

Growing up with dyspraxia: findings from a survey of over 1400 adults with a diagnosis of dyspraxia and those who suspect they have the condition.

Dyspraxia Foundation

August 2019

The online survey ran for 47 days from 16th June – 1st August 2019 and was promoted via the Dyspraxia Foundation website and social media channels (Facebook and Twitter).

Respondents

Of the 1455 valid responses, 471 (32%) were male, 966 (66%) were female and 18 (2%) preferred not to say.

- 398 respondents (27%) had been diagnosed with dyspraxia as a child.
- 439 (30%) were diagnosed as an adult
- 618 (43%) believed themselves to have dyspraxia but did not have a formal diagnosis.

Background

Dyspraxia (also known as Developmental Coordination Disorder-DCD) is a specific difficulty that affects gross motor skills (e.g. balance, posture, gait) and fine motor coordination (e.g. the ability to grip and handle tools and equipment). It can also affect speech, organisation, planning and time management. These difficulties impact on people's ability to carry activities that others manage easily, for example using cutlery, handwriting, taking a telephone message and learning to drive.

Once considered a condition of childhood, it's now known that difficulties associated with dyspraxia persist into adulthood in many cases (Kirby et al 2011). Despite being one of the most common developmental disorders of childhood (affecting around 5% of school-aged children, 2% severely - Lingam et al 2009), previous Dyspraxia Foundation research demonstrates that awareness of dyspraxia remains poor among teachers (2017), mental health practitioners (2018) and employers (2016).

The Dyspraxia Foundation adult survey 2019 included 439 respondents who were diagnosed with dyspraxia as adults, 618 people who suspect they have the condition but who do not have a formal diagnosis and 398 adults who have grown up with a diagnosis of dyspraxia.

Compared to other developmental disorders, dyspraxia is a relatively 'new' condition (diagnostic criteria for developmental coordination disorder – the preferred medical term for the condition – were published by the American Psychiatric Association in 1987) meaning that little is known about the experiences of people with dyspraxia as they become adults. Analysis of responses from the adults who were diagnosed in childhood therefore provides new insights into the experience of adults who have grown up with a diagnosis of dyspraxia.

Findings

Of the 398 respondents diagnosed with dyspraxia as children, most were diagnosed between the ages of 7-11 years (63% n=231).



41% (n=149) of adults diagnosed with dyspraxia as a child were in full time employment (compared to 44% who were diagnosed as an adult).

15% (n=54) were not in employment of education, compared to 10% (n=43) who were diagnosed as an adult).

51% (n=178) of adults diagnosed with dyspraxia as a child had at least one additional diagnosis including 8% (n=30) with ADHD/ADD, 23% (n=85) with dyslexia and 12% (n=45) with autism.

Impact on education

62% (n=165) respondents felt that having a diagnosis of dyspraxia as a child had helped their educational attainment. Having a diagnosis enabled some to access alternative exam arrangements, such as extra time or use of a laptop:

“Getting a diagnosis definitely helped with my education as I had vital extra arrangements for exams - such as a laptop and extra time - as well as support during my time at university. I am 100% certain that I would not have achieved as well in my education without this support.”

Having a diagnosis before finishing school enabled some respondents to apply for Disabled Students Allowance and other adjustments to support their learning and development at university or college. Having a diagnosis of dyspraxia did not always help people who left formal education at age 16 however, as poor awareness of dyspraxia affected their ability to access the reasonable adjustments, they needed to be successful in the workplace.

Impact on relationships

40% (n=108) of respondents felt that having a diagnosis since childhood helped relationships with family members and 28% (n=75) said having a diagnosis helped their relationships with others.

While not every respondent was confident enough to disclose their diagnosis, doing so helped their confidence and relationships:

“A diagnosis has helped my relationships and mental health as it gives me and others an understanding of why I do some of the things I do.”

Several respondents had benefitted from meeting others who share their diagnosis through the Dyspraxia Foundation, including the Dyspraxia Youth support group. Sharing experiences and coping strategies had benefitted their mental and social health.

Impact on identity and self-esteem

30% (n=82) reported that having a diagnosis of dyspraxia helped their mental health as they understood there was a reason to explain why they experienced life as they did:

“Having a diagnosis makes me realise I'm not stupid, I'm just different.”

Respondents had not always been confident about their diagnosis however; some admitted they had been ‘in denial’ as teenagers as it highlighted they were different to their peers. People who had been diagnosed as a child did not always feel they understood what dyspraxia meant until they sought help, often following a crisis at work or in their personal relationships as an adult:

*“Although diagnosed by an Educational Psychologist c1998 as part of SEN Statementing the dyspraxia diagnosis was never explained and I didn’t begin my journey of acceptance until approximately 22 years later with assistance from ***. Prior to this I thought my problems were down to my visual impairment and being useless and stupid.”*

The everyday challenge

Having a diagnosis of dyspraxia since childhood did not reduce the impact of the condition on respondents’ everyday experiences as adults:

“I still struggle daily”

“It’s been a hindrance in every aspect of my life”

Having a diagnosis did however provide an explanation for people’s difficulties and 48% (n=129) of respondents felt it helped them manage everyday activities by enabling them to identify tools and strategies to help:

“(Having dyspraxia) means I’ve had to think of new ways to do things”

Some respondents had turned their experience of living with dyspraxia into a strength that benefitted them and the people they live and work with:

“It’s massively helped me with realising my weaknesses and strengths”

“It’s given me tenacity and a strong work ethic and a desire to “prove myself” so I’m now successful”

Dyspraxia Foundation response to these findings

- Dyspraxia Foundation calls for people diagnosed with dyspraxia as a child to have the opportunity to revisit their diagnosis as adults to enable them to understand their unique profile of strengths and difficulties and identify strategies that support their performance and mental health
- Dyspraxia Foundation calls for greater awareness and understanding of dyspraxia in the workplace
- Dyspraxia Foundation calls for increased resources to enable people with dyspraxia to meet and share experiences/strategies with others who share their diagnosis.

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