Transforming children and young people’s mental health provision

Response to the Green Paper consultation on behalf of the
Dyspraxia Foundation

Date: 27th February 2018

1. Introduction

1.1. Dyspraxia Foundation welcomed the opportunity to contribute to the Green Paper consultation on mental health provision for children and young people.

1.2. To support our submission, we carried out an online survey from 2.2.18 to 25.2.18 which was promoted to our 1000 members and via our social media networks. The survey asked for detailed feedback on questions included in the consultation. We received 227 responses to our survey from 172 parents/carers of people with dyspraxia and 55 adults with dyspraxia.

1.3 Of the 172 parent/carers who responded to the survey, 75 had accessed specialist support for their child’s mental health while 12 adults with dyspraxia had accessed specialist support for their mental health as a child. 77 adults or children of parent/carer respondents had a diagnosable mental health disorder. By far the most common diagnosis was anxiety. Other diagnoses included depression, anorexia, mutism, bi polar and PTSD.

1.4 This paper summarises the information submitted to the consultation.

2. Response to the core proposals that:

- schools and colleges will be incentivised and supported to identify and train a Designated Senior Lead for Mental Health who will oversee the approach to mental health and wellbeing
- Mental Health Support Teams will be set up to locally address the needs of children with mild to moderate mental health issues, they will work with schools and colleges and link with more specialist NHS services
- Piloting reducing waiting times for NHS services for those children and young people who need specialist help

2.1. Do we think the core proposals have the right balance of emphasis across schools/colleges and specialist NHS young people’s mental health services?

“I think the proposal is exactly the type of support that is desperately needed within schools.”

75% of respondents felt the core proposals had the right balance of emphasis across schools/colleges and specialist NHS young people’s mental health services: “We need to get the support started within schools as a lot of issues start in the classroom and wider school life. If children know there is someone they can go to at school maybe issues can be addressed more quickly and help to have an immediate impact rather than waiting for a referral to join a long waiting list for..."
specialist services”. There was concern however, that the proposals should receive sufficient, additional funding and that funding for mental health support in schools should be ring-fenced. Several respondents were concerned that school staff did not have the time, skills or experience to deliver mental health support: “They are not trained counsellors and it is dangerous to expect them to pick up role of counsellor without training”. The lack of availability of skilled staff to provide specialist NHS mental health support was also highlighted as an area of concern “I am concerned that even if funds were available, do we have the skilled and committed personnel out there to get the job done well?” The need for young people not currently attending school to access mental health support was also highlighted.

2.2. NHS Mental Health Support Teams and Designated Senior Leads for Mental Health in schools/colleges will work closely together. How do we think the success of this arrangement could be measured?

Our top three suggestions were:

- The number of children/young people engaging with appropriate support for their needs
- Mental health knowledge and awareness among school staff
- Young people’s knowledge and understanding of mental health issues, support and self-care.

2.2. How can the views of children and young people be included in the development of Mental Health Support Teams?

“By listening. Really listening.”

Respondents had many ideas about how young people, especially those with dyspraxia/DCD who are often able to articulate their experience, could be included in the development of Mental Health Support Teams: “He would have some great ideas about how to help him feel more confident and comfortable at school.” The importance of including young people in service user panels during the development phase was highlighted, as was the need for local young people to be involved in the development and monitoring of local teams to ensure services are responsive to local need: “each team should have the flexibility to adjust to the needs of the children & young people they serve”. The need to access young people in rural settings was specifically mentioned. Methods for gathering the views of young people included surveys (online or delivered through schools) on the help they have received and the difference this made to their mental health; focus groups in schools and PRUs; face to face conversations with young people who have accessed services in a non-clinical setting; use of creative activities and animations or cartoons to stimulate class discussion; discussions with pupil reps/school councils; discussion in PHSE lessons; and discussion with individuals as part of the SEN annual review process. For those who have difficulty articulating their views, asking siblings and/or parents/carers was suggested. Other ideas included ‘Exit interviews’ for young people to find out whether they felt the support was successful, and why/why not.

2.3. Schools publish policies on behaviour, safeguarding and special educational needs and disability. To what extent do we think this gives parents enough information on the mental health support that schools offer to parents?

- Some of the information that parents need

Respondents felt that school SEN policies tended to focus on physical and/or learning needs and that the impact of conditions such as dyspraxia/DCD on mental health were rarely mentioned, even

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though this was an area of considerable concern to parents/carers. Even when policies did include reference to mental health support, these could be difficult to find or understand (by parents/carers and school staff) and failed to give specific details about what mental health support is available or how this could be accessed: “Are these policies accessible both physically and in terms of how they are framed, or are they like car and house insurance documents? It needs to be transparently obvious how to get help.” In some cases, the lack of information about mental health support included in school policies was thought to reflect the lack of mental health support that was available: “There is no information provided by schools on mental health support because there is no provision given by schools for mental health support”. In many cases respondents felt that schools didn’t deliver what was included in the policy: “It outlines what they should give, but in my experience this does not always reflect what they actually do”. Some respondents felt that there should be a separate policy for mental health support, as mental health should be recognised as important as safeguarding and SEN.

2.4. How can schools/colleges measure the impact of what they do to support children and young people’s mental wellbeing?

Impact should be measured by an independent evaluator to minimise bias. Suggestions included reviewing case studies that document the experience of young people and families and gathering feedback through focus groups and surveys from young people, parents/carers, teachers and mental health professionals about the difference that mental health support provided in schools has made. Changes in knowledge/understanding of mental health should be monitored as well as pupils’ ability to recognise symptoms in themselves and others; and knowledge about where to seek help and what they can do to promote their own mental well-being. Teachers’ confidence in supporting pupils’ mental health needs could also be monitored.

Quantitative impact measures include attendance, number of exclusions, incidents of bullying, happiness, behaviour, participation in clubs/activities, engagement in lessons, educational attainment and whether those identified with mental health needs continue into higher education: “Attendance and attainment are directly affected by mental health issues as if a child is not emotionally secure and settled at school they won’t want to attend and even if they do, successful learning is unlikely to take place”.

It was recognised that “No-one comes for help with their mental health at the drop of a hat, meaning anyone coming for help can be counted as a success” so impact could be measured by the number of pupils accessing and engaging in mental health interventions and the number of appropriate referrals to external mental health support agencies. The number of students with SEN accessing mental health support should be specifically measured.

2.4. How teams could work with children/young people who experience different vulnerabilities will be considered in the development of Mental Health Support Teams. How could the Support Teams provide better support to children/young people with dyspraxia/DCD?

Respondents felt that training should be provided to ensure that staff understand and recognise the motor and non-motor (organisation, planning etc) difficulties associated with dyspraxia/DCD and their impact on mental health: “Academically able children with dyspraxia and anxiety develop amazing coping strategies, so often get overlooked. I’d like to see more acknowledgment of this and more time invested to ensure these children’s mental health and emotional needs are not being ignored/misunderstood”. Young people with dyspraxia/DCD need easy access to someone who understands their condition and who can advocate on their behalf. Occupational therapists were identified as key members of Mental Health Support Teams who could train staff and identify and support the physical and mental health needs of young people with dyspraxia/DCD. Interventions should help young people with dyspraxia/DCD develop strategies to reduce the practical/organisational challenges that make them feel inadequate. Other interventions include counselling, CBT and group work for anxiety management, building self-esteem, reducing social isolation and promoting a positive sense of identity as a young person with dyspraxia (or another
specific learning disability). Mental Health Support Teams should provide a safe, calm and caring place for young people to share any concerns. Peer support workers, identifying positive role-models and sign-posting to opportunities where young people can have meaningful interactions with peers outside school are also recommended. The need for staff to develop a personal relationship with the young person and their parents/carers was highlighted as each person with dyspraxia/DCD is different.

2.5. How do you think the Government can test whether children and young people with special educational needs or disability (specifically dyspraxia/DCD) are able to access support?

Several respondents felt that mental health provision for children and young people should be included in Ofsted/CQC inspections which would enable Government to test whether young people with SEN/disability can access support. For children with an EHCP, the annual review process could be used to record whether young people have been offered support and if this has been taken up; this information should be monitored and reported by Local Authorities. For young people with SEND who do not have an EHCP, information could be provided by the SENCO as part of school census data. Organisations such as the Dyspraxia Foundation can carry out surveys (such as the one we developed for this consultation) to gather data and case studies that illustrate the personal experiences of young people with SEND and mental health support needs. This would be a good way to test whether young people with specific learning difficulties who don’t meet the threshold for an EHCP/Senco input receive support for their mental health needs. Data could also be gathered from CAMHs teams regarding the number of young people referred who have SEND. A quality mark for schools that provide good mental health support for all pupils, including those with SEND might also be introduced and the number of schools taking this up recorded.

2.6. Evidence of the proportion of children with diagnosable mental health conditions who would benefit from support from Mental Health Support Teams.

According to our survey, 33% of children with dyspraxia/DCD had a diagnosable mental health disorder. By far the most common diagnosis was anxiety. Other diagnoses included depression, anorexia, mutism, bi-polar and PTSD.

2.7. Evidence of the proportion of children with pre-diagnosable mild or low-level mental health problems who would benefit from support from the Mental Health Support Teams.

Research suggests that “motor impairments in childhood are associated with a twofold or greater increase in the odds of experiencing persistent anxiety in late childhood and adolescence” (Sigurdsson, van Os et al. 2002). This was reflected in the findings of our survey: 77% of respondents felt they (or their child) had mild or low-level mental health needs that put them at risk of developing a diagnosable mental health disorder. Respondents identified problems with bullying, low self-esteem, social isolation, frustration, under-achievement and anxiety that impacted on their mental health: “My child is likely to suffer from low self-esteem and depression due to peer pressure and his difficulties in achieving ordinary activities like riding a bike.” Many had been unable to access mental health support because their needs weren’t great enough.

2.6. Please tell us about any interventions for children with mild to moderate mental health needs that you/your child has experienced and the difference these made. This could include their impact on mental health and on other outcomes including education, employment, physical health and so on.
Some of our respondents had been fortunate to receive some support for their mental health and reported the following:

We have used a cognitive behaviour approach which has helped us overcome a lot of his anxieties.

Once I was diagnosed and told that everything I was struggling with was because of this, my anxiety definitely reduced.

A school counsellor has weekly sessions with my eight year old son which he has found incredibly helpful and reassuring

School counselling - which didn't help. Specialist counselling from Occupational Therapy - which did help

My daughter has weekly counselling sessions which we pay for privately to help her manage her general anxiety and in particular her extreme phobia of dogs and cats. The counsellor has helped my daughter to try and think about and verbalise her feelings and by setting small achievable goals every week which are monitored and celebrated as real achievements. For example, looking at a neighbour's dog behind the gate to observe a specific characteristic rather than rushing past in a panic without looking at it. We work together to support our daughter in the work that she does with the counsellor and it helps us to know how to reinforce the strategies at home. As much as we tried to acknowledge the fear, reassure and listen to my daughter, parents can only do so much to help and support their children with complex needs and they should be able to access professional support before the problem becomes too debilitating.

A private therapist that gave her the chance to talk about her diagnosis, self-esteem, impact of bullying and anxiety. She learned strategies to be able to calm herself. We learned strategies to help her too

I didn't have any interventions in childhood, sadly, as I was not diagnosed until in my 50s. I have in adulthood had counselling sessions at various stages, which have been very helpful.

CBT - 10 week programme ongoing counselling paid for privately Impact: emotional regulation improved which in turn has improved his ability to manage school environment - he used to be excluded weekly, now once in 2 years

My child has accessed ELSA support at school and continues to receive support when needed. He has also accessed a course in managing anger with The Emotional Wellbeing Service. These have made a world of difference to his behaviour at home and at school and, as a result, my son is much happier in himself.

My daughter had 6 months of counselling with a specialist Learning Disabilities Psychologist. This was hugely helpful to her. However, I do feel that some ongoing, low level support (almost 'someone to chat to') would have been really effective in reducing the potential for her having further severe difficulties in the future.

My son was lucky enough to attend a school with a designated and qualified counsellor. During yr 5, over the period of a year, his mental health and self-esteem raised considerably. His mindset altered from fixed to growth, and his resilience increased. He is much much happier and now has a set of friends - his first since joining school. The school has really turned him around. Up until this point, we were looking at home schooling because his depression was so bad. I now feel positive about him completing his education.

Morning mindfulness sessions have supported him to remain calm and focus on his abilities

Play therapy (delivered in school) was accessible and useful for my son who made progress across many areas of school life.

ELSA & mindfulness course have helped with extreme anxiety, overwhelming emotion, negative feelings, lack of self esteem and exam anxiety
I received CBT therapy due to stress at work at around 27, it helped me manage my stress. I often think if this had been available for me at an early age I would have been confident to do a job that helps others and impacts society early on. Luckily enough I went to university at a time when people believe dyspraxia exists, and that I know I’m not abnormal and capable. Had I have been older I probably would be struggling with mental health issues and in low paid jobs.

Survey analysed and responses submitted by Sally Payne, Trustee, 27th February 2018

The Dyspraxia Foundation added to their submission by responding to questions 17, 18, 19 and 21 as follows:

Question 17:

Please provide any evidence you have on the proportion of children with diagnosable mental health disorders, who would benefit from support from the Mental Health Support Teams

Dyspraxia/development co-ordination disorder (DCD) affects 5% of the UK population and up to 2% severely. It is a condition that is commonly overlooked and is often confused with dyslexia, Asperger’s Syndrome/ASD and ADD/ADHD. Whilst these conditions can often co-exist in the same individual, dyspraxia/DCD is a separate condition which requires a unique set of interventions.

Dyspraxia/DCD is formally recognised by international organisations including the World Health Organisation and occurs across the range of intellectual abilities. Individuals may vary in how their difficulties manifest themselves and these may change over time depending on environmental demands and life experiences.

During the crucial early school years, symptoms can include delayed speech, clumsiness and ungainliness, hyper mobile joints, poor hand-eye co-ordination, and an inability to complete everyday tasks such as tying shoelaces or attending to personal hygiene.

According to research, an undiagnosed child with dyspraxia is up to two times more likely than an average child to suffer from mental health problems by the time they are 16. Lack of identification and intervention can lead to longer term consequences including poor academic performance, low self-esteem, poor self-perception, withdrawal, behavioural problems, anxiety and depression.

The underlying cause of Dyspraxia/DCD is unclear, although research suggests that it may be the result of delayed maturation of the nervous system. Genetic factors may also play a part and children born early or with a low birth weight are at increased risk of the condition. An individual’s motor performance is influenced by environmental factors, including having the opportunity to practice and master skills.

For many people, dyspraxia/DCD is a lifelong condition for which there is no “cure”, yet public awareness of the condition remains low compared to other developmental disorders (Dyspraxia Foundation 2007).

Dyspraxia is commonly perceived as a ‘male’ disorder. While UK research indicates that two boys to every girl experience motor difficulties associated with Dyspraxia/DCD (Lingam et al 2009) a Dyspraxia Foundation survey (2015) revealed that girls are typically not diagnosed until adulthood meaning they are missed in the classroom.
However, there is a positive side to dyspraxia/DCD in that people with the condition tend to be creative lateral thinkers who are empathetic, determined and good at solving problems.

**Question 18**

Please provide any evidence you have on the proportion of children with pre-diagnosable mild to low-level mental health problems who would benefit from support from the Mental Health Support Teams.

Currently, it takes on average 2.5 years for a child to receive a diagnosis, which generally does not happen until the age of 7.

According to Dyspraxia Foundation research 42% of teachers say that they are not able to recognise the symptoms of dyspraxia/DCD and 60% of teenagers with dyspraxia/DCD report they have never been offered professional help to assist with challenges such as coping with higher education, finding a job and developing independence skills.

Referrals, when they happen can result in a child having to be seen by up to five professionals before a successful diagnosis can be made. Services and support provided by local authorities is also varied from county to county.

50-70% of children with dyspraxia/DCD will continue to have difficulties into adulthood. This means that around 3% of the adult population are affected.

**Question 19:**

Please provide any evidence you have of the impact of interventions for children with mild to moderate mental health needs, as could be delivered by the Mental Health Support Teams. We are interested both in evidence of impact on mental health and also on wider outcomes such as education, employment, physical health etc.

The Dyspraxia Foundation believes that if steps are taken to ameliorate the outcomes of dyspraxia/DCD it will, in turn, reduce the cost to the NHS for future mental health treatment; prevent individuals from becoming reliant on the benefits system; boost the wider economy by reducing days lost at work; and unleash the creative talents of children growing up with dyspraxia/DCD.

This view is borne out by research which links the numbers of young people with mental health issues and the wider impact it has on the economy.

A 2016 report prepared by LSE’s Personal Social Services Research Unit (PSSRU), supported by YoungMinds, and funded by the NHS Confederation Mental Health Network, was the first of its kind to analyse the economic impact of youth mental health services in the UK. It found:

- 27% of young people aged 16 to 25 with mental health issues were not in employment, education or training (NEET) compared to 16% of young people that age without mental health issues;
- 27% of young people with mental health issues were on benefits compared to 14% of those without mental health issues;
• 55% of young people aged 12 to 25 with a mental health issue were not receiving mental health services. For those young people aged 21 to 25 with a mental health issue, 64% were not receiving mental health services.

The National Mental Health Development Unit in collaboration with the NHS, Local Authorities and other major stakeholders has made an assessment of the costs of treatment associated with mental health.

• The unit estimates that better mental health support in the workplace could save UK businesses up to £8 billion a year;

• It adds that Improved early intervention and home treatment could save up to £38 million through reduced acute hospital admissions (700 per annum), shorter lengths of hospital stay (25%), and less use of high-cost intensive interventions;

• The financial costs of the adverse effects of mental illness on people’s quality of life are estimated at £41.8 billion per year in England;

• Evidence-based parenting support for families and at-risk children prevents mental health problems in later life and results in better outcomes in health, education, employment, education and relationships;

• Interventions in families with children at higher risk of conduct disorder would cost £210 million but save £5.2 billion.

While these figures are representative of mental health issues as a whole rather than dyspraxia/DCD specifically, there is a clear correlation between numbers of young adults seeking help for mental health issues and the 3.5 million adults of working age with dyspraxia/DCD who have gone through the school system without treatment and who continue to have difficulties.

The benefits of helping them do so are clear. Research conducted by Texas University has shown that ‘Individuals with DCD show consistent and early emergence of mental and physical health problems, which can greatly impact healthcare, in both costs for the government and wellness of the patient, especially in the long term.’ (Cacola et al 2016)

Question 21:

Is there any other evidence that we should consider for future versions of the Impact Assessment?

Education and what can be done

Despite a current lack of provision in the teacher training syllabus dealing with a broad range of neurological issues, many parents of children with Dyspraxia/DCD are advised by experienced teaching staff that there may be a developmental issue and that they should seek a referral from GP.

A referral will be either to paediatric services or occupational /physiotherapy depending on clinical pathways and funding arrangements in their local area. As mentioned above it can take up to three or four years before a diagnosis is given with children often having to see up to five professionals during
the crucial early years. A successful referral can often be reliant on the extent that the GP understands the issue.

Not all children with dyspraxia/DCD require an Education Health Care (EHC) plan. The needs of many can (and should) be met from schools existing resources, as long as they have the training to recognise and culture to implement appropriate reasonable adjustments.

If the child does require an EHC plan, it is jointly funded by the Department for Education and the Department for Health and can provide physiotherapy, occupational training and equipment.

As with mental health and physical conditions, patients are subject to a postcode lottery whereby the level of treatment and support available is dependent on the funding arrangements and the fiscal priorities set by individual county councils and Clinical Commissioning Groups.

Medically there is consensus around the definition, diagnosis and intervention of dyspraxia/DCD published in Europe by the European Academy of Childhood Disability (EACD, 2011) and in the UK by Movement Matters, an umbrella organisation representing the major national groups of clinicians, practitioners and academics concerned with children and adults with coordination difficulties.

Interventions do not need to be costly or time consuming. Simple measures such as breaking down tasks and building timeouts into the day, as well as occupational therapy and exercise have clearly measurable outcomes.

The criteria of the review should consider:

- The ability of schools to refer directly to professionals;
- The extent that local health authorities offer a clear pathway to diagnosis and for local education authorities to know what these are so they can refer children to the appropriate health service.
- Although there is a nationally agreed criteria for identification, diagnosis, assessment and intervention (the EACD guidelines), this should be implemented across the UK.
- The need for clearly defined funding streams for assessment, diagnosis and intervention/support to address the practical and mental health needs of young people with dyspraxia/DCD.