Australian Government Research Training Program scholarship. Mark Boyes is supported by the National Health and Medical Research Council, Australia (Investigator Grant 1173043). Hannah Pizzey was supported by a Curtin Faculty of Health Sciences Summer Scholarship.

## CONFLICT OF INTEREST STATEMENT

No conflicts to declare.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

## ETHICS STATEMENT

Curtin University Human Research Ethics Committee (HREC) has approved this study (HRE2021-0084).

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## SUPPORTING INFORMATION

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**How to cite this article:** Wilmot, A., Pizzey, H., Leitão, S., Hasking, P., & Boyes, M. (2023). “I struggle at times to see her struggle”: Mothers' perspectives on dyslexia-related school struggles and the inter-connected nature of mother and child well-being. *Dyslexia*, 29(2), 136–150. <https://doi.org/10.1002/dys.1733>