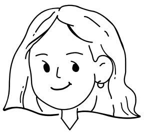
Impact of Developmental Coordination Disorder (DCD) in the UK

This describes the data collected during a national survey measuring the impact of Developmental Coordination Disorder (DCD) / Dyspraxia in the UK. This was completed by parents of children (aged 5-18 years) with DCD.

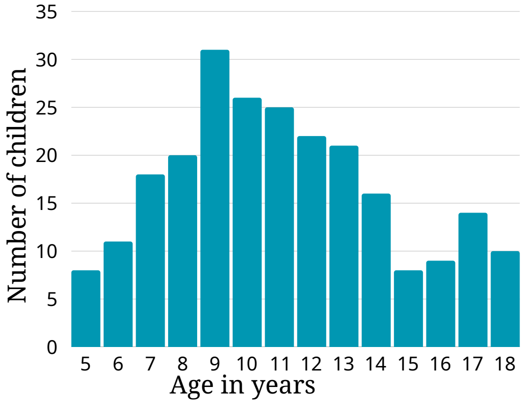
Who took part in the survey?

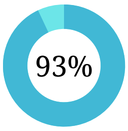
241 parents took part

173 of the children were described as boys

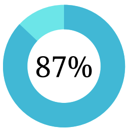


67 of the children were described as girls



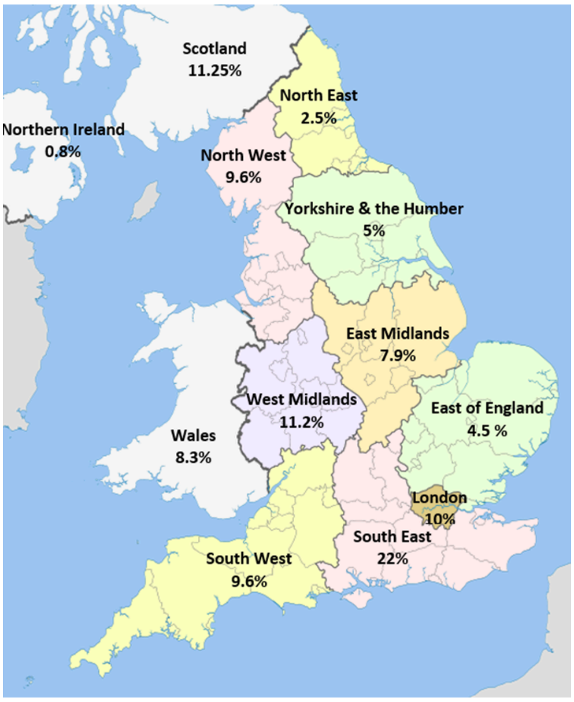


of the children were white



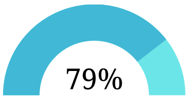
of the children were born after 37 weeks

Geographical spread of participants

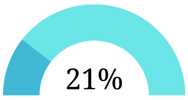


Impact of diagnosis

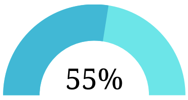
The average wait between first seeking help and diagnosis was 2.8 years



of children had a diagnosis for their movement difficulties

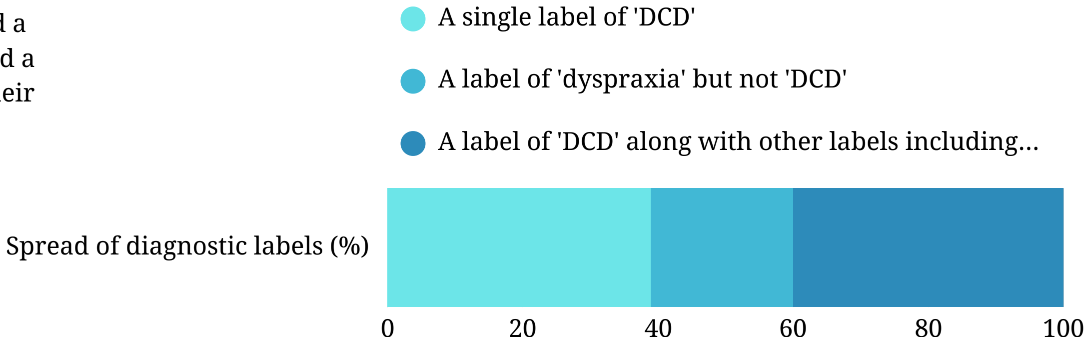


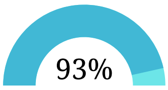
of children were awaiting a diagnosis for their movement difficulties or had not yet started this journey



had co-occurring diagnoses for other difficulties

of those who had a diagnosis **13%** had a single label for their movement difficulties





of parents said the diagnosis was helpful

- It helped to provide an explanation of the difficulties their child experienced
- It provided parents with understanding
- It allowed the family to access support groups

Despite these benefits parents also showed disappointment that a diagnosis didn’t always change the support their child received from school.

It is helpful for us at home but not at school. I raised concerns via school who said my child was ‘fine’ and they had no concerns. Following a diagnosis, they ignored recommendations

Nothing really changed within school for him

When support was given by occupational therapists this was valued, but felt limited

71% of families who had a diagnosis got the majority of their support from the internet

Impact of everyday functions

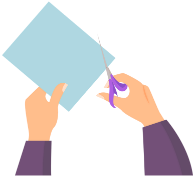
Top five activities reported as being most difficult for their child

Eating

Dressing

Drawing / writing

Self care



Cutting with scissors

When comparing their child to other children

98%

of parents reported it took their child **longer to perform movement**

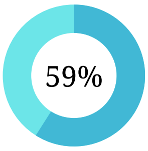
92%

of parents reported their child was **more fatigued by**

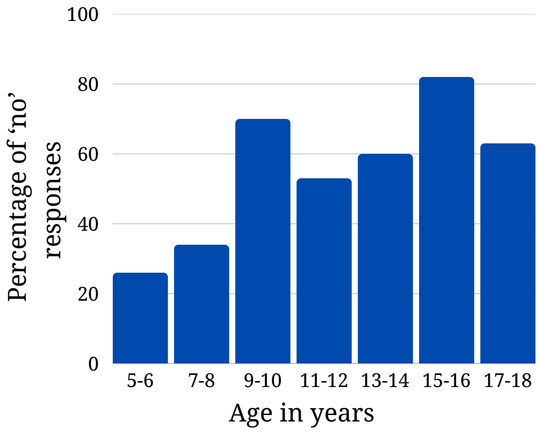
82%

of parents reported their child was **more tired at the end of the**

Then, when focusing on physical activity parents were asked ‘Does your child enjoy physical activity?’

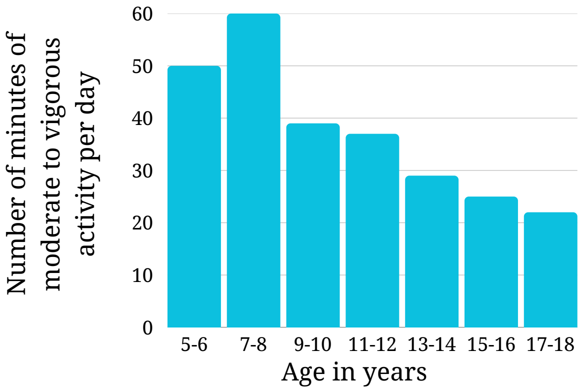


of parents reported that their child **did not** enjoy physical activity



Government guidelines recommend an average of at least 60 minutes of moderate to vigorous activity per day

Only **36%** of children met this (nationally 45% of children meet this)



59%

of parents were concerned about their child’s physical health

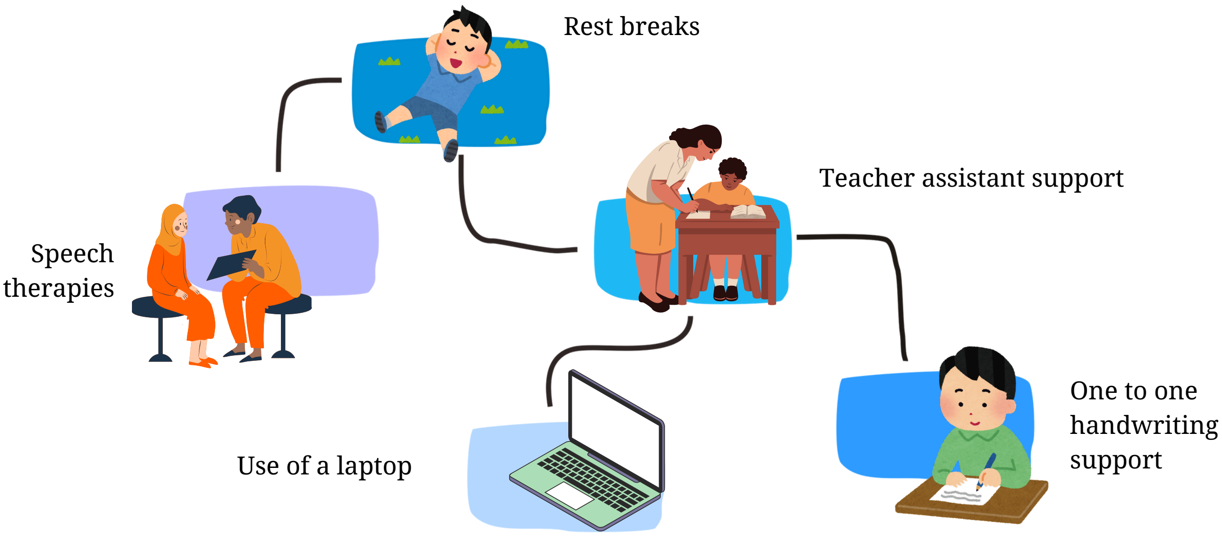
> His dislike of sports means he only gets regular exercise because of PE and games lessons at school. His unwillingness to engage in sport without being forced to is building bad habits for the future and his ability to stay healthy

Impact on Education

One in three parents reported their child did not enjoy going to school

Although **81%** of teachers were aware of the child’s movement difficulties only 56% of children had an individual learning plan in place

Support provided by schools



Rest breaks

Speech therapies

Teacher assistant support

Use of a laptop

One to one handwriting support

Academic Impact

81%

of parents felt their child’s movement difficulties impact **negatively on their education**

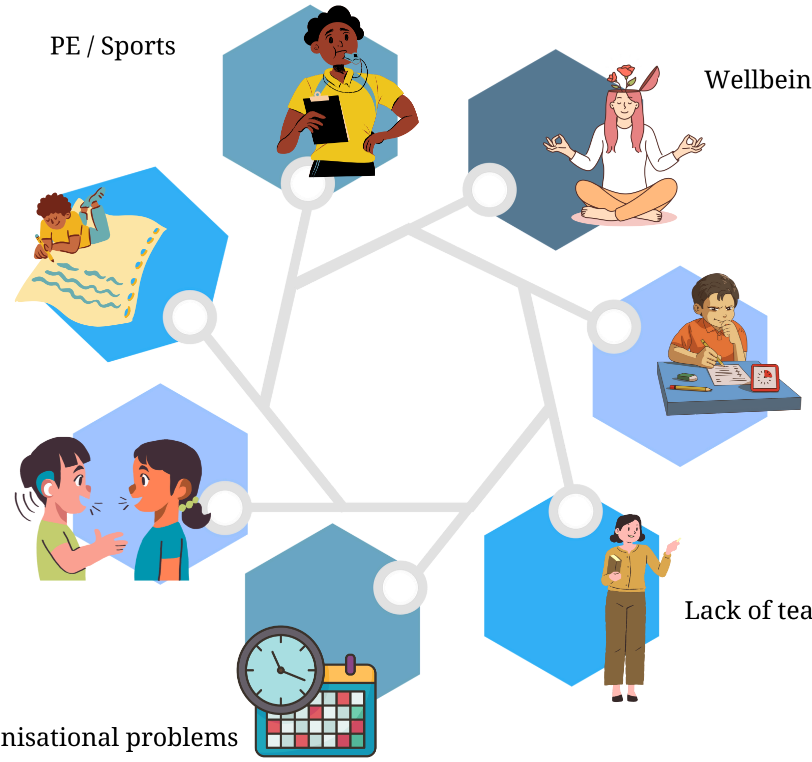
80%

were concerned about the impact on their child’s ability to gain **future employment**

> [I am concerned] that my bright, capable, warm, funny child will struggle to achieve the grades which he’s intellectually capable of

> She is clever but if she can’t write her answers down quickly enough in exams then she won’t be able to show her knowledge

Greatest school based challenges



PE / Sports

Wellbeing

Handwriting

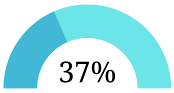
Falling behind

Social aspects of school

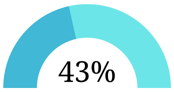
Lack of teacher support

Organisational problems

Physical Education (PE)



37%
of children were reported not to enjoy PE.

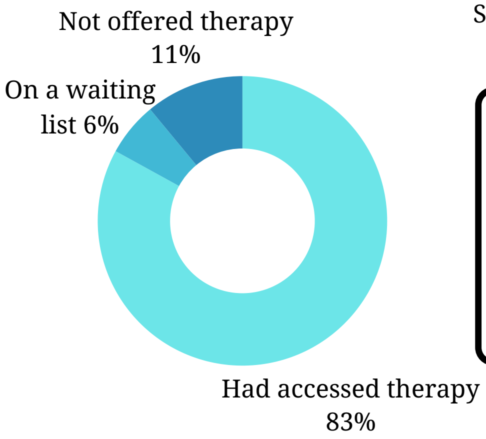


43%
of parents felt their child was not supported in PE

No support or understanding for PE lessons, no accommodations provided since recent change of teacher. (Child commented that he enjoyed previous PE lessons and support, and understanding was given - specifically stated that he felt involved, although knew he was often given supporting roles, he still felt part of the team and never felt embarrassed)

PE teachers haven’t got a clue about dyspraxia [DCD]

Impact of Therapy



Some parents really valued the therapy their child received

OT literally changed my son's life - he was lucky to get support for almost 4 years. ALL children should have OT - I cannot express how much of a difference it made

But not everyone was offered therapy

It makes me cross that once your child is diagnosed you are left to do what you can do………… it feels like you are left to it after diagnosis and that's it. I have done a lot of research and so the best I can but you definitely feel alone with the condition

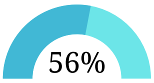
80% of the children received therapy from more than one professional

66% saw an **occupational therapist** which lasted an average of **18 months**

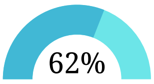
36% saw an **physiotherapist** which lasted an average of **13 months**

28% saw a **speech and language therapist** which lasted an average of **28 months**

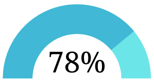
Other professionals accessed included psychologists, podiatrists, counsellors and play therapists



accessed therapy funded by the NHS, the rest sought therapy privately

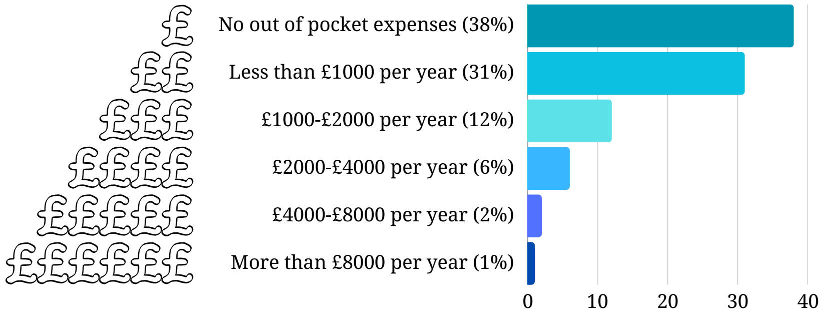


felt supported to maintain the progress that their child had made during therapy



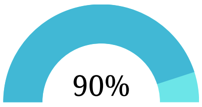
did not feel the therapy was sufficient to support their child with the movement difficulties

The cost of therapy



Other non-financial costs associated with therapy included parents having to take time off work and missed school time

Impact on Social and Emotional Health



of parents were concerned about the impact pf their child’s movement difficulties on their social and emotional health.

Their main concerns fell into 10 categories

- Poor mental health
- Low confidence
- Poor self-esteem
- Acceptance
- Self-harm
- Friendships
- Bullying
- Difficulty keeping up
- Exclusion by peers
- Isolation / withdrawal

> Since his diagnosis he has repeatedly struggled with being different, and has on occasion said he doesn’t belong here and doesn’t deserve to be alive. His internal dialogue is set to negative thoughts, and he often berates himself and tells me he is terrible and stupid.

> I know it bothers him every time he faces a new challenge that his friends don't even have to think about. For example, we're now agonising over whether he should try and learn to drive or not. He really wants to but he knows in reality it's probably unlikely and that starts to really affect him. He is also concerned about his body image as he is not as toned or fit as his friends. He loves playing football and whilst he attends training every week he rarely gets picked to play in the match - at best he gets 10 mins right at the end if he's lucky.

> Sometimes he gets down about it and I can usually help him feel better. The concern would be if I couldn't help him feel more confident as he grows older.

Parents reported their child always or often.......

62% ....felt anxious when learning or performing motor activities.

56% ....withdrew from movement activities.

47% ....had difficulties socialising with peers.

44% ....had difficulties making friends.

56% ....felt happy.

34% ....felt angry or mad.

Impact on the family

68% of parents always or very often had emotional **worry or concern**

77% of parents always or very often had concern about the **future**

21% of parents always or very often felt **financial strain**

52% of parents always or very often felt the **time** for their own needs was limited

48% of parents always or very often felt limited in what **family activities** were possible

How do these children compare to other children in the UK?

We used the **Strengths and Difficulties Questionnaire** (Goodman, 1997) to compare aspects of social and emotional development to that seen in other children in the UK.
Below we show the percentage of children from this cohort who score above or below the level we would expect

64% of children showed high or very high levels of **emotional problems** compared to the UK average

63% of children showed high or very high levels of **peer relationship problems** compared to the UK average

42% of children showed low or very low levels of **pro-social behaviour** compared to the UK average

Key priorities identified by parents

Parents were asked to identify what they felt the key priorities should be for children with DCD. These fell into six different areas and they are summarised below

7% indicated that support groups were needed locally.

72% stated that more training was needed to increase teacher knowledge and understanding on how children with DCD should be supported in schools.

12% said a higher societal awareness is needed.

72% indicated frustration with GPs not understanding DCD and 10% indicated a need for a simipler and quicker pathway to diagnosis.

11% said more therapy is needed and 12% indicated resources to help parents are needed.

20% indicated more support is needed for mental health concerns

Key recommendations

Based on the findings of the survey and considering the priority area identified by parents the following key recommendations were developed alongside a small group of parents of children with DCD, young adults with DCD family and professionals who work with this group.

Awareness
Diagnosis
Education
Social and Emotional Health
Support

Awareness

- Advocacy organisations to hold **awareness campaigns** for the public and professionals to highlight DCD and the impact it has in different aspects in children's lives
- Local Authorities and Department of Health and Social Care to signpost practitioners, educators and parents to **appropriate resources**.
- Raise awareness of parents, educators and health professionals about the link between DCD and **mental health difficulties**.

Diagnosis

- Provide parents, educators and GPs with a clear outline of the diagnostic pathway for the relevant NHS trust/Health Board and how to identify signs of motor difficulties and refer parents for support.

Education

- The Department for Education needs to incorporate information on how to support children with DCD into teacher training and ongoing professional development.
- The Department for Education to provide local education authorities with the tools to help educators identify children with DCD.

Social and Emotional Health

- Health professionals (General Medical Council) and educators (Department for Education) should be provided with **information regarding the relationship between DCD and mental ill health** and refer to a psychologist, counsellor or, a mental health nurse.

Support

- Where appropriate increase the support for children with DCD and families to address both difficulties of motor skill and a child's health and wellbeing that can start while on a waiting list.

For further support

International Society for Research and Advocacy for Developmental Coordination Disorder (ISRA-DCD). ISRA-DCD is a non-profitable organisation and aims to advance knowledge of DCD/Dyspraxia and global awareness. It provides information about DCD and websites of helpful resources for parents/carers, educators, medical and health professionals developed globally.

DCD Kids: Awareness & Advocacy for DCD in Children. This a Canadian parent-run organisation aiming to raise awareness of DCD and advocate for better support in the education system and the wider community. It provides information about DCD, helpful resources and stories to support parents and their family.

Developmental Coordination Disorder (DCD) Australia. DCD Australia provides information about DCD, its impact, diagnosis and DCD in adulthood. It includes useful fact sheets for parents, educators and medical and allied health professionals.

Sheffield Children's NHS Foundation Trust. The motor skills team provides information about DCD, websites and resources for parents and educators. For example, there are videos and resources to provide tips and advice how to teach independence skills such as dressing, brushing teeth, using a knife and fork

Suggested citation

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References

Goodman R (1997) The Strengths and Difficulties Questionnaire: A Research Note. Journal of Child Psychology and Psychiatry, **38**, 581-586.

Acknowledgments

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The authors

Project leads

Dr. Charikleia Sinani

Professor Kate Wilmut

Other UK team members

Dr. Judith Gentle

Dr. Catherine Purcell

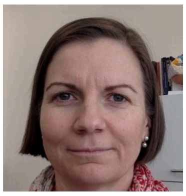
Mr. Sam Hudson

Dr. Mark Mierzwinski

Dr. Greg Wood

Founders of the DCD impact study

Dr. Melissa Licari



Dr. Jacqueline Williams