

## Mental health support needs of teenagers with dyspraxia



Feedback from a consultation carried out as part of the Dyspraxia Foundation 'Dyspraxia Diffusion' learning event for young people, parents and professionals at Birmingham City Football Ground on 4th March 2016.

Dyspraxia Foundation is a small national charity (and Company Limited by Guarantee) that aims to enable all children, young people and adults with dyspraxia in England and Wales to reach their full potential in life by providing high quality information and support to people with dyspraxia, their families and professionals. This is delivered via a Helpline service, literature, website/social media, conferences/events, Awareness Week campaigns and a network of local support groups.

Dyspraxia Foundation represents the views and values of people with dyspraxia and those who support them, working to ensure their needs are recognised and understood by members of the public, policy makers and professionals working in health, education and employment.

Dyspraxia Foundation believes that the views of people with and affected by dyspraxia are important in helping to improve understanding and support for the mental health needs of teenagers with dyspraxia. We thank all those who contributed to this consultation.

### Definition of terms

**Dyspraxia** is a common developmental disorder affecting gross and fine motor coordination in children and adults. Common associated problems include difficulties with organisation, planning and time management. Dyspraxia can also affect speech. The preferred medical term for dyspraxia is 'developmental coordination disorder' or **DCD**. Motor and non-motor difficulties associated with dyspraxia affect everyday life at home, at school/in the workplace and in other community and leisure settings. Although a unique condition, dyspraxia often occurs alongside other disorders including autism, dyslexia and ADHD. Around 5% of school-aged children in the UK are affected by dyspraxia, 2% to a severe degree. The condition affects around two boys to every girl. There is growing evidence that dyspraxia persists into adulthood in many cases. Secondary social and emotional difficulties are common and have a significant negative effect on mental health, confidence and self-esteem in young people and adults. Adults with dyspraxia often experience social isolation and have problems getting and maintaining a job. With the right help and support however, people with dyspraxia can lead full, productive and satisfying lives.

**Mental health** refers to:

- How we feel about ourselves and others;
- Our ability to make and keep friends and relationships;
- Our ability to learn from others and to develop psychologically and emotionally;
- Having the strength to overcome the difficulties and challenges we face in our lives at times; and
- Having the confidence and self-esteem to take decisions and believe in ourselves.

## Research

There is increasing evidence of associated anxiety, depression, behavioural disorders and low self-esteem in children, teenagers and young adults with dyspraxia/DCD:

- Children with DCD exhibit more aggressive behaviour than age-matched controls (Chen et al 2009). Young people who externalise anger and frustration are more likely to socialise with 'deviant' peers than their more coordinated peers (Wagner et al 2012).
- Young people and adults with dyspraxia are at risk of disengaging and 'opting out' of activities and situations for fear of embarrassment when their difficulties are exposed (Poulsen et al 2011, Stephenson and Chesson 2008, Missiuna et al 2008), increasing the risk of social isolation.
- High levels of anxiety have been reported in young people and adults with dyspraxia/DCD (Skinner & Piek 2001, Schoemaker & Kalverboer 1994). Motor impairments in childhood are associated with a twofold or greater experience of persistent anxiety in late childhood and adolescence (Sigurdsson, van Os et al. 2002).
- Greater levels of anxious and depressive symptoms have been reported in twins with a motor disorder compared to twins without, suggesting that anxiety/depressive symptoms are linked to the motor disorder, rather than to genetic factors (Pearsall-Jones et al. 2011).
- Parents of children with DCD report their children feel over-whelmed because of the expectations and work required of them and 'mask' their problems by putting in extra effort so that their difficulties weren't noticed (Missiuna, Moll et al. 2007).
- Young people with DCD are more prone to somatic symptoms of stress and anxiety such as aches and pains, dizziness, tiredness and nausea than more coordinated peers (Missiuna, Moll et al. 2006, Dewey, Kaplan et al. 2002).
- Young people with DCD experience high levels of 'panic anxiety' when faced by a task that they have previously found challenging (Pratt and Hill 2011), leading to avoidance behaviour.
- Young people with DCD use more resignation strategies than their typically developing peers, suggesting an association between passive strategies and lower self-esteem (Watson and Knott 2006).
- Young people with persistent coordination difficulties have lower aspirations than students with milder motor difficulties and those who are physically able (Cantell et al 1994). This is of concern given that DCD does not affect intelligence (American Psychiatric Association 2013).
- Emotional concerns persist (or even increase) as young people with dyspraxia grow older (Stephenson and Chesson 2008) and are more of a concern to parents than their child's motor difficulties over time.
- Kirby et al (2011) suggest that difficulty dealing with stress, social withdrawal and anger increases the risk of associated psychiatric disorders such as obsessive compulsive disorder in young adults with dyspraxia/DCD.
- Participation in meaningful pro-social activities is related to higher life satisfaction, lower internalizing and externalizing behaviour, and is negatively related to depression, anxiety and loneliness (Poulsen, Ziviani et al. 2006)

## Consultation aims

The consultation aims were to understand from the perspective of those living with or affected by dyspraxia:

- What are the mental health needs of teenagers with dyspraxia?
- What could be done to support the mental health of teenagers with dyspraxia?

The consultation was carried out during a 'Dyspraxia Diffusion' learning event at Birmingham City Football Ground on Friday 4<sup>th</sup> March. This event was organised by Dyspraxia Foundation and included the following presentations:

- Introduction to dyspraxia – Dr Sally Payne, Occupational Therapist
- Support for mental health and well-being for children and young people – Dr Mark Lovell, Consultant Child and Adolescent Intellectual Disability Psychiatrist
- Changes to benefit systems for disabled people – Andy Poole, Welfare Benefits Advisor
- Dyspraxia and exams – Gill Dixon, Dyspraxia Foundation Trustee and parent
- Practical support whilst looking for employment – Katheryn Wood, Remploy
- Raising neuro-diverse children – Monique Crane, Coaching and Advocacy Services
- Employment law and reasonable adjustments in the workplace – Richard Todd, specialist workplace assessor
- When inclusion in the workplace works – Jonathan Andrews, future trainee solicitor and Professional Ambassador for Aspiring Solicitors
- Looking after yourself and your family – Judi Smith, parent and SEN tutor

## The event was attended by 96 individuals including:

- Professionals = 37
- Parents = 23
- Youth = 8
- Adults = 14
- Dyspraxia Foundation staff = 5
- Speakers = 9

## The consultation comprised:

- 1) A focus group attended by 8 young people with dyspraxia and the Dyspraxia Foundation Youth Officer. The session was chaired by Sally Payne, Occupational Therapist, Heart of England Foundation NHS Trust and Dyspraxia Foundation Trustee. Questions asked were:
  - How do you think dyspraxia affects teenagers' mental health?
  - What could be done to better support the mental well-being of teenagers with dyspraxia?
- 2) A 'post-it note' exercise in which all event participants (people with dyspraxia, parents and professionals) were invited to respond to the following questions:
  - What are your mental health concerns for young people with dyspraxia?
  - What support would you like for the mental health/well-being of young people with dyspraxia?

Feedback was analysed after the event by Sally Payne and reviewed by Dyspraxia Foundation Trustees and members of the Youth panel.

## Findings

The following is a summary of consultation findings and combines the views and opinions of the young people's focus group and others who attended the Dyspraxia Diffusion learning event. Findings are presented under two headings: **the mental health needs of teenagers with dyspraxia** and **strategies and supports for the mental health of teenagers with dyspraxia**.

### The mental health needs of teenagers with dyspraxia

**Anxiety** was the most common mental health concern reported by participants who identified the following:

- **Anticipatory anxiety** – fear of embarrassment and worrying about things that might go wrong meant teenagers with dyspraxia sometimes avoided situations and events, putting them at risk of social isolation and limiting opportunities for positive experiences when situations/activities went well.
- **Anxiety about learning new skills** – young people worried about how they would manage new tasks and activities. Their preference for predictability and familiarity sometimes limited opportunities to develop new skills necessary for independence.
- **Using public transport** – young people were concerned about the risk of tripping/falling in front of others because of their poor balance; sensory overload; difficulty organising themselves and their bags; and finding their way around new environments. Fear of using public transport affected their motivation to attend events and activities away from home.
- **Transition to secondary school** – parents and professionals highlighted anxiety associated with the transition to secondary school because of teenagers' poor organisational and time management skills, their social and communication difficulties and the challenge of using new equipment and materials as part of the secondary school curriculum. The pressure of constant assessment was highlighted as a particular concern.
- **Impact of fatigue on anxiety** – one participant linked the physical effort required by people with dyspraxia to manage daily activities to levels of anxiety. Anxiety increased towards the end of the day/week/term and affected teenagers' performance and confidence.

**Low confidence and self-esteem** featured highly among the mental health concerns raised by participants:

- **Self-confidence** – young people's confidence was constantly eroded by their failure to manage tasks and activities that their peers managed easily
- A **focus on disability rather than ability** affected teenagers' confidence and was reinforced by diagnostic and academic assessments that focused on deficits rather than strengths.
- Young people's confidence was also affected by adults and professionals who had **low expectations of teenagers' performance** because they judged teenagers' intelligence by their presentation rather than the content of their work.
- **Feelings of inadequacy** were heightened when teenagers compared themselves unfavourably to their peers.

**Social isolation** was identified as having a significant impact on the mental health of teenagers with dyspraxia:

- Young people and adults with dyspraxia said they experienced **social isolation** in their early teens because difficulties associated with dyspraxia make it hard for them to participate in some socially-valued activities (including sports). *"My daughter feels invisible, socially isolated, not knowing what to say. Anxiety, tiredness, frustration, depression, feeling down."*

- **School systems** mean teenagers with dyspraxia are often grouped with students with other learning needs which add to teenagers' sense of difference. One adult said that being put on the '*dumbo table*' at school isolated him from more able peers with whom he probably had more in common.
- **Bullying** in the early teenage years (a time when conformity is valued more highly than difference) was reported by members of the youth focus group and by parents.
- **Communication difficulties**, including not knowing what to say and how to say it affected teenagers' confidence in social situations. Some individuals continued to experience social anxiety in adulthood.
- Some parents were concerned about the social vulnerability and the risk of **cyber bullying** of teenagers with dyspraxia when using social media.

**Emotional sensitivity** was reported by some members of the youth focus group:

- Some members of the youth group had a **strong sense of empathy** which they regarded as both a strength and a challenge. In some cases, individuals felt overwhelmed by the strength of their emotions because they over-empathised with others.
- Some individuals had **difficulty regulating their emotional responses**, particularly when tired or anxious or when experiencing sensory overload. Fear of embarrassment affected social relationships.

The impact of dyspraxia on teenagers' **sense of identity** was highlighted as a concern by members of the youth group, adults with dyspraxia, parents and professionals:

- **Not knowing anyone else with dyspraxia** made it hard for teenagers to understand their difficulties and to incorporate dyspraxia into their sense of identity.
- As a result, some young people and adults **doubted their competence and questioned their intelligence**. Their sense of inadequacy was reinforced adults (especially teachers) who dismissed their difficulties as unimportant. Some adults with dyspraxia recalled feeling frustrated that others didn't take their difficulties seriously and didn't recognise the impact of their motor and organisational difficulties on all aspects of daily life.
- Delays in identifying and diagnosing dyspraxia added to teenagers' **sense of difference**. One adult said "*When you don't know you have dyspraxia you think you're mad, crazy*".

**Poor awareness and understanding of dyspraxia** among members of the public and professionals was a concern for many participants:

- Youth members felt that poor recognition and understanding of dyspraxia added to their sense of **feeling 'different'**. They were frustrated because people assumed they had dyslexia rather than dyspraxia and were tired at having to explain their difficulties over and over again.
- Poor understanding of dyspraxia in schools meant some teenagers were accused of **laziness or lacking in motivation**. Parents reported that some teenage children internalised this feedback and disengaged from learning.
- **Poor understanding of dyspraxia by mental health professionals** meant some young people were unable to access appropriate help and support for their emotional wellbeing, increasing their risk of anxiety and depression in adolescence and into adulthood.

**Anger and frustration** was a common concern for members of the youth focus group, parents and professionals:

- Teenagers were **frustrated** at not being able to express their thoughts, ideas and learning because of their poor written skills. As a consequence, their grades did not reflect their abilities leading to frustration and disappointment.

- Some young people with dyspraxia **expressed their frustration and anger physically**. Parents were concerned that without help to manage their temper outbursts this would lead to further problems and depression in adolescence and adulthood: *“I’m worried about what happened as he becomes a teenager if he is not given the strategies to cope now.”*
- Parents were also concerned that their child would be **labelled as naughty** and poor understanding of their needs would mean they didn’t receive the help and support they needed: *“He is the one getting into trouble and hurts others out of frustration, anger and communication issues. School have always focused on his behaviour but with no real results.”*

The risk of **depression** was highlighted by several participants:

- While some teenagers expressed their anger, disappointment and frustration physically, others **internalised** these feelings which manifested as depression.
- The **physical and cognitive effort** of getting through a typical day contributed to teenagers’ low mood.
- There was concern that a lack of emotional support in childhood could have **long term consequences** for a person’s mental health during adolescence and into adulthood.
- The risk of having a **‘mental breakdown’** when coping strategies were no longer effective was highlighted by one adult participant.
- The risk of **self-harm** was mentioned by several members of the youth focus group and some adult participants. One adult made a link between body dysmorphia, dyspraxia and self-harm commenting *“My body lets me down and won’t do what I want”*.

### Strategies and supports for the mental health of teenagers with dyspraxia.

Consultation participants emphasised the continuing need to raise **awareness of dyspraxia** (which they described as a ‘hidden disability’) among the general public. The following recommendations to improve support for the mental health of teenagers with dyspraxia were also made.

**Dyspraxia training for education professionals** (including teaching assistants and SENCos) so that:

- the needs and potential of teenagers with dyspraxia are recognised;
- education staff understand the differences and similarities between dyspraxia and other conditions including dyslexia and autism;
- appropriate adjustments are put in place to enable teenagers to reach their academic, social and personal potential;
- staff recognise the impact of their interactions on the well-being of teenagers with dyspraxia;
- staff can identify students with dyspraxia whose emotional well-being may be at risk.
- Participants also recommended the provision of additional resources (printed or online) to support the training programme including advice re. anxiety, self-calming strategies, social impact of dyspraxia etc.

**Specialist outreach support to:**

- Provide training for staff and support for students with dyspraxia similar to that provided for students with autism.
- Promote good teaching practice with students with dyspraxia, enabling staff to recognise and support difficulties with handwriting/PE/organisation/social participation to prevent secondary mental health problems from developing.
- Provide individual support to students with dyspraxia, empowering them to understand their unique profile of strengths and difficulties and to use strategies that enable their success.

### **Dyspraxia awareness training for mental health professionals & commissioners** to ensure that:

- teenagers with dyspraxia have access to appropriate support for their mental health, including anxiety management and assertiveness training.
- mental health professionals understand the impact of dyspraxia on teenagers' mental health, in particular the impact of sensory overload and motor incoordination on anxiety, self-esteem and grief. Some members of the youth panel who had accessed mental health services hadn't found the support useful because the root cause of their anxiety/depression was not really understood.

### **Social and support groups for teenagers with dyspraxia**

- These should provide 'safe spaces' for teenagers to meet others who share their difficulties and to develop social skills. The emphasis should be on fun, participation and support rather than performance. *"My 17 year old son has low mood because of dyspraxia. He doesn't socialise and doesn't know anyone with the condition."*
- These should take place outside the school environment and should be facilitated by trained youth workers who have an understanding of dyspraxia
- Some members of the youth focus group felt it was easier to share experiences and problems anonymously and recommended more access to safe (moderated) 'virtual' social networks.
- Identification of positive role models to inspire teenagers with dyspraxia that they can achieve their life goals

### **Information and support for parents/carers of teenagers with dyspraxia**

- Local support groups facilitated by experienced parents to help parents/carers understand what they can do to support the mental health of teenagers with dyspraxia and to support parents' own well-being
- Better signposting to appropriate sources of support so that parents/carers know where to find help for the mental health needs of their young people.

### **Targeted support for the mental health needs of teenagers with dyspraxia**

- Timely access to multidisciplinary assessment/diagnostic services for teenagers (and adults) with dyspraxia to identify the root cause of their mental health needs. *"Where do I go for assessment and support as a young adult?"*
- Anxiety management and assertiveness training workshops facilitated by therapists and/or trained youth workers.
- Peer-mentoring schemes in schools where young teenagers with dyspraxia are mentored by older students who may or may not have dyspraxia.
- Involving older teenagers with dyspraxia as peer mentors (and in other leadership roles) enables them to use their own skills and experience and helps to build their own self-esteem.
- Signposting to trusted organisations/websites/apps that provide quality information and advice to support teenagers' mental health.
- Easy access to free and timely face-to-face counselling support for older teenagers and adults with dyspraxia
- Text/IM counselling support from trained counsellors that can be accessed at any time of day/night.
- Participants also called for clear access criteria and referral pathways for mental health services to ensure timely service provision.

### Targeted support for adults with dyspraxia

- Better diagnostic pathways for older teenagers/adults with dyspraxia so that individuals can find an explanation for their difficulties and can access appropriate help/support
- Local support groups specifically for adults with dyspraxia
- Peer mentoring schemes for adults with dyspraxia

### Useful resources:

#### *Websites:*

[www.dyspraxiafoundation.org.uk](http://www.dyspraxiafoundation.org.uk) – for information, advice and support about dyspraxia

[www.mind.org.uk](http://www.mind.org.uk) – For advice and support re all mental health issues (including anxiety)

[www.anxietyuk.org.uk/](http://www.anxietyuk.org.uk/) – Lots of excellent information, advice and support available here.

<http://www.mindful.org/mindfulness-practice/mindfulness-the-basics> – Lots of us think about trying mindfulness meditation, but it can be hard to know where to begin. This site will show you how to start, feel better, reduce your stress, and enjoy your life a little more.

<http://www.nhs.uk/conditions/cognitive-behavioural-therapy/pages/introduction.aspx> – For information re CBT (Cognitive behavioural therapy.)

#### *Other information*

Anxiety information sheet for teenagers and adults with dyspraxia

<https://dyspraxiafoundation.org.uk/managing-anxiety-advice-sheet-adults-teenagers/>

Anxiety information sheet written by and for young people with dyspraxia

<https://www.dfyoung.org.uk/wp-content/uploads/2016/02/Managing-Anxiety-v1.1.pdf>

#### *Blogs*

<http://thinkoutsideofthecardboardbox.blogspot.co.uk/2014/01/dyspraxia-anxiety-and-me.html> – a blog in which the author (who has dyspraxia) describes how anxiety affects her and the strategies she uses to manage these feelings

---

### Further information available from

**Dyspraxia Foundation, 8 West Alley Hitchin Herts SG5 1EG**  
**Tel 01462 454986 (Helpline 9 – 1, Mon - Fri)**  
**01462 455016 (Admin) Email: [info@dyspraxiafoundation.org.uk](mailto:info@dyspraxiafoundation.org.uk)**  
**Website: [www.dyspraxiafoundation.org.uk](http://www.dyspraxiafoundation.org.uk)**

Registered Charity No 1058352 A Company limited by guarantee. Registered in England No 3256733