Sinani, Charikleia ORCID: https://orcid.org/0000-0001-8942-8780, Mierzwinski, Mark ORCID: https://orcid.org/0000-0002-9751-5865, Williams, Jaqueline, Licari, Melissa, Purcell, Catherine, Gentle, Judith, Wood, Greg and Wilmut, Kate (2023) The Impact of Developmental Coordination Disorder in the UK. In: UNSPECIFIED. (Unpublished)

The Impact of Developmental Coordination Disorder in the UK DCD UK Full slides

Presentation · July 2023

DOI: 10.13140/RG.2.2.34919.42400

8 authors, including:

Charikleia Sinani
York St John University
24 PUBLICATIONS **84** CITATIONS

Judith Gentle
University of Surrey
7 PUBLICATIONS **50** CITATIONS

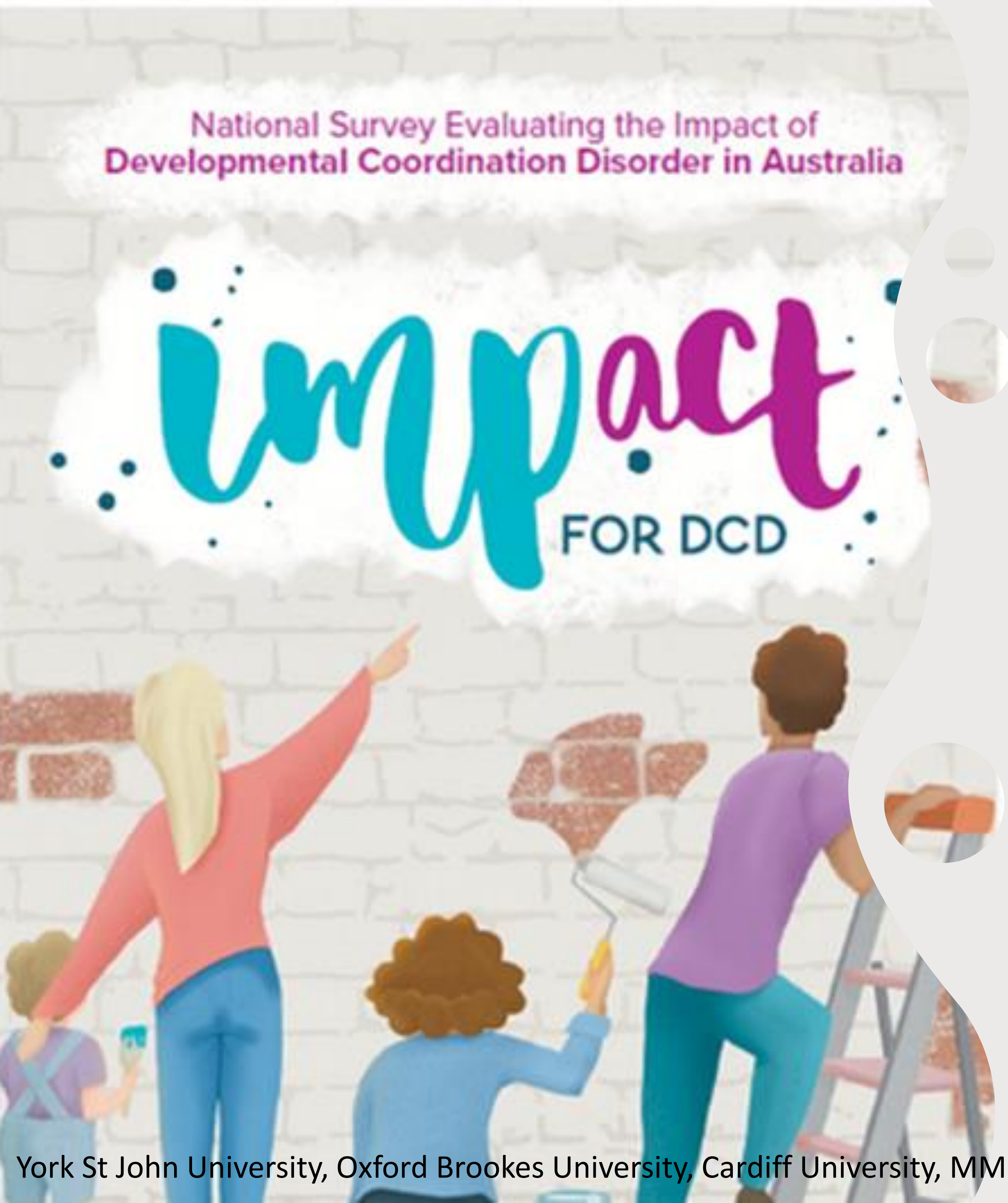
The Impact of Developmental Coordination Disorder in the UK

IMPACT FOR DCD

Dr. Charikleia Sinani, Dr. Mark Mierzwenski, Dr. Jacqueline Williams, Dr. Mellissa Licari, Dr. Catherine Purcell, Dr. Judith Gentle, Dr. Greg Wood & Professor Kate Wilmut.

Est. 1841 YORK ST JOHN UNIVERSITY

York St John University, Oxford Brookes University, Cardiff University, MMU, Victoria University, Western Australia University & Telethon Kids Institute



Background

- In 2020, an Australian research group carried out one of the largest surveys conducted in the world to identify the challenges experienced by children with DCD and their families - https://www.telethonkids.org.au/projects/impact-for-dcd/
  - Key findings:
    - delays in diagnosis,
    - the use of inconsistent terminology,
    - limited funding for support,
    - lack of awareness amongst teachers and health professionals
    - high rates of mental health issues

York St John University, Oxford Brookes University, Cardiff University, MMU, Victoria University, Western Australia University & Telethon Kids Institute

The UK study - aims

Following on the Australian study there was a clear need for this study to be replicated in the UK to:

i) understand the scale and breadth of issues experienced in DCD *and*

ii) to identify and prioritise areas in which children with DCD and their families require support.

The UK study

- Questionnaire adapted based on the Australian study
- Included questions around the following areas:
  - family and diagnostics,
  - movement & difficulties,
  - activity,
  - schooling,
  - therapy,
  - social and emotional impact on the child (some questions based on the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1987) https://www.sdqinfo.org/
  - Demographics, socioeconomic status,
  - parents to identify priorities and further comments.

The UK study

- Questionnaire adapted based on the Australian study
- Included questions around the following areas:
  - family and diagnostics,
  - movement & difficulties,
  - activity,
  - schooling,
  - therapy,
  - **social and emotional impact on the child** (some questions based on the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1987) https://www.sdqinfo.org/
  - Demographics, socioeconomic status,
  - parents to identify priorities and further comments.

Who took part in the study

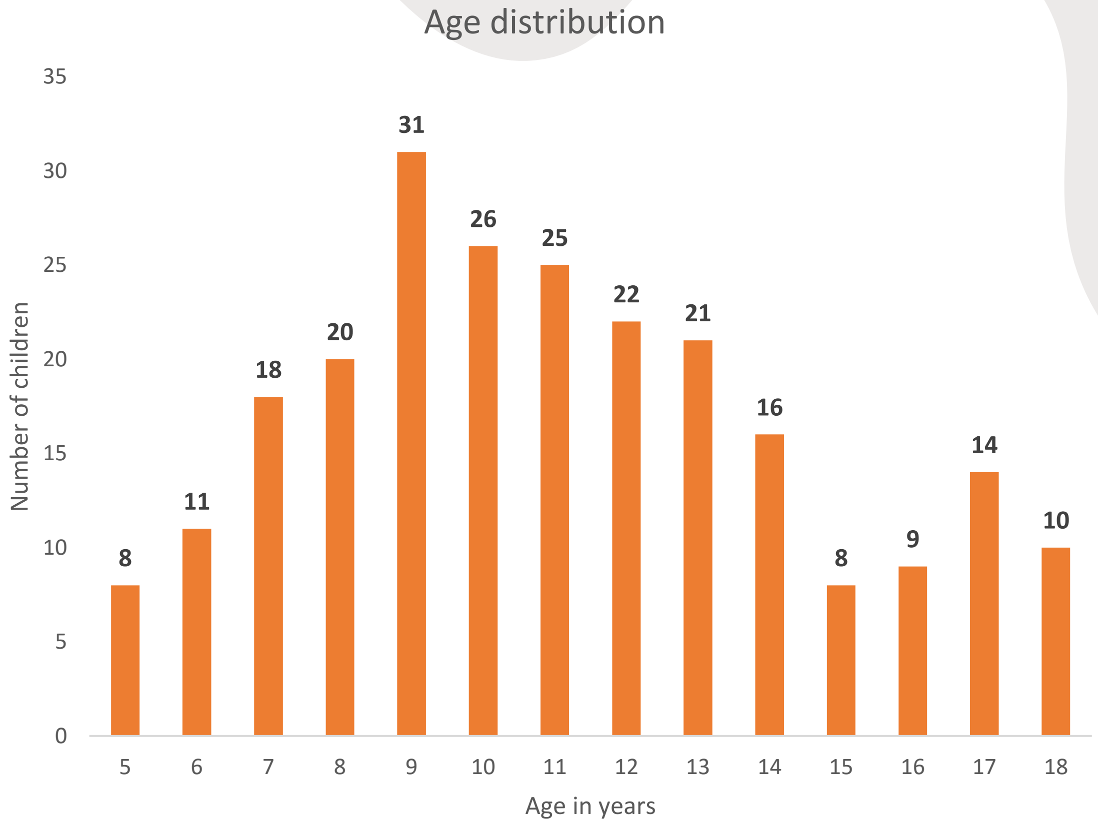


Figure 1. Distribution of age

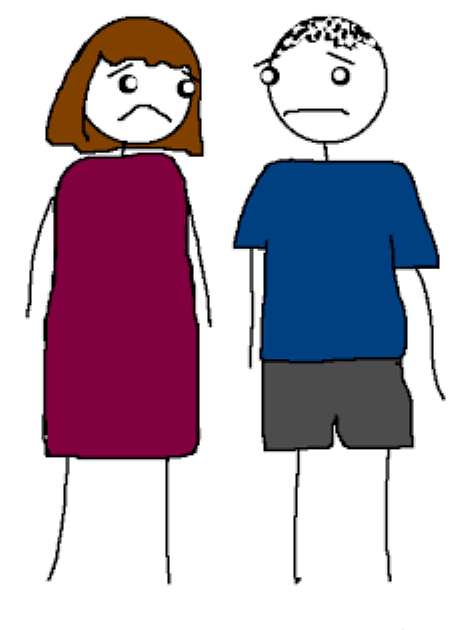
- 240 parental responses included:
  - 5-18 years (mean age of 11.10 years).
  - 71.1% (N=173) male and 27.9% (N= 67) female.
  - Ethnicity: 93.3% (white), 3.33% (mixed heritage), 3.33% (Asian).
  - 79.17% had a diagnosis for their movement difficulties
    - 55% had been diagnosed with co-occurring conditions
    - 45% had been diagnosed with more than one

Social and Emotional Impact on the child

Parental concerns (89.6% concerned, 4.2% not sure)

1. Poor mental health including anxiety and depression (N=44)
2. Friendships (N=41)
3. Low confidence (N=39)
4. Poor self-esteem (N=37)
5. Difficulty with keeping up (N=31)
6. Acceptance (N=17)
7. Bullying (N=15)
8. Isolation and withdrawal (N=12)
9. Exclusion by peers (N=7)
10. Suicidal thoughts / self-harm (N=3)

"Masking difficulties, his anxiety has started to come out by self harming, we only discovered this a few weeks ago."

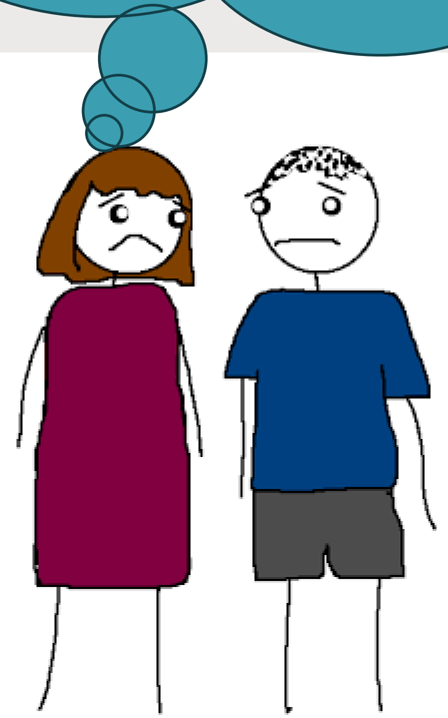


Social and Emotional In

Parental concerns (89.6% concerned, 4.2% not sure)

1. Poor mental health including anxiety and depression (N=44)
2. Friendships (N=41)
3. Low confidence (N=39)
4. Poor self-esteem (N=37)
5. Difficulty with keeping up (N=31)
6. Acceptance (N=17)
7. Bullying (N=15)
8. Isolation and withdrawal (N=12)
9. Exclusion by peers (N=7)
10. Suicidal thoughts / self-harm (N=3)

> *"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."*

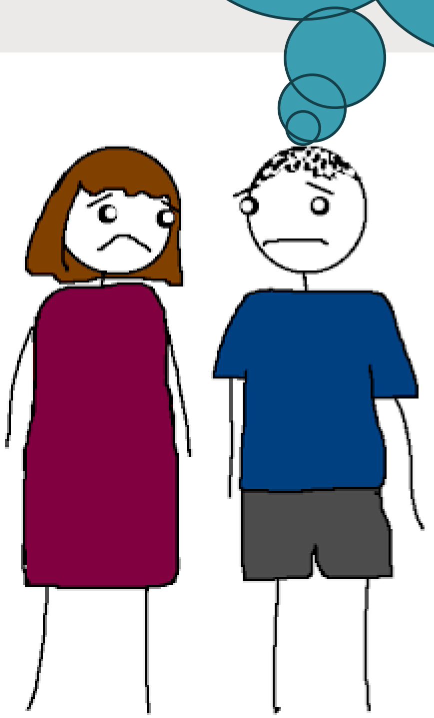


Social and Emotional Impact

> *"Low confidence, people sometimes judge him (been voted most clumsy in school year book) . Not socially confident at all outside his friendship group"*

Parental concerns (89.6% concerned, 4.2% not sure)

1. Poor mental health including anxiety and depression (N=44)
2. Friendships (N=41)
3. Low confidence (N=39)
4. Poor self-esteem (N=37)
5. Difficulty with keeping up (N=31)
6. Acceptance (N=17)
7. Bullying (N=15)
8. Isolation and withdrawal (N=12)
9. Exclusion by peers (N=7)
10. Suicidal thoughts / self-harm (N=3)



York St John University, Oxford Brookes University, Cardiff University, MMU, Victoria University, Western Australia University & Telethon Kids Institute

Social and Emotional Impact on the child

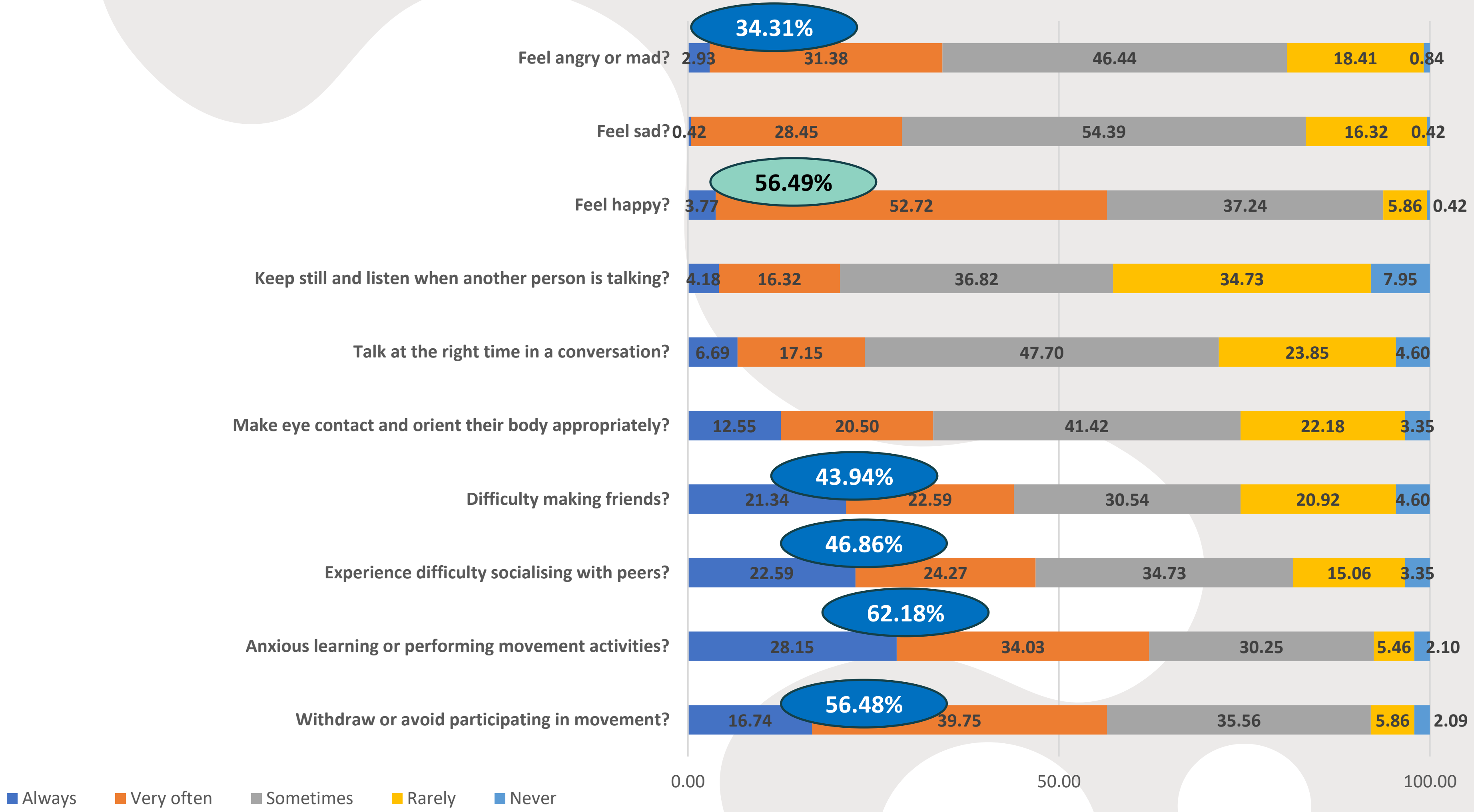


Figure 2. Frequency of socioemotional problems as reported by parents.

Socioemotional Symptoms – measured using the SDQ

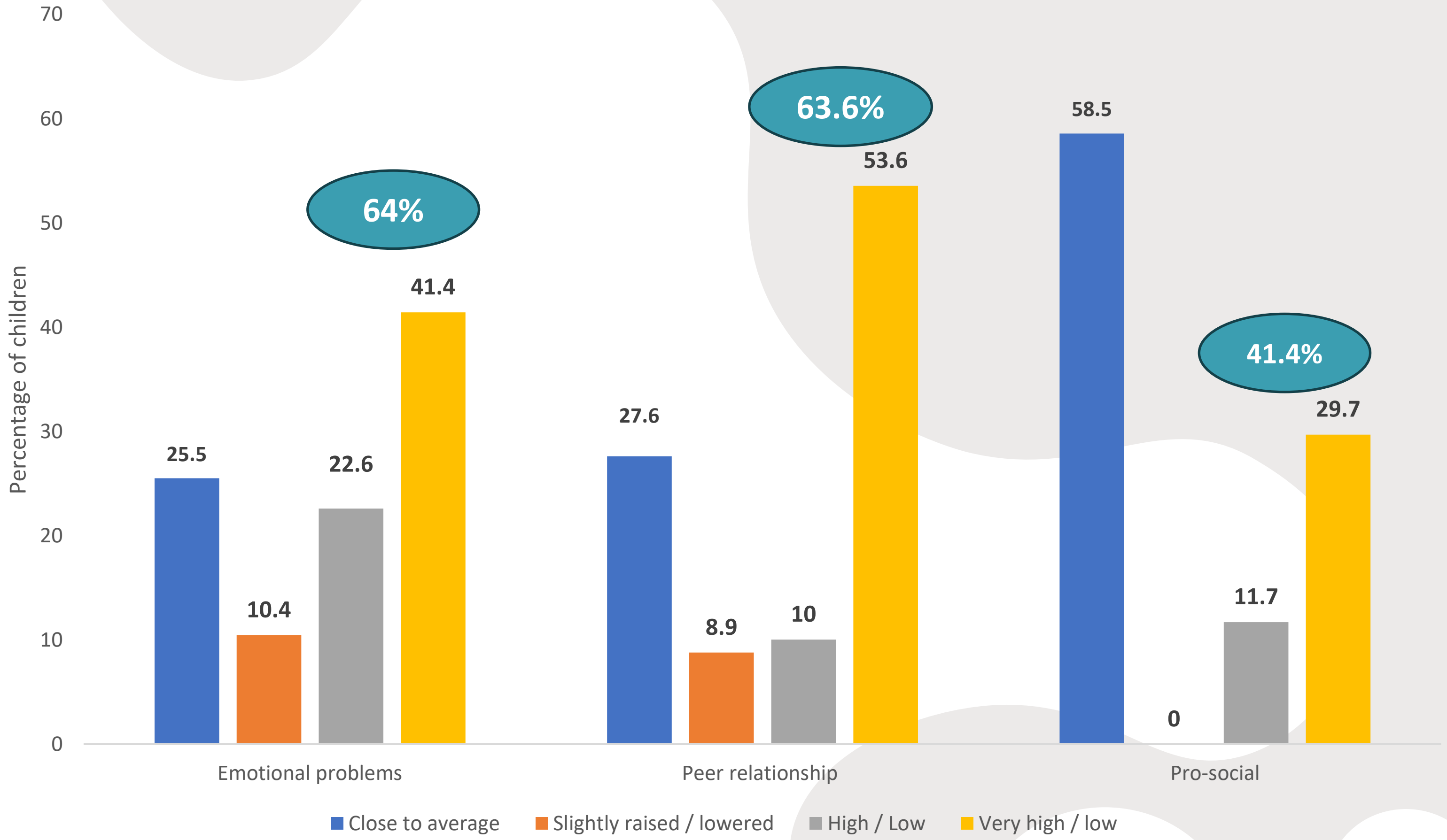


Figure 3. Illustration of the outcome of the Strengths and Difficulties Questionnaire using the categories supplied with the questionnaire.

Socioemotional symptoms by age – measured using the SDQ

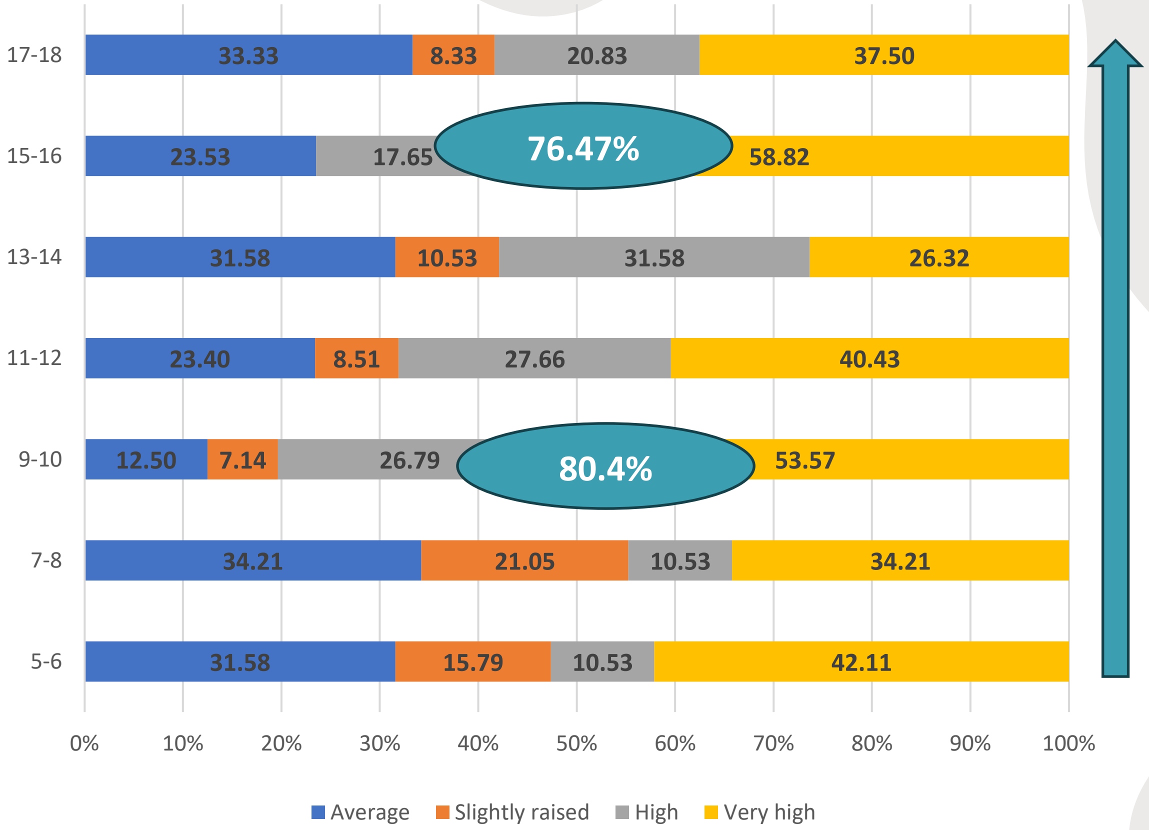


Figure 4. Breakdown of the **emotional problems** experienced by age group

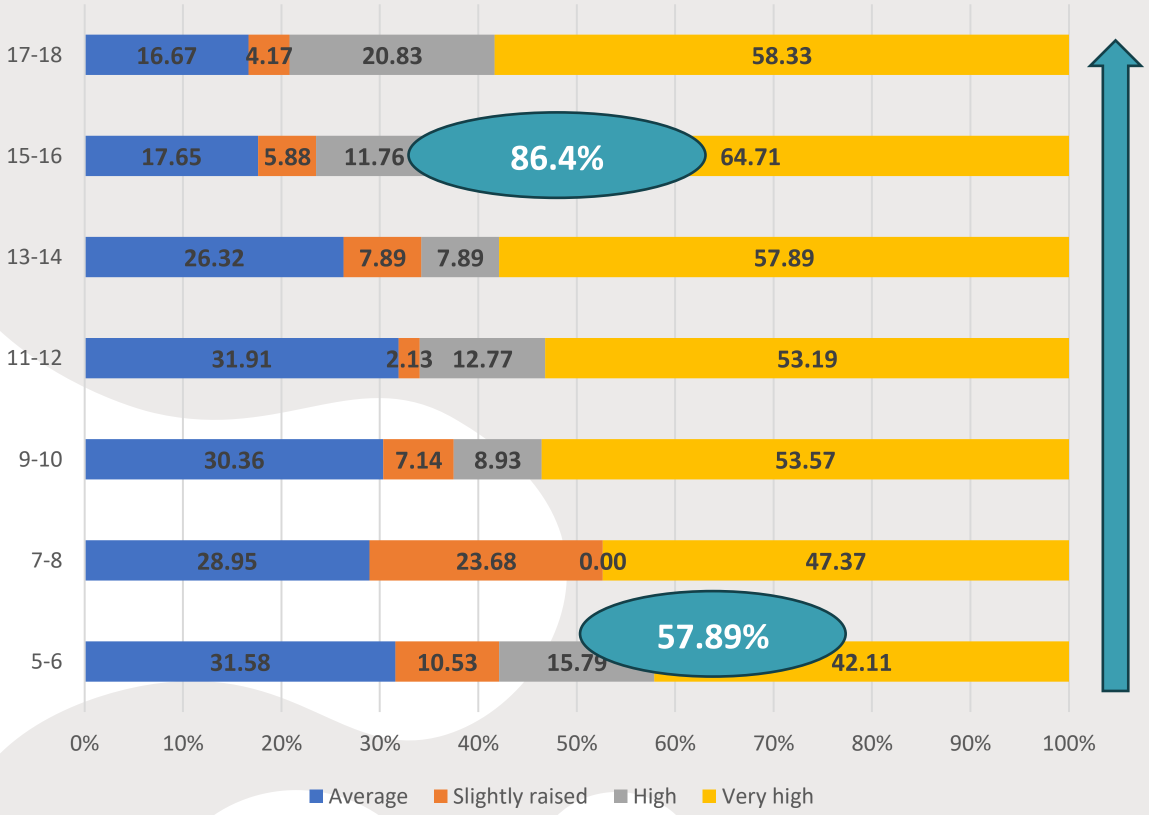


Figure 5. Breakdown of the **peer problems** experienced by age group

Socioemotional symptoms by age – measured using the SDQ (continued)

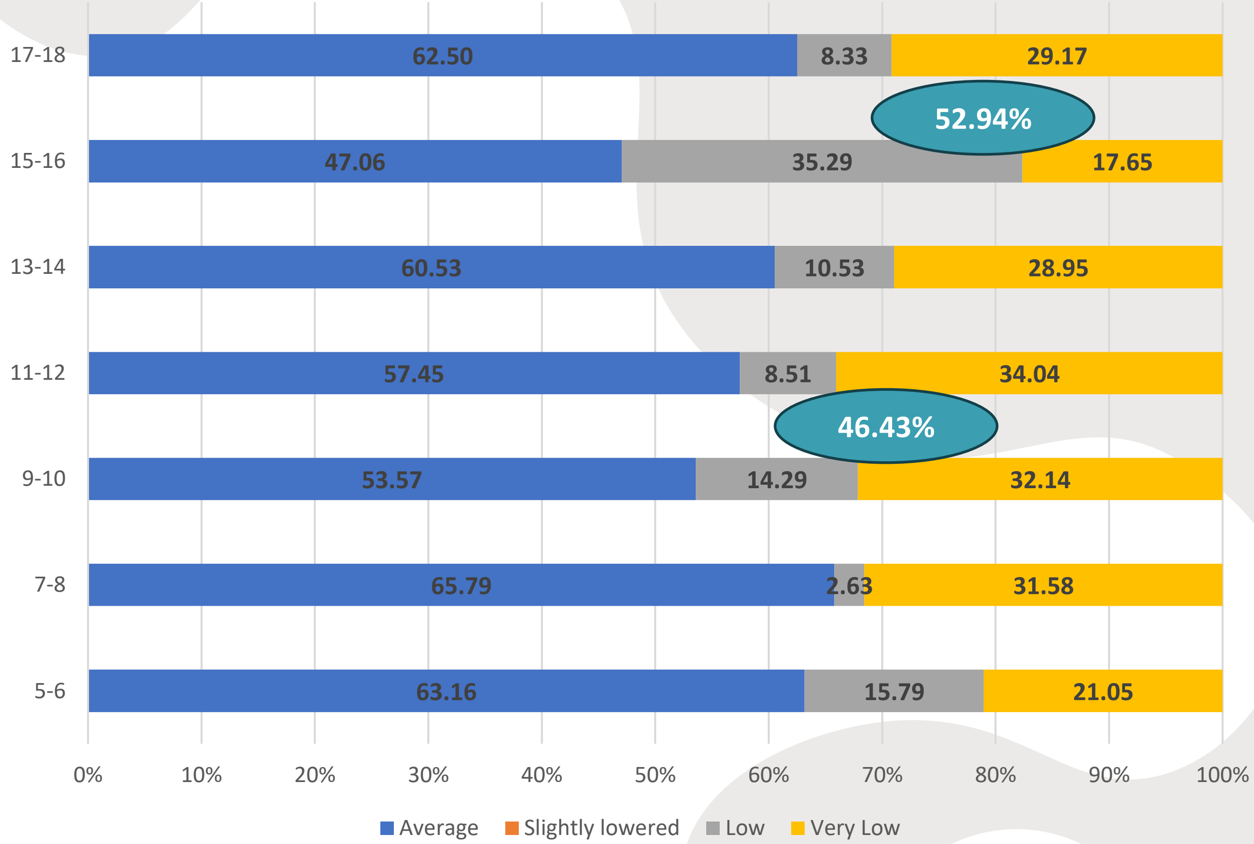


Figure 6. Breakdown of **prosocial problems** experienced by age group

Socioemotional symptoms by occurrence – measured using the SDQ

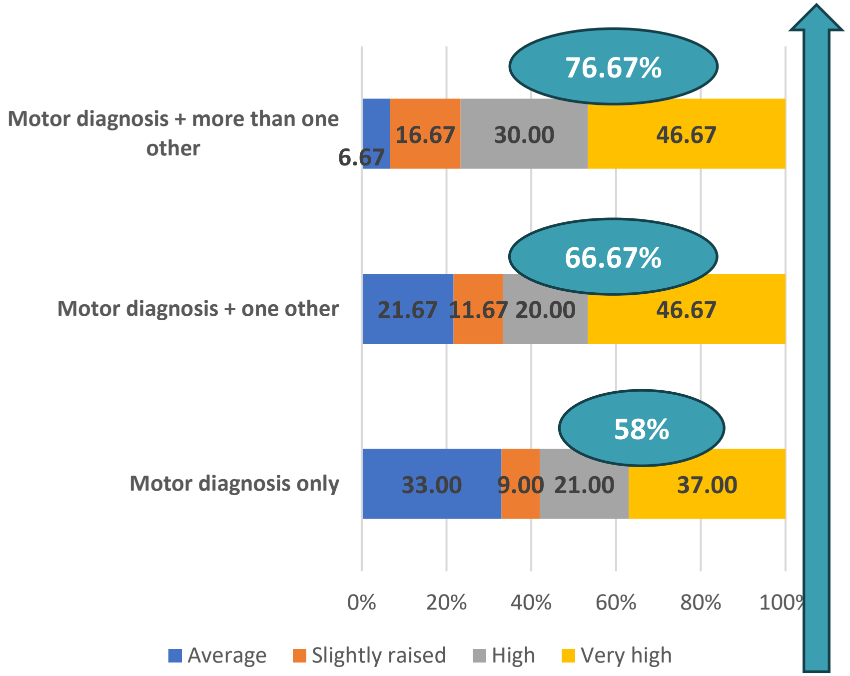


Figure 7. Breakdown of the **emotional problems** experienced by co-occurrence

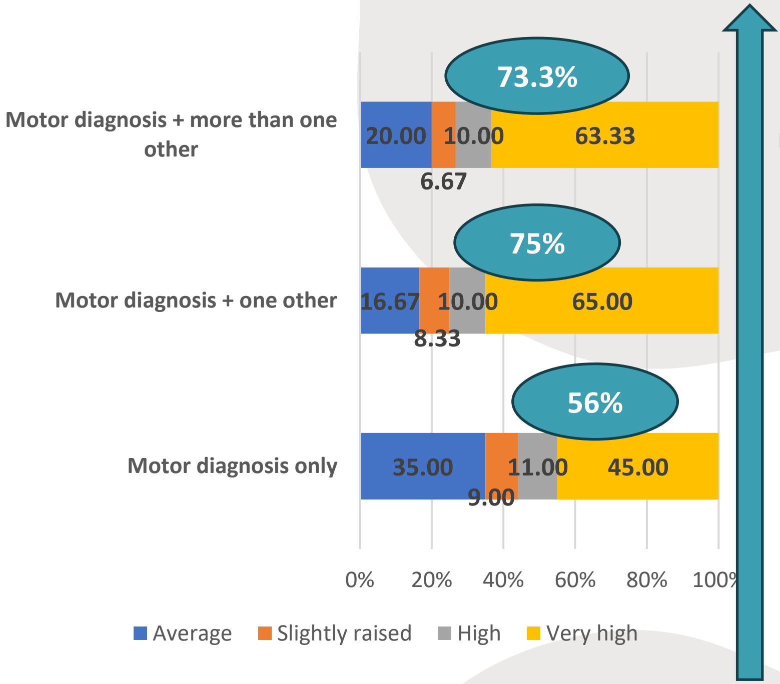


Figure 8. Breakdown of the **peer problems** experienced by co-occurrence

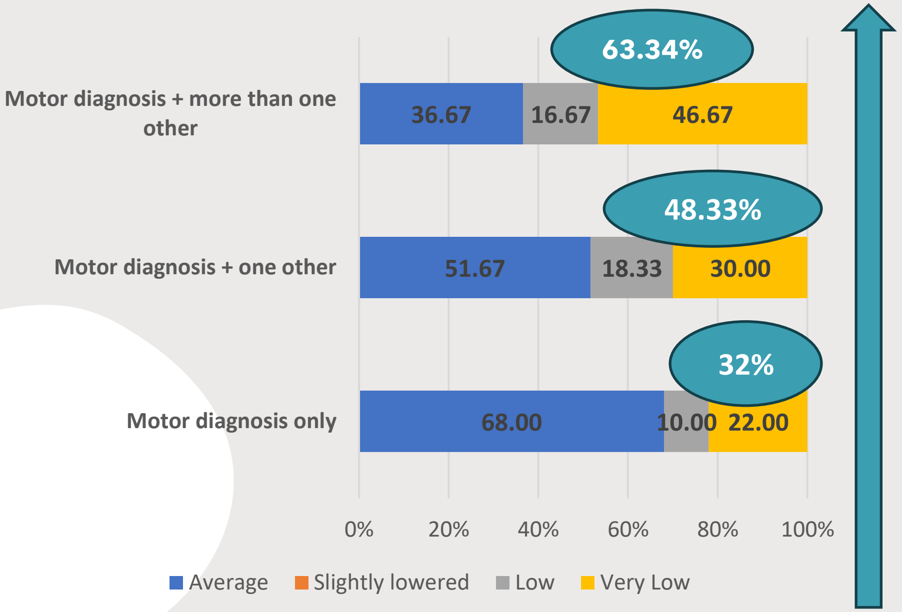


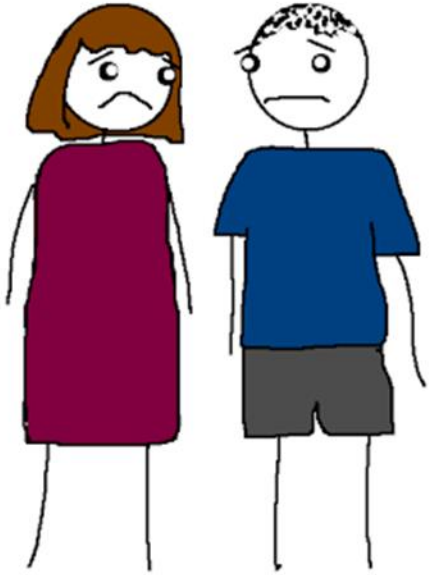
Figure 9. Breakdown of the **pro-social behaviour** experienced by co-occurrence

Conclusions

- 89.6% of parents were concerned about the impact of their child’s movement difficulties on their social and emotional health
- Two thirds of children scored in clinically concerning ranges in relation to emotional difficulties and peer problems.
- These problems seem to get worse the older the child gets and when a motor diagnosis is accompanied by more than one other diagnosis.
- Peer and prosocial problems either peeked or increased within the age ranges of 9-10 and 15 -16 years old.
- Over half of families reported that their child is 'always' or 'very often’ **anxious learning or performing movement related activities** and **withdraws from such activities.**

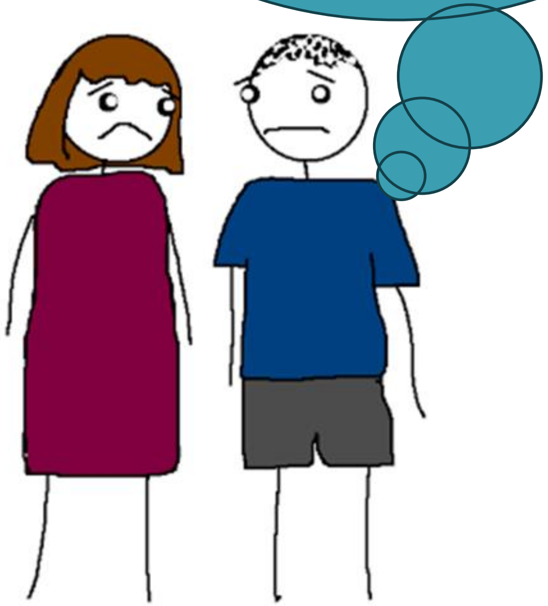
York St John University, Oxford Brookes University, Cardiff University, MMU, Victoria University, Western Australia University & Telethon Kids Institute

Conclusions



- **Mental health was one of the major parental concerns and one of the main priority areas for their child.**
- Assessments of co-occurring conditions and mental health problems should be incorporated.
- Intervention should address mental health problems as well as motor development.
- There is a clear need to educate not only families but also professionals working with children with DCD about the signs of poor mental health and the services available to support families and child but also increase the resources available.

> *“There needs to be far better recognition and acceptance of the mental health needs of young children and how mental health is deeply intertwined with a child’s physical and overall well being. We have been repeatedly ignored and let down by CAMHS, pushed off onto the medical side who in turn offer no supportive therapies, leaving it to the school to pick up and provide what little they can manage. The entire system is broken and letting children down, not just those with DCD, but all children with extra needs.”*



ne of the major parental
ne of the main priority areas for

- ments of co-occurring conditions and mental health problems should be incorporated.
- Intervention should address mental health problems as well as motor development.
- There is a clear need to educate not only families but also professionals working with children with DCD about the signs of poor mental health and the services available to support families and child but also increase the resources available.

"Mental health support is very hard to access and is often focused on general anxiety with very little support focusing on the causes"

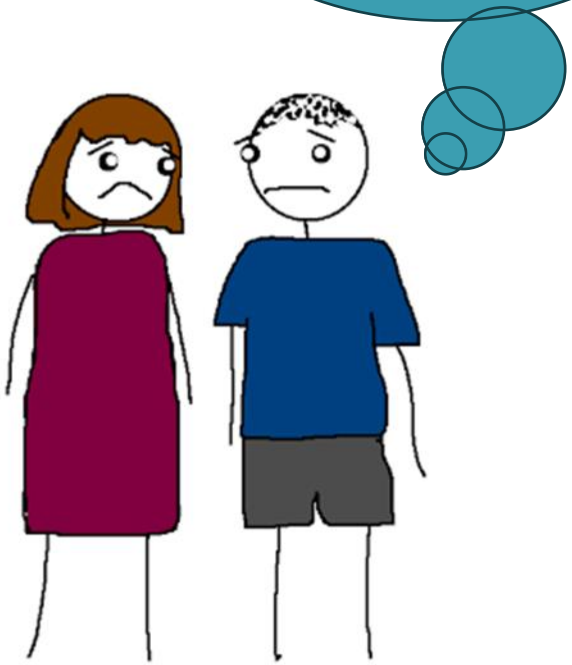
- **Mental health was one of the major parental concerns and one of the main priority areas for their child.**
- Assessments of co-occurring conditions and mental health problems should be incorporated.
- Intervention should address mental health problems as well as motor development.
- There is a clear need to educate not only families but also professionals working with children with DCD about the signs of poor mental health and the services available to support families and child but also increase the resources available.

York St John University, Oxford Brookes University, Cardiff University, MMU, Victoria University, Western Australia University & Telethon Kids Institute

Co

impact FOR DCD

"The government cite Mental Health awareness, but provide no support and the NHS are under-funded for this. A neurodiverse condition, such as DCD, can lead to mental health issues due to not understanding why you can't do the same things others can do and the frustration and anger that arises from this. People can feel very isolated and unworthy as a result."



n was one of the major parental
ns and one of the main priority areas for
child.

- Assessments of co-occurring conditions and mental health problems should be incorporated.
- Intervention should address mental health problems as well as motor development.
- There is a clear need to educate not only families but also professionals working with children with DCD about the signs of poor mental health and the services available to support families and child but also increase the resources available.

Est. 1841 YORK ST JOHN UNIVERSITY

Acknowledgements

- Children and families who participated in this survey
- Dyspraxia Foundation
- Funders: York St John University and Oxford Brookes University
- Dr. Mark Mierzwenski, Dr. Jacqueline Williams, Dr. Mellissa Licari, Dr. Catherine Purcell, Dr. Judith Gentle, Dr. Greg Wood & Professor Kate Wilmut.

impact FOR DCD

You can find us on twitter @impactdcduk and on Facebook ImpactDCDUK | Facebook

Email: C.Sinani@yorksj.ac.uk

References

- Goodman R. (1997) The Strengths and Difficulties Questionnaire: a research note. Journal of Child Psychology and Psychiatry, 38, 581-586

impact FOR DCD