



The human cost of dyslexia

The emotional and psychological impact of poorly supported dyslexia

Report from the All-Party Parliamentary Group for Dyslexia and other SpLDs

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Quotes

“This report is stark reading and shows irrefutably that we need to do more to identify people with dyslexia sooner and support them better to reduce the emotional and mental health issues that are currently too prevalent.”

Sharon Hodgson MP, Chair, APPG for Dyslexia and other SpLDs

“I feel I've failed my child by placing him in the education system that doesn't cater for him.”

Parent's comment in survey for APPG for Dyslexia and other SpLDs

“As a teacher, I'm told to tell parents that you can't test for dyslexia and that parents need to pay privately if they wish. But we, as a school, don't have to follow private assessments. Parents are also told it's not possible to recognise before seven.”

Anonymous testimony from a teacher (all this advice goes against legislation directing schools on how to manage dyslexia)

“The question screaming out for an answer is ‘knowing what we know, and have known for the last 40 years, why are we forcing dyslexic children through an education system that can have a traumatic effect on them, is of little benefit, and can have lifelong emotional repercussions?’”

Pennie Aston, Director, GroOops Dyslexia Aware Counselling

“I was extremely fortunate in my position, to have parents who financially supported me to get the extra support I was never given in school. Yet, I still faced so many struggles, both academically and mentally, which is often a common theme for many dyslexics in the education system today.”

Jo Crawford, MA student at University of Exeter and British Dyslexia Association Ambassador

“The human cost of dyslexia is too high, and we need to change that.”

Helen Boden, CEO, British Dyslexia Association

Executive summary

Between 10 to 15 percent of people have dyslexia. This means that dyslexia is the most common specific learning difference, effecting between 6.6 and 9.9 million people in the UK and between 800,000 and 1.3 million young people in education¹.

Whilst dyslexia is not directly linked to emotional or mental health issues, failing to diagnose dyslexia early, and inadequate support – both academic and emotional – during education and beyond leads often to a short and long term human cost of dyslexia.

Drawing on the work of the All-Party Parliamentary Group (APPG) for Dyslexia and other Specific Learning Difficulties (SpLDs), this report explores the extent of the psychological impact dyslexia is having on people with dyslexia and their families in the UK. This report also makes recommendations on how to improve the provision to directly and indirectly reduce the emotional and mental health issues discussed.

Psychological impact on dyslexic of growing up with dyslexia

- It is not that dyslexia means people are less able to cope with complex emotions than their neurotypical cousins, but that they are having to cope with far more unresolved problems from the past where the focus had been on deficit. Also, few understood the presentations of dyslexia other than a difficulty with reading and writing. The result is that dealing with the emotional repercussions of **dyslexia is dealing with trauma**.²

Impact on family supporting young people with dyslexia

- **95 percent of parents feel they lacked the skills and knowledge** to support their dyslexic child.³
- Nearly half of parents reported that they **spent over £1,000 extra per year because of their child's dyslexia**.⁴
- 58 percent of parents report their children try to avoid discussing their dyslexia, **a staggering 82 percent of parents report their children try to hide**

¹ Based on UK population of 66.4 million and 2018 DfE figures for young people in education, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/719226/Schools_Pupils_and_their_Characteristics_2018_Main_Text.pdf.

² Evidence from the Pennie Aston, Director, GroOops Dyslexia Aware Counselling to APPG for Dyslexia and other SpLDs.

³ Research developed for the APPG for Dyslexia and other SpLDs. Distributed through social media (Facebook, Twitter and LinkedIn). Over 1,300 responses were received. Survey participants were self-selecting and in addition to answering short, closed questions relating to their experiences of dyslexia, they were also able to write open-ended comments giving more detail, in their own words – in excess of 2,500 comments were received. The survey ran between 7 February 2019 and 18 March 2019.

⁴ Research developed for the APPG for Dyslexia and other SpLDs. The survey was distributed through social media (Facebook, Twitter and LinkedIn). Over 1,300 responses were received.

their difficulties relating to dyslexia and 85 percent of parents report their children feel embarrassed by their dyslexia.⁵

Improving public policy to support young people with dyslexia

- The clearest solution lies in the training of specialist dyslexia teachers. Such teachers would be able **to support learners, oversee and direct teaching and support provision, and carry out diagnostic assessments that identify individual needs.**⁶
- Training for classroom teachers has been light touch and focussed on awareness raising and **not training at the specialist level that is required in order to support learners and enable them to access the curriculum** in a way that leads to engagement and longer-term academic success.⁷
- There is currently **no roadmap for how young people’s mental health should be supported**, despite commitments to developing parity between its treatment and that of physical health.⁸
- Parents want accessible information of a good standard. If formal guidelines are put in place, local authorities will have to comply, and **parents will be better informed to support their children.**⁹
- Fragmentation of the SEND support systems under the Children and Families Act 2014 has created confusion for parents and has made the system problematic for non-experts to navigate – schools with multiple LAs in their vicinity are confronted with incoherent paperwork and practices, which **makes implementing appropriate support problematic.**¹⁰

⁵ Research developed for the APPG for Dyslexia and other SpLDs. The survey was distributed through social media (Facebook, Twitter and LinkedIn). Over 1,300 responses were received.

⁶ Evidence from the British Dyslexia Association to APPG for Dyslexia and other SpLDs.

⁷ Evidence from the British Dyslexia Association to APPG for Dyslexia and other SpLDs.

⁸ Committee of Public Accounts, 2018.

⁹ Evidence from the British Dyslexia Association to APPG for Dyslexia and other SpLDs.

¹⁰ Evidence from the British Dyslexia Association to APPG for Dyslexia and other SpLDs.

Sharon Hodgson MP, Chair, APPG for Dyslexia and other SpLDs



During my time chairing this APPG and many years involved with the issues around dyslexia and other SpLDs, I hear time and time again people's stories of how missed or poorly supported dyslexia during education has made them feel stupid, unvalued by society, guilty and disinterested in education.

This sticks with them through to adulthood. Whilst dyslexia does not affect intelligence and the contribution of dyslexic thinking to our country is undoubtedly great, almost all adults you speak to with dyslexia however successful they have been – will tell you they have at times felt less than their peers in the general population and have irrational feelings of failure that hark back to their childhood. At the extreme end of the situation, dyslexia leads to disengagement from society, reflected in share of dyslexics in the criminal justice system being many fold higher than in the general population¹¹.

This report is stark reading and shows irrefutably that we need to do more to identify people with dyslexia sooner and support them better to reduce the emotional and mental health issues that are currently too prevalent. We also must take steps to support those who have already suffered a human cost from growing up with dyslexia.

¹¹ 50 percent of juveniles in the largest young offenders institution in Scotland were found to have dyslexia (Kirk and Reid, 2001). The DYSPEL project, based in the London area, screened for dyslexia and found rates of 40-50 percent among offenders (Klein, 1998). Morgan's pilot study within the DYSPEL project showed 52 percent of probationers to have strong indicators of dyslexia (Morgan, 1997). The STOP project revealed that 31 percent of their offender sample showed positive indicators of dyslexia (Davies and Byatt, 1998). The British Dyslexia Association found a 56 percent incidence of dyslexia among young offenders in Bradford (British Dyslexia Association, 2004).

Helen Boden, CEO, British Dyslexia Association



For over four decades the British Dyslexia Association has supported and empowered people with dyslexia and those around them. Our job has been as much about helping people to overcome the commonly understood challenges around reading and writing that dyslexia presents, as it has been about not letting their negative experiences of being dyslexic hold them back in life.

Our work as Secretariat of the APPG for Dyslexia and other SpLDs has been an amazing opportunity to bring together the dyslexic community to help legislators better understand the direct and indirect challenges and abilities of dyslexia to build a legislative environment that ensures the amazing contribution the dyslexic community to our country continues to grow.

This report is difficult reading. Anecdotally, we have heard it all before, but to see in cold hard statistics and experts and individual evidence that hundreds of thousands of kids are unnecessarily anxious and undervalued and millions of parents are struggling to give their children the support they need is hard reading. This issue strikes to the very core of humanity.

We understand this is only one part of the picture and over the coming months and years we will look in more detail at the education system, workplaces and society more widely. But this report shows at the most fundamental level, the human cost of dyslexia is too high, and we need to change that.

Background

What is dyslexia?

Dyslexia is likely to be a combination of both abilities and difficulties. It is called a SpLD. The reason it is called specific is because it only impacts on certain areas of an individual, rather than being a general learning difference that has an impact on all areas of someone's performance.

- **It occurs independent of ability and socio-economic background:** There is no connection between dyslexia and intelligence. Dyslexia occurs across all sectors of society.
- **A different way of processing information:** Research tells us that dyslexia stems from differences in the way that the brain processes certain sorts of information, particularly, it is thought, language-based information. The key point here is that it is these physiological differences in the brain that lead to the challenges that dyslexic individuals experience, it is not lack of ability, poor parenting, or poor education. There is an underlying cause. We are really only just starting to understand a bit more about the brain and the complex nature of how it works, so there is a lot more research to be done on this area.
- **Every individual is likely to be different:** As human beings we are all different. Whilst there may be some commonalities associated with dyslexia, each individual is likely to be different. People are shaped not just by their dyslexia but by personality, experiences, parents, environment and numerous other factors. Therefore, it is not possible to either provide a template of what dyslexia is, nor, is it possible to provide a full proof template of support. Each individual should be treated as an individual.
- **Dyslexia quite often co-occurs with other SpLDs:** It is not unusual for dyslexia to co-occur with other SpLDs such as Attention Deficit Disorder (ADD), Dyspraxia/Developmental Coordination Disorder, Autistic Spectrum Disorder (ASD), Dyscalculia (difficulty with maths), or Speech, Language and Communication difficulties.
- **Incidence Rate and heritability:** It is estimated 10 percent of the population are dyslexic; this rises to 15 percent when co-occurrence is included. Statistically, this makes dyslexia the highest incidence SpLD. Dyslexia is genetic in origin and therefore is inheritable.

How does legislation support and recognise dyslexia currently?

There are a number of pieces of legislation and government publications that relate to dyslexia. These are:

- **The Equality Act 2010:** This means that dyslexia is legally a disability. The act does not mention any disability specifically by name but accompanying guidance and case law affirm that dyslexia is encompassed by the act.
- **The Children & Families Act 2014:** This act legislates for support for young people with dyslexia in education.
- **The SEND Code of Practise 2014:** Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities.

How does the support provisioned in legislation work in practice?

Young people who have dyslexia and who have an identified need in line with the Children and Families Act 2014, will often require special educational provision and/or support. The nature of that provision will depend on the severity and type of need experienced by the learner. Generally, for learners with dyslexia, it is expected that needs will be met in the classroom through high quality teaching and differentiated learning materials.

For many there may also be need for learners to have access to specialist teaching to meet their needs. It is unusual for such provision to be accessible within a mainstream setting, as resources tend not to allow the budget for such specialist dyslexia intervention. As such, while small group literacy intervention support may take place, the likelihood is that it is not run or overseen by a dyslexia specialist teacher.

What happens when dyslexia is missed or poorly supported?

- **Mental health and behavioural difficulties:** Research has shown that young people who have dyslexia and/or literacy difficulties report higher levels of mental health difficulties¹². In addition to the internalised mental health difficulties, young people with dyslexia often display externalised behaviours which are linked to their literacy difficulties. These behaviours are often contrary to school expectations and can negatively impact their academic progress and lead to further negative consequences for their educational and post-school outcomes. Feedback received from the survey¹³ identified a recurring theme of anxiety and mental distress from both children and their parents.
- **Academic underachievement and post-school pathways:** Learners who experience literacy difficulties can lack the skills necessary to be able to engage effectively with the curriculum. When further combined with the increasing number of exclusions from school and the increased numbers of

¹² Evidence from Dr Helen Ross, dyslexia/SpLD expert, Helen's Place to APPG for Dyslexia and other SpLDs.

¹³ Research developed for the APPG for Dyslexia and other SpLDs. The survey was distributed through social media (Facebook, Twitter and LinkedIn). Over 1,300 responses were received.

children, including those of primary age, entering pupil referral units (PRUs) there is significant grounds for concern about disengagement from education. The skills necessary to engage with the curriculum are also necessary for learners to be able to achieve well academically, particularly in examinations. Those with literacy difficulties because of their dyslexia may not achieve academic success. Linked to academic underachievement and poor literacy is a lack of ability to be able to engage well with professional life after school. Much research has shown a disproportionately higher rate of dyslexia in offender cohorts. As such, it is vital that the needs of dyslexic learners are identified early, and appropriate support is implemented.

The psychological impact of growing up with dyslexia



In practice, many dyslexics live much of their life under a cloud of believing they were rather thick and stupid. Following a diagnosis of dyslexia, it can be alarming to discover things could have been very different. This realisation creates an emotional soup where the person is no more equipped to deal with additional learning, i.e. software and skills training as an adult, than they were when their problems initially became apparent – usually in their early school years.

Pennie Aston, Director, GroOops Dyslexia Aware Counselling, said at the APPG for Dyslexia and other SpLDs on 24 April 2019:

“In the 12 years we have been operating we have identified a core matrix of presenting problems that are common to all our clients. They are not exclusive to neurodiversity but the frequency, intensity and energy required to cope with them, is. Our investigations have also looked at the origins of the presenting problems which we find firmly embedded in early years experiences.”

It is not that dyslexia means people are less able to cope with complex emotions than their neurotypical cousins but that they are having to cope with far more unresolved problems from the past where the focus had been on deficit. Also, few understood the presentations of dyslexia other than a difficulty with reading and writing. The result is that dealing with the emotional repercussions of dyslexia is dealing with trauma.

In psychology, trauma is defined as a deeply distressing or disturbing experience. Symptoms of psychological trauma are shock, confusion, anger, irritability, mood swings, anxiety and fear, guilt, shame, self-blame, withdrawing from others, feeling sad or hopeless, and feeling disconnected or numb. During the APPG for Dyslexia and other SpLDs on 24 April 2019, Pennie explained that all these symptoms are commonly present in GroOops Dyslexia Aware Counselling clients. Add to this an ignorance of how dyslexia can present itself, and at the extreme end you have someone convinced they are good for nothing and at risk of becoming disconnected with normal humanity.

Pennie shared stories of clients GroOops Dyslexia Aware Counselling have worked with that are reflective of the common psychological impact resulting from growing up with dyslexia. These clients shared that they were dependent on an understanding partner who supported their dyslexic needs allowing them to focus on strengths. However, all struggled throughout school having received no interventions. Many developed strategies to cope but have ended up with a fractured relationship with parents who it was felt tortured them by sending their child back into school where they were bullied, shamed and humiliated by teachers and students.

One person's breakdown came when they watched their gentle natured seven-year-old son turning into a raging, distressed monster going through the same experiences as their parent – with a 25-year gap. This parent is unable to drop their child off at school or attend parents' evenings without experiencing flashbacks and panic attacks leaving them vomiting with distress.

Others relayed that, despite their success, they had never told anyone about their dyslexia because they felt it was a badge of shame – something that was inexplicably wrong no matter how much effort was put in. Many have split their lives into two parts. The first, school and family where nothing could be done right and failure was dismal and inevitable. The second, where an escape to a creative environment allowed latent talents to be focused on by perceptive mentors who recognised dyslexia.

Many left school with no qualifications, have now achieved PhDs and work in high level positions in The City, the pharmaceutical industry, architecture and engineering. Unfortunately, the early years damage caused kept telling them they weren't good enough, not able enough and constantly on guard as to being found out, resulting in fragmented personal and professional relationships. Deep depression has impacted on their ability to enjoy successes. The legacy of their early years.

What the evidence provided by Pennie Aston of GoOops Dyslexia Aware Counselling shows us is that commonly childhood experiences of growing up with dyslexia result in psychological trauma, which degrades a person's life experience substantially. Pennie's evidence also shows that no amount of success in later life or professional psychological support fully repairs the damage done in childhood. Childhood matters and the only solution to ending psychological trauma resulting from growing up with dyslexia is to ensure the education system and society does not cause it in the first place.

Being dyslexic in today's education system



My relationship with dyslexia was a struggle for the majority of my time in the education system. My mental health and academic growth were severely impacted, due to a lack of awareness and support provided in school.

I was diagnosed as dyslexic in Year 2. The majority of my dad's family are dyslexic and my then teacher's son is also being dyslexic, which meant it was not hard to recognise that something wasn't quite right. For the majority of my time in primary school I thought nothing of my dyslexia label. Even though I had to have dyslexia training after school, eye-tracking sessions, Kumon¹⁴ classes and being the bottom set for maths, I enjoyed my learning.

In Year 6, we had to do the eleven-plus, in order to determine what school I would be going to. Even with two years of training, I failed both the exams, as I couldn't finish the paper, as I had no extra time. I felt like a failure, and this is when I felt a divide between my classmates and me.

My parents appealed, and I was given a place at my local grammar school. Immediately, I recognised that I was not meeting the expected academic standard of everyone else. I received no support in class, and was only given dyslexia support sessions, which involved me being taken out of my lessons to do joined-up handwriting exercises. I very quickly fell behind, most significantly in maths. I would often get into trouble for not concentrating or not being able to do the homework – but seeing as I couldn't understand what was being taught, I didn't see the point in trying.

My mental health suffered badly: I assumed I was stupid, unable to do well, unable to achieve. In Year 10, I was told that I needed to start improving my grades, otherwise I would not be able to get into my school's sixth form. This was when I realised I needed to get my act together, but even then, I did not think I would be able to achieve the required B in maths, let alone a D.

Luckily, my parents were able to send to me a maths tutor who specialised in dyslexia. In the first session, I learnt what a fraction was, something I couldn't get my head around for the whole of my time at school. In the space of two years, I managed to go through about six years of the maths I had missed out on. From long division to multiplication, my ability to understand maths was completely transformed as my tutor taught me in a way that worked for me.

This was eye opening. I had assumed that I would never be able to do well in anything, let alone maths, and so I applied the strategies my tutor gave me to the rest of my subjects. When I got my GCSE results back, I think many people were shocked. I had got an A* in maths, after only having learnt what a fraction was under two years before.

¹⁴ <https://www.kumon.co.uk/>

I was often told it was unfair I received extra time, or that I had a laptop in exams. I still get these comments today. However, if I had not been given the support from my tutor to recognise that I was not stupid and that I was just being taught in a way that didn't work for me, I would never be where I am today.

My mental health has significantly improved and I have achieved so much academically.

What should be taken from my story is that I was extremely fortunate in my position, to have parents who financially supported me to get the extra support I was never given in school. Yet, I still faced so many struggles, both academically and mentally, which is often a common theme for many dyslexics in the education system today.¹⁵

Jo Crawford, MA student at University of Exeter and British Dyslexia Association Ambassador

¹⁵ Evidence provided to APPG for Dyslexia and other SpLDs following her presentation at 24 April 2019 meeting.

Managing dyslexia as a family



In a legislative environment that enshrines parental advocacy in so many ways and scant resources available in schools, the reality is that young people with dyslexia are heavily dependent on their families, both financially and practically, to diagnose their dyslexia and support them with it.

Whilst having a child with dyslexia is inevitably going to add an extra burden to families, and parents want to support their children to overcome this challenge like the many others common in childhood, it is currently placing a massive emotional and financial strain on families because the education system and other parts of our society are failing to take their fair share of responsibility.

As part of the work of the APPG for Dyslexia and other SpLDs, the British Dyslexia Association has worked with parenting and neurodiversity coach John Hicks to gain a snapshot of familial experiences of dyslexia and its impact. Dr Helen Ross, dyslexia/SpLD expert and SEN practitioner at Helen's Place joined the project to guide data processing and analysis.

The survey was distributed through social media (Facebook, Twitter and LinkedIn). Over 1,300 responses were received. Survey participants were self-selecting and in addition to answering short, closed questions relating to their experiences of dyslexia, they were also able to write open-ended comments giving more detail, in their own words – in excess of 2,500 comments were received.

Commenting on the findings she analysed, Dr Helen Ross, dyslexia/SpLD expert and SEN practitioner, Helen's Place, said:

“It is hugely disappointing to see the extent to which parents still feel that schools are not able to support young people effectively. As researchers and teachers, we find it is frustrating that we are still not equipped by the legislative environment to meet the needs of dyslexic children – particularly when the established strategies that support dyslexic learners work well for all learners.”

How helping your child to navigate education feels

Key findings:

- 95 percent of respondents felt they lacked the skills and knowledge to support their children
- 95 percent of respondents worried about what the future held for their dyslexic children

Parents reported that they felt guilt and that the current system was a significant source of difficulty for them and their children.

"The fact I have to send my son into a school every day by law that will not help him... I feel guilty every single day."

"I feel I have failed my child by placing him in the education system that doesn't cater for him."

Some parents found that their children's experiences of school changed due to the effects of their dyslexia, noting that their children did not wish to attend school and were beginning to disengage with some aspects of education.

Parents were concerned about their children's future prospects and their ability to succeed academically at school.

"Exams in the future are a worry – that a bright boy is at a disadvantage as he will struggle to read and process everything."

Where children and young people were disengaging from education, parents raised issues of concern about their future prospects and the difficulties experienced by young people in today's mainly exam-based education system.

Parents did not feel that they knew how to support their children pragmatically academically.

“I also feel that there is very little support out there for children and parents. We are guessing most of the time and feel like we are screaming for help.”

It appeared that lack of information, resources and support were central to parents' anxiety, leaving them potentially helpless when trying to meet their children's educational needs.

Interactions between parents and schools

Key findings:

- 70 percent of parents felt that their school did not support their child's dyslexia
- 74 percent of parents said they felt anxious when they had interactions with their child's school
- 70 percent of parents felt that their child's school did not take their concerns about dyslexia seriously
- 70 percent of parents said they felt disempowered during interactions with their child's school
- 76 percent of parents felt that the school was not doing a good job supporting their dyslexic child
- 72 percent of parents felt that their school did not value or nurture their child's abilities and potential
- 55 percent of parents felt they were unable to communicate effectively with their child's school
- 82 percent of parents said that they sometimes feel angry with their dyslexic child's school

Some parents noted that schools give misleading advice and appear to want to avoid potentially costly interventions.

"As a teacher, I'm told to tell parents that you cannot test for dyslexia and that parents need to pay privately if they wish, but we as a school don't have to follow private assessments. Parents are also told that it's not possible to recognise before seven years old."

The inconsistent information accessed by parents was reported as problematic, with some parents whose professional activities encompassed working with young people with dyslexia reporting that schools appeared to actively misinform parents about their children's needs. Other parents felt that schools did not know how to support parents and young people.

Despite explicit instruction within the Special Educational Needs and Disability Code of Practice 2015 and the Children & Families Act 2014 that the views of parents and young people are central to the development of provision for young people with SEND, our data shows that parents do not feel empowered to share their views and indeed that some parents felt that their opinions were disregarded by schools.

Interestingly, some parents were anxious that their children were not getting sufficient support. They felt that other 'needs' eclipsed those of young people with dyslexia.

"I could see that she was struggling but got fobbed off by the school that it was a phase and she would eventually get it. She is such an anxious and angry girl who hates school and has to be physically held some days to go in."

Managing dyslexia at home

Key findings:

- 77 percent of parents felt exhausted by having to deal with their child's dyslexia

- 76 percent of parents said that they sometimes lost patience and got frustrated with their dyslexic child

Our data shows that dyslexia has a significant effect on family dynamics. They felt that this is due to the increased focus on the dyslexic sibling due to increased time commitments relating to homework, extra tuition or emotional support. Nearly half of parents reported that they spent over £1,000 extra per year because of their child's dyslexia. This extra focus, expense and commitment left many parents feeling that they neglect other family members, and that relationships between all family members are impacted by dyslexia and its effects.

Homework was a very emotive subject and almost all parents commented that it was problematic for themselves, their dyslexic children and their siblings.

“My daughter feels I don't care about her as much, as I pay for tuition for son but not her. I can't afford it as a single mum with a non-paying ex.”

“At the weekend, I take my daughter to her tutors so I miss every Saturday morning with my other children. By the time I come home, I have just enough time to get through the housework before dinnertime.”

The emotional effects of dyslexia on parents and their relationship with children was also documented. A large proportion of participant families reported that they experienced frustration linked to their children's dyslexia, describing changes in their role as a parent resulting from their children's dyslexia.

Parents found that there was an emotional cost linked to supervising homework and were concerned about its long-term effects on their relationship with their children.

“I feel that I have become my child's teacher and not their mum. I have even trained as a specialist teacher in order to support them. At times, I am frustrated that I cannot just be mum, but the lack of support and understanding from school means I feel I have to support them in order for them to reach their potential.”

“Our youngest has dyslexia, but we also have two older neuro-typical children who definitely miss out on time with us because of the additional attention our dyslexic daughter needs to complete homework, etc.”

What these results demonstrate is that dyslexia places both an emotional and financial cost on families. The lack of support, that should be available in schools, is negatively impacting on home life.

The cost of dyslexia on the child

Key findings:

- 82 percent of parents said their dyslexic child tries to hide their struggles
- 88 percent of parents said their child has poor self-esteem because of their dyslexia
- 84 percent of parents said their child suffers from anxiety relating to their dyslexia
- 52 percent of parents said their child tries to avoid school because of their dyslexia
- 78 percent of parents said their child feels embarrassed because of their dyslexia
- 48 percent of parents said their child has been bullied because of their dyslexia
- 95 percent of parents said that their child experiences frustration because of their dyslexia

58 percent of parents reported that their children try to avoid discussing their dyslexia and a staggering 82 percent responded that their children try to hide their difficulties relating to dyslexia. This suggests that children and young people are uncomfortable, and experience negative emotions linked to their dyslexia. With 85 percent reporting that their children feel embarrassed by their dyslexia we believe that our data may demonstrate an association between dyslexia and mental health difficulties.

Parent's descriptions of their children's mental health varied from describing their children as having slight anxiety to them experiencing significant difficulties requiring intervention.

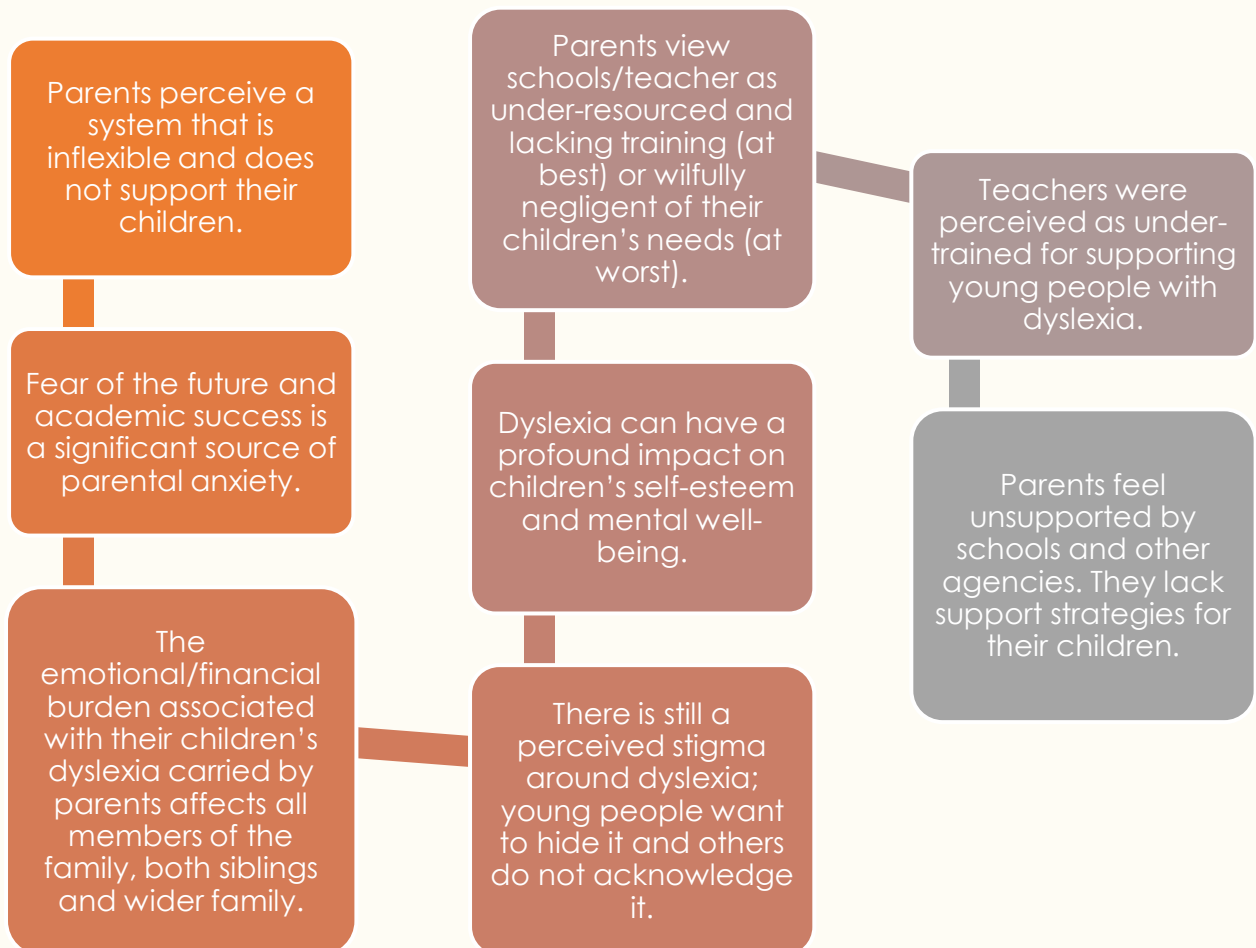
"Huge emotional repercussions resulting from dyslexia. My child has had CBT through CAMHS for anxiety, anger and low self-esteem."

"When your son is screaming he wants to kill himself, harm himself, and repeatedly running away at the age of 6 because he feels stupid, it's so difficult."

Over half of the participants' children try to avoid school suggesting that there is a potentially significant link between dyslexia and mental health difficulties. Given the current mental health crisis in schools, we feel that our data shows the need to acknowledge the impact that dyslexia has on mental health and that appropriate resources and funding be put in place to support both the educational and additional needs of young people with dyslexia within their educational setting.

What these figures illustrate is not only the emotional cost that dyslexia has on a child, but also implies how little we have moved on in developing an inclusive education system if our current system allows children to experience these emotions in relation to a disability, and fails to address these issues.

Patterns emerging from research



Recommendation of the APPG for Dyslexia and other SpLDs to reduce the human cost of dyslexia

Where young people are supported, they are less likely to 'fall off the map' and disengage from active participation in their community. While there may be a cost implication in the short term for school funding, there will be long term savings in terms of taxes gained and earnings of individuals.

The British Dyslexia Association and Driver Youth Trust have provided evidence to the APPG for Dyslexia and other SpLDs on policy changes that could be made to improve support for young people with dyslexia and their families.

Whilst more work needs to be done to look across the sector at themes around how the legislative environment should change to improve outcomes for people with dyslexia, this section is a snapshot of some policy recommendations from independent charities in the sector.

Specialist support in each school

The British Dyslexia Association says that the clearest solution lies in the training of specialist dyslexia teachers. Such teachers would be able to support learners, oversee and direct teaching and support provision and carry out diagnostic assessments that identify individual needs. In this way, expertise and knowledge would be readily available to class teachers in every school or every cluster of schools.

High levels of spending on litigation by parents fighting to access support for their children is estimated to rise to £100 million in 2019¹⁶. Currently, this process of litigation is the only avenue available for parents seeking support for their dyslexic children where the schools or local authorities (LAs) are unable or unwilling to provide adequate support. This can often lead to social injustice for those who are unable to pursue legal action.

An approach of strategic investment in specialist teachers would, the British Dyslexia Association believe, remove pressure on the current Special Educational Needs and Disabilities (SEND) Education, Health and Care Plans (EHCP) and appeals process. It costs c£3,500 to train a specialist teacher. Such investment would in effect, release funds within this sector for those individuals with high or more complex needs.

Training of classroom teachers

The British Dyslexia Association also recommends that there is increased focus of SEND within initial teacher training (ITT) programmes but is also mindful that this is a crowded curriculum already. It, therefore, would recommend that newly qualified teachers (NQTs) are enabled to access mandatory CPD leading to a Level 2 or 3 Award in dyslexia and SpLD as part of a continuing professional development (CPD)

¹⁶ Based on 2019 research by the British Dyslexia Association.

programme within the first two years of becoming qualified teachers. It is only in this way that all teachers can truly become teachers of SEND. Even with such CPD, however, there would still be a need for dyslexia specialist teachers to support learners who are dyslexic, and teachers.

The British Dyslexia Association acknowledges that there has been some investment in training from the Department for Education.¹⁷ This training has, however, been light touch and focussed on awareness raising and not training at the specialist level that is required in order to support learners and enable them to access the curriculum in a way that leads to engagement and longer-term academic success.

The Driver Youth Trust says Ofsted should judge ITT providers on the quality of training delivered to trainee teachers on SEN including supporting learners with literacy difficulties. They add that Department for Education should ensure that all funded literacy CPD includes training on literacy difficulties.

With regard to better ways of working with the sector, Driver Youth Trust say teacher educators should develop NPQs in SEN and literacy as part of the new plan to support teachers to develop and progress their career without needing to pursue a traditional leadership route.

Furthermore, researchers should develop a “what works” evidence base for learners with literacy difficulties and discover how many learners with literacy difficulties there are.

Reinforcing this, school leaders should ensure their provision enables learners with literacy difficulties to access the curriculum and that the door to a more rigorous education and curriculum is open to all.

Teachers, across all areas of the curriculum and all school phases, should know how to adjust their teaching for learners with literacy difficulties.¹⁸

Ensure that adequate pastoral, academic and mental health provision is made in schools

There is currently no roadmap forward for how young people’s mental health should be supported, despite commitments to developing parity between its treatment and that of physical health (Committee of Public Accounts, 2018). While mental health difficulties and learning difficulties are identified within policy as SEND matters, some schools have systems which do not integrate or allow for robust support between the different aspects of academic difficulties and social, emotional and mental health (SEMH), and their link to behavioural difficulties. Schools must take care to ensure that they assess the potential needs of any learners who do find positive engagement with schools difficult.

¹⁷ Department for Education provided funding for a dyslexia and SpLD project between 2016 – 2017. The project was managed by British Dyslexia Association and other partners included Patoss, Dyslexia Action, Helen Arkell, Manchester Metropolitan University, Dyspraxia Foundation. The project value £750,000. The purpose was to develop resources for all SpLDs and to provide awareness training.

¹⁸ Literacy difficulties: The DYT position, 2019.

Ensure that adequate information for parents is accessible and that there are national minimum standards that are enforceable for provision

Supporting and engaging with parents is written into current statutes. However, the current frameworks are too vague, and our findings reflect this. Parents want accessible information of a good standard. If formal guidelines are put in place, LAs will have to comply, and parents will be better informed to support their children.

Schools should invest in training and resourcing so that they meet nationally recognised standards such as the British Dyslexia Association's Dyslexia Quality Mark for Dyslexia Friendly Schools

While there is a minimal cost implication for initial investment and then maintenance for schools who choose to invest in the British Dyslexia Association's Dyslexia Quality Mark, this is offset with the development of robust, cost efficient support strategies for young people with dyslexia that are embedded across all aspects of the school.

Potentially this could reduce staffing and resource costs as young people's needs will be appropriately met in class, with quality first teaching from their class teachers who are well informed and suitably trained. It is likely though that there will be some severely dyslexic individuals who will still require specialist teaching intervention.

Ensure coherent national frameworks

National standards for procedures and pathways towards securing support for learners should be developed. The fragmentation of the SEND support systems under the Children and Families Act 2014 has created confusion for parents and has made the system problematic for non-experts to navigate – schools with multiple LAs in their vicinity are confronted with incoherent paperwork and practices, which makes implementing appropriate support problematic.



British Dyslexia Association

The British Dyslexia Association provides the secretariat to the All-Party Parliamentary Group on Dyslexia and other SpLDs

<https://www.bdadyslexia.org.uk/about/appg-dyslexia-and-spld-all-party-parliamentary-group>

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