

Emotional support needs of teenagers with dyspraxia: findings from a survey exploring the perspectives of parents/carers

Mental health problems are common in teenagers with dyspraxia, causing distress for those affected and for the people who care for them.

Mental health problems are common in young people with neurodevelopmental conditions including dyspraxia ([Care Quality Commission 2017](#)) and this is reflected in the increasing number of calls to the Dyspraxia Foundation helpline from distressed parents/carers looking for help for their teenager's mental health.

Dyspraxia Foundation believes that teenagers with dyspraxia are slipping through the net and that they not receiving the mental health support they need when they need it most.

Dyspraxia Foundation believes that the prevention and treatment of mental health difficulties in teenagers with dyspraxia should be a focus for intervention and that ***parents and carers also need help and support to help them manage the emotional consequences of their son or daughter's dyspraxia.***

Dyspraxia (also known as Developmental Coordination Disorder-DCD) is a relatively common but poorly understood condition that affects fine and gross motor coordination in children and adults. It can also affect organisation, planning, time management and speech. Dyspraxia/DCD affects around 5% of children, 2% severely (Lingam et al 2009) and makes it difficult for people to carry everyday activities that others manage easily for example using cutlery, handwriting, riding a bike and kicking a ball. It is estimated that 50-70% of children with DCD who do not receive intervention will continue to have difficulties in adulthood (Kirby et al 2011). While people with dyspraxia/DCD can be very successful in their lives, there can be serious negative consequences for a person's academic achievement and their physical, social and emotional well-being for those who do not receive appropriate recognition, help and support during adolescence.

A Dyspraxia Foundation [survey](#) in 2014 revealed that 40% of teenagers with dyspraxia/DCD felt anxious 'all the time' while 20% 'never' felt confident. This shocking finding supports research (summarised by [Cacola](#), 2016) which reports that ***young people with dyspraxia/DCD are at increased risk of depression and anxiety, have fewer friends, are more socially isolated and report lower self-esteem*** than their peers.

The survey

In July/August 2018 the Dyspraxia Foundation carried out a survey to explore parents' perceptions of the emotional support needs of people with dyspraxia/DCD. The online survey ran for 44 days from 16th July to 28th August 2018 and was promoted via the Dyspraxia Foundation website and social media channels (Facebook and Twitter).

Respondents

- 583 people responded to the survey, including 253 parents/carers of teenagers aged 11-18 years.
- 93% respondents were female (n= 547) and 7% were male (n=36)
- Of the 253 responses relating to young people aged 11-18 years, 62% were parents/carers of boys and 38% were parents/carers of girls.

- Respondents were mainly from England (86%), the remainder being from Scotland (7%), Wales (3%) and Northern Ireland (2%). 2% came from elsewhere (including the Channel Islands).

Survey findings

As adolescence is a key life stage associated with mental health needs, **responses from the parents/carers of teenagers aged 11-18 years** were analysed separately and are reported here.

Anxiety

55% of parents/carers described their teenager as ‘frequently’ or ‘nearly always’ anxious. Anxiety is a common underlying cause of mental health issues for people with dyspraxia and many parents/carers described their son or daughter **worrying about things that might happen because of their poor coordination or organisational skills**:

“There is a lot of low level anxiety with regards to a fear of losing things. This will manifest in having to take every little thing along with him wherever he is going ‘just in case’.”

Parents felt that teenagers’ anxiety about things that might happen because of their coordination and organisational difficulties was based on their previous experience of things going wrong; this is sometimes referred to as ‘anticipatory anxiety’. Some teenagers managed their anxiety by being ‘over-prepared’ – for example taking everything to school ‘just in case’ – but the stress of trying to be ready for anything could be overwhelming.

26% of parents/carers in our survey felt strongly that their son/daughter was unwilling to participate in activities (especially physical activities) because they were **anxious about drawing attention to their coordination difficulties**:

“My daughter is plagued by anxiety and increasingly feels bad about being ‘different’ from other children. She’s very bright and creative but disorganised. In a city where virtually everyone cycles, she’s deeply embarrassed that she’s unable to cycle.”

The cumulative impact of anxiety and concern about how others viewed them had significant consequences for teenagers’ mental health and the well-being of the whole family:

“Anxiety has been our family’s constant companion”.

Social isolation and fear of being perceived as different

43% of parents/carers described their son/daughter as **lonely** and 67% were worried or very worried that their child was **socially isolated** and didn’t have many friends. Teenagers were at risk of taunts from peers at secondary school because of poor handwriting or difficulty with sports and physical skills. Some teenagers with dyspraxia were excluded by their peers while others withdrew from social situations to protect themselves.

“He is usually made sad by other kids taunting him over his handwriting and difficulty with ball sports at school. He feels inadequate.”

Parents/carers reported that some teenagers with dyspraxia/DCD who had coped or done well at primary school experienced mental health problems at secondary school because of lack of awareness or support for their difficulties:

“My child is 14 and frequently has difficulties socialising. Her frustration comes across as anger and she is often misunderstood. She was a confident child until she entered senior

school. Everything changed and support dwindled. She is now emotionally and psychologically unstable.”

Others described how their son or daughter tried to ‘fit in’ by mixing with the ‘wrong’ crowd with distressing consequences:

“My son’s mental well-being has declined drastically since starting high school. He is alone, isolated and marginalised – initially due to his difficulties making it difficult for him to fit in, and now because of the behaviours that he is doing in an attempt to fit in: stealing alcohol from local shops during school breaks, drinking alcohol and smoking. These behaviours make would-be, potential friends not want to know him.”

Teenagers’ anxiety about fitting in and how others viewed them were identified as underlying causes of mental health problems by many parents/carers who responded to our survey:

“A lot of our son’s anxiety, poor self-esteem and frustration stem from factors like fitting in, feeling different and ignorance.”

Frustration

59% of parents/carers described their son/daughter as frustrated by their coordination and organisational difficulties. **38% identified needing more help with personal care activities such as tying shoelaces, washing their hair and shaving as a particular cause of frustration:**

“We have to do an awful lot for him and be very creative. We have adjusted his PE/school shoes so he doesn’t need to tie shoelaces, using Velcro school shirts (he is unable to do buttons), have to wash his hair for him, comb it for him (he has an afro), cut his finger/toe nails etc.”

“There is a lot of frustration when things are lost or things are forgotten. This manifests as anger and shouting.”

“My son is often frustrated because he can’t do things others do easily. He often feels a failure to the extent he will refuse to do something rather than do it and be embarrassed at falling short.”

Parents/carers also felt that a lack of understanding of their son or daughter’s difficulties fuelled their frustration and had a negative impact on their mental health:

“Anger and frustration are common in my son. School gives little support and the high expectations remain unattainable because there is no understanding, interest or support given by them.”

Academic underachievement

60% of parents/carers felt strongly that their child wouldn’t reach their academic potential because of poor organisational and study/revision skills. Teachers’ **poor awareness and understanding of dyspraxia/DCD** was also highlighted as a factor affecting teenagers mental health because they were unable to provide appropriate help and support:

“My son is a very intelligent child who is not reaching his potential in school despite being in an academically selective grammar school. He loves to learn but struggles with

concentration, organisation and writing. Teachers do NOT understand his needs and he can become very frustrated with his own difficulties”

“We have had no help from his teachers or GP until too late to help with GCSE’s and A’ levels... We expect poor results and he feels he will fail at University so does not wish to apply despite being in a high intelligence percentile”

Parents identified the transition to secondary school as a particularly challenging time for teenagers with dyspraxia because the social, academic and environmental demands increased while understanding and support often reduced. Previous coping strategies, for example relying on friends for help with organisation might no longer work if they weren’t in the same class or school, and difficulties with handwriting were magnified as expectations of quality and quantity increased. Many parents highlighted the how receiving poor feedback for schoolwork affected teenagers’ self-esteem and optimism for their future.

Low mood and self-esteem

26% of parents described their teenagers as frequently or almost always sad and only 28% felt their teenager was happy with the way they are. **Bullying, isolation and a persistent sense of failure** were identified as key factors influencing self-esteem and mood:

“My son is now 17 and wasn’t diagnosed until he was 15 after severe bullying at school and a long wait in the system. I worry that he feels hopeless, useless and has feelings that he doesn’t want to be here due to his lack of confidence, memory, co-ordination and social ability. He’s so eager to please others at the detriment of himself.”

Accessing support for teenagers’ mental health

Many parents/carers had tried to access support for their son/daughter’s mental health but had been frustrated by long waits, high thresholds for accessing services and poor understanding of how dyspraxia/DCD affected teenagers’ mental health. Parents felt teenagers with dyspraxia/DCD were disadvantaged because they worked hard to cover up their difficulties and their mental health needs only became obvious when they reached crisis point.

Mental health services

50% parents/carers of teenagers with dyspraxia/DCD had sought support for their child’s mental health from **Child and Adolescent Psychiatric services** (CAMHS). Many had however, found CAMHS services difficult to access because their child’s difficulties were not deemed severe enough:

“I requested CAMHS support in Year 4, the hardest year, but they were too busy with more severe cases. GP said we were ‘middle tier’ and so we had to manage. We did, but it was hard.”

“It’s taken me 12 months to get my son counselling after countless appointments with doctors, CAMHS, school. Because my son wasn’t suicidal or self-harming he was put on the waiting list. 12 months on he is worse and now won’t go into school at all.”

Parents felt that teenagers had to reach crisis point before help and support was provided which affected the whole family and had distressing consequences for the individual’s long-term mental health:

“He was extremely frustrated and anxious before he was 13 and struggled. He was diagnosed with severe depression when he was 13, prescribed anti-depressants and that’s when the support finally became available to him.”

Some parents/carers felt that the mental health support provided by schools or the CAMHS did not meet their teenager’s needs because the challenges experienced by people with dyspraxia/DCD were not well understood:

“They do not recognise my daughter’s anxiety because she doesn’t look anxious. They had no insight into the challenge of dyspraxia.”

Others felt that the lack of on-going mental health support (particularly at times of transition) put teenagers with dyspraxia/DCD at risk of deterioration or relapse:

“CAMHS, although restricted has done an awful lot of good work with my son. Sadly his case was closed too soon and there is no walk-in facility. Sometimes he really does need extra support. I support him all I can, but a lot more work could have been done – a follow-on service and 6-monthly review would be really beneficial to many, especially at times of change in school/college as many dyspraxics (like people with autism) struggle very much with change.”

School-based counselling and support from other agencies

60% of parents had sought support for their son/daughter from **school counselling services**, but many felt that counsellors did not have the skills or understanding to support the practical and mental health needs of young people with dyspraxia/DCD:

“He was given counselling at junior school, but the counsellor made things worse for him. She had no background in special needs or kids, let alone both!”

When counsellors did have a good understanding of dyspraxia/DCD however, this support could be very effective:

“Last year when my son was in Year 6 he was extremely unhappy and anxious. However, when he started secondary school he met with the school counsellor who talked things over with him. Now he is in a more understanding environment he is much, much happier. When I talk to him about his last years at primary school he describes himself as being ‘depressed’. The environment plays a key part to how he feels and when he is understood he feels much happier (I guess we all do).”

33% of parents/carers had enlisted the support of **charities or other organisations** (including the Dyspraxia Foundation) for their teenagers’ mental health, while a further 44% reported accessing **online support** via an app or website. Many parents funded private counselling because their son/daughter’s difficulties did not meet the threshold for accessing CAMHS services, or because the waiting times were too long. However, finding the right support was itself challenging:

“It’s been difficult to find a counsellor willing to take on our son. He has a burning rage within and very low self-esteem and needs help to put things into perspective. This affects the whole family.”

Diagnosis

Receiving a diagnosis was regarded as a positive step by many parents/carers because it helped to explain their son/daughter’s difficulties and differences:

“Tom was diagnosed with dyspraxia this week. He has struggled with friendships at school and is due to start secondary school in September. As well as the enormity of the school and the changes this transition brings, his biggest concern is being bullied and crying in front of others. Tom is the sweetest, kindest young lad who adores animals. He said last night that he ‘just wants to be someone’s best friend’. As parents, the route to diagnosis and the emotional impact this is having on Tom has been hard to witness.”

However, unclear, under-resourced or age-restricted assessment and diagnostic pathways for teenagers meant that securing an assessment/diagnosis of dyspraxia/DCD was a long, painful and distressing process in many cases. Sometimes diagnosis came too late to prevent negative, secondary consequences for teenagers’ social, emotional and academic achievement:

“My son was not diagnosed until he was 14. He is angry, frustrated, disruptive and very behind at school. He has made very poor friend choices and is frequently sad.”

“My daughter is 18 and was diagnosed 8 months ago. She finds it hard to accept and difficult therefore to embrace strategies that would alleviate some of the feelings you’ve surveyed. It’s tough.”

Parents/carers also identified a need for post-diagnostic intervention and support to minimise the impact of the condition on their teenagers’ mental health:

“We have found relief and understanding since our son’s recent dyspraxia diagnosis and he has been happier since, but we are very aware of the affect it has on his well-being and self-esteem. He worries continually about friendship issues, feels excluded often at school and frustrated by his difficulties. He also has frequently sleep problems.”

Continuing mental health needs of adults with dyspraxia/DCD

The Dyspraxia Foundation survey was open to parents/carers of people with dyspraxia/DCD of all ages and responses were received from 85 parents/carers of people aged 19-25 years and 47 from parents/carers of people with dyspraxia/DCD aged 26+ years. The survey highlighted a worrying **trajectory of increasing anxiety** among people with dyspraxia/DCD as they moved into adulthood. The number of parents/carers who described their son/daughter as frequently or almost always anxious was:

- 55% for young people with dyspraxia/DCD aged 11-18 years
- 61% for people with dyspraxia aged 19-25; and
- 70% for people with dyspraxia aged 26+.

Our survey highlights the **continuing mental health support needs of young people with dyspraxia/DCD as they move into adulthood** and the need for the focus of intervention to shift from developing motor skills to promoting **self-awareness, self-management and resilience** during adolescence and into adulthood:

“Our son is 17 and received a lot of support when he was at primary school when it was very obvious he needed support. At secondary school he learned to ‘cope’, mask his needs and frustrations and insisted he didn’t want support as he was desperate to fit in. He has recently finished first year A’ levels and after being a high achiever he is struggling with the lack of structure and degree of organisation required and has basically had a melt-down. He now accepts he has dyspraxia and needs support and the school have been great, but this year

has been a nightmare. The point I am making is we need to recognise that it is very difficult for teenagers anyway and the pressures to fit in may make them pretend to be coping. We made the mistake of thinking he had 'grown out of' many of his problems (because he insisted he had) and didn't realise that his anger and frustration was driven by panic, fear and self-loathing as his school work suffered. He has turned a corner now, but this is a very vulnerable time when parents and schools need to be more aware of the support that may be needed (even when their young adult/child says they are 'fine')."

How the Dyspraxia Foundation can help

The Dyspraxia Foundation is proud to be regarded as a credible and trusted source of information and support for people with dyspraxia/DCD, parents/carers and professionals. Demand for our services is however increasing and the organisation is drastically under-funded; we cannot provide the service that is required. We require additional funding and support to help us achieve our vision of a world where dyspraxia/DCD is recognised and understood and where dyspraxia/DCD is not a barrier to opportunity and fulfilment. You can help us achieve this aim by becoming a member or making a donation today.

For more information about the Dyspraxia Foundation and how to support our mission to transform the lives of people with dyspraxia/DCD see www.dyspraxiafoundation.org.uk

The Dyspraxia Foundation calls on schools, local authorities, clinical commissioning groups and health service providers to:

- Recognise the relationship between dyspraxia/DCD and mental health in children, young people and adults.
- Increase awareness of dyspraxia in secondary schools so that teenagers receive support for their motor and non-motor difficulties, reducing the risk of secondary consequences for their mental health, academic performance and social participation.
- Develop clear pathways and ensure timely access to assessment and diagnosis of dyspraxia/DCD to provide an explanation for a person's difficulties, enabling them to access appropriate help and support.
- Work in partnership with people with dyspraxia/DCD and their families, and across health, education and employment to ensure that services are coordinated and graduated to build skills and foster resilience. This will reduce the risk of mental health difficulties and the need to draw on stretched NHS mental health resources.
- Increase understanding of dyspraxia/DCD among mental health practitioners including the role of anticipatory anxiety.
- Support and promote sports clubs and organisations that provide a safe environment for teenagers with dyspraxia/DCD to participate and realise the benefits of physical activity for their mental well-being.

Dyspraxia Foundation resources to help teenagers with dyspraxia/DCD and the people who support them at home, in education and in employment

Dyspraxia Foundation membership – membership is open to anyone over the age of 18 (parents/carers, adults, professionals). Membership benefits include access to special content on the website (including e-books and presentation notes from previous events), reduced rates for conferences/events, monthly newsletters and access to local group activities.

<http://dyspraxiafoundation.org.uk/members/join-foundation/>

Dyspraxia Foundation website – this includes information for parents/carers, professionals and adults including links to information sheets, forthcoming events, videos and the online shop. Additional content is available to members in the members-only area.

Dyspraxia Youth website – The Youth section of the Dyspraxia Foundation website includes information sheets, blogs, videos and information about activities/events for young people aged 13-25 years. <https://www.dfyouth.org.uk/>

Dyspraxia Foundation helpline – staffed by volunteers, the telephone helpline is open from 9am – 1pm Monday to Friday. Email enquiries can be sent at any time via the website:

<https://dyspraxiafoundation.org.uk/helpline/>

Dyspraxia Foundation Facebook page – with more than 35,000 followers, this page provides an active forum for information sharing and support.

Dyspraxia Youth Facebook Group – this closed group is moderated and provides a safe space for young people with dyspraxia/DCD aged 13-25 years to share experiences and support each other.

Twitter – follow us @DYSPRAXIAFDTN and @DyspraxiaYouth to keep up to date with information and events.

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