

National Survey Evaluating the Impact of
Developmental Coordination Disorder in Australia

impact

FOR DCD



ACKNOWLEDGEMENTS

First and foremost, we would like to thank all the families who participated in this survey. We know for many the journey has, and continues to be, a long and difficult road. This survey was initiated by families for families to help gather the vital evidence for people to understand the significant unmet needs of children living with Developmental Coordination Disorder (DCD). We believe these valuable and informative results have the power to initiate change.

Working together with the research team on this project is DCD Australia Incorporated, the national peak body supporting people with DCD and their families. You have been on this journey with us since the very beginning and your involvement has been instrumental each step of the way. We thank you for your partnership on this project and for the work that you do to support and inspire families.

As an unfunded study, we are indebted to all the individuals and health services across Australia that helped to develop and promote the survey. We would especially like to thank all the members of our parent, teacher and clinical service reference groups who played an integral role in developing and refining the survey questions.

We would also like to thank the Biostatistics team at Telethon Kids Institute for their guidance with the data analysis, along with Sarah and Daniel Pillar for the beautiful artwork and graphic design featured in this report.

SUGGESTED CITATION

Licari, M., Williams J., and the Impact for DCD Team. (2020). National Survey Evaluating the Impact of Developmental Coordination Disorder in Australia: Summary of Results. Telethon Kids Institute, Perth, Western Australia

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CONTENTS



What’s in this report?

Letter from the Director of DCD Australia Inc.	4
Glossary	5
Definition of Terms	5
Executive Summary	6
Introduction and Background	8
Research Team	11
Participants: Who took part in the survey?	13
Summary of key findings	14
Summary of recommendations	16
Survey Sections	
Section 1: Diagnosis	18
Section 2: Activity & Participation	26
Section 3: Education	32
Section 4: Therapy	38
Section 5: Social & Emotional Impact	44
Priority areas identified by families	52
References	56



The physical and emotional struggles associated with Developmental Coordination Disorder (DCD) have a profound impact on both the affected person and their entire family. The sacrifices, burdens and emotional stresses that these families go through every day is heartbreaking.

In many cases these families feel like they are struggling alone, because DCD is complex and not well understood among educators and health professionals, or by the decision makers of our society.

Developmental Coordination Disorder Australia Inc. is the peak body for DCD in Australia. We stand with families and connect people struggling with DCD to the understanding and support that they need and deserve.

Our primary focus is on raising awareness of the complex nature of DCD. We support research that will advance the understanding of DCD and produce strategies and teaching programs for educators and allied health professionals. Most importantly, we provide community connection and support to families and children affected and living with DCD every day.

Working with researchers on the Impact for DCD study has brought the challenges, sacrifices, financial burdens and emotional stresses of the families together into one place. On behalf of these families I thank you for taking the time to read through this report.

Let us stand together to get children and families living with DCD the understanding and support that they need and deserve.


Samantha Elbers
Director & Co-founder
DCD Australia Inc.

Abbreviations used in this report

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CAS	Childhood Apraxia of Speech
DAMP	Deficits in Attention, Motor Control and Perception
DCD	Developmental Coordination Disorder
DSM	Diagnostic Statistical Manual
ECEI	Early Child Early Intervention
NDIS	National Disability Insurance Scheme
SDQ	Strengths and Difficulties Questionnaire

DEFINITIONS

Terms used in this report

- Activities of daily living:** movement-oriented tasks that individuals carry out throughout their lives required for everyday needs.
- Comorbidity:** refers to the co-occurrence of two or more behaviours, deficits or disorders.
- Fine motor skills:** movements recruiting smaller muscle groups in the body such as the hands and fingers.
- Fundamental movement skills:** foundation or precursor movement patterns to more specialised, complex skills used in play, leisure and sporting activity.
- Gross motor skills:** movements recruiting the larger muscle groups of the body such as the arms, legs and trunk.
- Motor development:** change in motor behaviour during the life cycle.
- Motor skills:** learned goal-oriented movement tasks or actions.
- Occupational therapy:** a form of therapy using various assessment, intervention and management strategies to achieve the goal of enabling people to participate in meaningful everyday life activities and roles.
- Physiotherapy:** a form of therapy using various assessment, intervention and management strategies to improve movement and physical function.

This report presents the main findings of the 2018-19 *Impact for DCD Survey* conducted in Australia and contains key recommendations to help improve the lives of those impacted by DCD. The findings are relevant to individuals with DCD and families raising children with DCD, medical and allied health professionals who support diagnosis and treatment, and teachers who play an integral role in adapting learning environments to support children's needs at school.

Impact for DCD is the largest survey conducted in the world to identify the challenges experienced by children with DCD and their families. The survey examined a variety of domains, including the challenges related to obtaining a diagnosis, impact of the disorder on activity and participation, difficulties encountered within the school environment, access to therapy, and the social and emotional impacts.

Whilst the primary aim of the study was to collect critical data to highlight the magnitude of the issues surrounding DCD in Australia, another key component of the study was to hear from families and to allow them to assist in identifying and prioritising areas for improvement.

The responses revealed that families in Australia are experiencing enormous challenges, especially in relation to obtaining a diagnosis for their child's movement difficulties and subsequently receiving recognition and support.

The responses also revealed the considerable impact that DCD has in everyday life, especially the impact that it has both socially and emotionally. More specifically, findings of the *Impact for DCD survey* revealed:

- There is no consistent terminology or standardised practice for the diagnosis of DCD in Australia.
- 82% of families felt that their child's DCD was negatively impacting their child's ability to reach their potential at school.
- Families reported that teacher awareness of DCD was the greatest challenge at school.
- One in four parents reported their child did not enjoy going to school.
- 62% reported their child had difficulty making friends.
- 92% of families were concerned about the impact DCD was having on their child's social and emotional health.
- 78% of families were concerned about their child's future.
- Two thirds of children scored in clinically concerning ranges in relation to emotional difficulties and peer problems.

Based on the findings of the *Impact for DCD survey* and the priority areas identified by families completing the survey, key recommendations were developed in collaboration with family and professional reference groups.

These key recommendations highlighted the need for:

- Adoption of a standardised practice for the diagnosis of DCD in Australia.
- Utilisation of the correct diagnostic term, being DCD.
- Increased screening for DCD when diagnosing commonly co-occurring neurodevelopmental disorders.
- Identifying children 'at risk' of DCD before five to enable early intervention to commence.
- Increased use of evidence-based strategies that are based on comprehensive needs assessment.
- Education departments across Australia to recognise DCD as a disorder affecting a student's ability to reach their full potential and to provide appropriate provisions and support.
- Awareness and education campaigns for teachers and educators about DCD.
- Development of resources to assist teachers and educators in making schooling more accessible and enjoyable for children with DCD.
- Schools funded to include screening measures to evaluate movement as part of entry evaluations during the first year of schooling.
- Education for families about signs of poor mental health and the services available to support themselves and their child.
- Support for further research to improve ground level support to children and their families.

Ultimately, we hope this report will be the first step to shape a new future for people living with DCD.

Developmental Coordination Disorder or DCD is a neurodevelopmental condition characterised by marked impairments in the development of motor coordination. These impairments significantly impact many aspects of life, including activities of daily living, academic and occupational achievement, and participation in leisure and play (APA, 2013). The impacts often extend beyond the motor domain to include secondary mental and physical health issues. With an estimated prevalence of ~5% of children, DCD affects an average of one or two children in every Australian classroom.

DCD appears in the Diagnostic and Statistical Manual (DSM) for Mental Disorders (DSM-5, APA, 2013) as a neurodevelopmental condition. Classed as a motor disorder, diagnosis currently requires meeting four diagnostic criteria:

- A. Learning and execution of coordinated motor skills is below age level given the child's opportunity for skill learning.
- B. Movement difficulties significantly interfere with activities of daily living, academic productivity, prevocational and vocational activities, leisure and play.
- C. Onset is in the early developmental period.
- D. Motor coordination difficulties are not better explained by intellectual delay, visual impairment, or other neurological conditions that affect movement.

Source: DSM-5, 2013

Even though DCD has appeared in the DSM since 1987, the disorder remains under-recognised in Australia

and internationally. This likely reflects the use of inconsistent terminology, with a diagnosis of DCD often used synonymously with terms such as dyspraxia and motor delay (Gibbs et al., 2007). There is also limited education, training and resources on DCD available for clinicians, allied health professionals and teachers in identification, diagnosis, evidence-based interventions and educational supports.

DCD is often described as a “hidden disability” (Novak et al., 2012). The movement difficulties experienced by individuals are not as marked as other movement-related conditions (e.g., cerebral palsy, neuromuscular disorders). The characteristics of DCD are also not as prominent as behavioural symptoms associated with other neurodevelopmental conditions (e.g., ASD, ADHD), even though DCD frequently co-occurs with many of these neurodevelopmental conditions. As such, the movement difficulties associated with DCD are often overlooked because they are not considered as “prominent” or “functionally impactful” to warrant the support that other movement-related or neurodevelopmental conditions receive.

A diagnosis of DCD is often associated with secondary impacts on mental and physical health (Caçola, 2016). Because of movement differences, children with DCD may struggle to keep up both classroom and playground activities, or experience exclusion and bullying by their peers. DCD can therefore have substantial impacts on a child's confidence and self-esteem, and often leads to anxiety. Reduced ability to participate also leads to avoidance and withdrawal from physical activities,

further impacting on a child's ability to learn movement skills, causing them to fall additionally behind in skill acquisition.

DCD is a lifelong disability, impacting most aspects of daily living that involve movement. Infants who later go on to receive a diagnosis often display delays in the achievement of motor milestones (e.g., walking, Faebo Larsen et al., 2013), and young children struggle with activities such as learning to eat using utensils, drinking from a cup, dressing themselves, running, climbing and playing. On entry to school, movement difficulties may become particularly noticeable. Children are expected to perform some movement skills relatively independently and movement differences then become much more noticeable when observed next to their peers. They may have difficulty learning to hold a pencil and write, cut with scissors, open their bag and lunchbox items, and engage in activities in the playground. Their movement can appear uncoordinated and physically awkward. Furthermore, the inefficiency and additional mental effort that goes into processing, planning and executing their movements often results in tiredness and fatigue. These difficulties continue to challenge children throughout schooling, especially keeping up with written work in the classroom.

Movement difficulties experienced in childhood continue to exert an impact throughout adolescence and adulthood. For example, difficulties organising themselves in their surroundings can make activities such as navigating road crossings and learning to drive a car particularly challenging.

Without appropriate provisions in place, academic performance and future opportunities are likely to be impacted. Some individuals experience difficulties in finding and maintaining employment (Kirby et al., 2013), as well as challenges in developing social relationships (Gagnon-Roy et al., 2016), which may be due to a reduced functional capacity and minimised confidence in engaging in activities in front of others that they find difficult.

To minimise these impacts and provide opportunities for people with DCD to reach their full potential, the movement difficulties associated with DCD need to be identified early in life and children need to have access to appropriate therapy and support. Within Australia, the process of identifying children at risk for DCD is simply not occurring. While these children are likely to present with markers very early in life, children with potential DCD are not prioritised for therapy, and rather, a ‘watch and wait’ approach is commonly employed. It is not until children start school that movement difficulties are most commonly flagged, with no nationally consistent referral, diagnostic or therapy pathways in place between states or diagnostic/intervention services. Families are often left to navigate very challenging healthcare and education systems, systems hindered by a general lack of knowledge about DCD.

To tackle this, there was a clear need for research in Australia to:

1. Understand the scale and breadth of issues experienced in DCD; and
2. Identify and prioritise the areas in which children with DCD and their families require support.

In August 2017, researchers working in the field met with board members from DCD Australia Inc. Together, they launched *Impact for DCD*. This project was designed to measure the **impact** and challenges of DCD to assist in the initiation of **action** required for change.



To measure the impact, a survey was developed in collaboration with parent, teacher and clinical service reference groups, along with the Research Impact Academy and DCD Australia Inc.

Ethics approval for this project was received from the Human Research Ethics Committee at the University of Western Australia (Ethics #RA/4/20/1045). The survey was launched using Qualtrics over a 12-month period (February 8th 2018 - February 8th 2019) and promoted using social media platforms (Facebook, Twitter), DCD Australia Inc. website and service providers around Australia.

The survey covered questions relating to five key areas (impact domains) that were identified during survey development (Figure 1). The findings of this survey are included in this report to highlight parent experiences and areas they would like to see change and the initiation of action. Quotes from parents collected during the survey are interspersed throughout this report.



Figure 1: Impact domains

Project Leads



Dr Melissa Licari

Telethon Kids Institute & The University of Western Australia

Melissa is a researcher specialising in the movement difficulties associated with neurodevelopmental conditions. She has worked with children with DCD and their families for over 15 years and is passionate about helping to improve their lives.



Associate Professor Jacqueline Williams

Victoria University

Jacqueline is a researcher and lecturer specialising in DCD and the impact it has on children and their families. She is driven to reduce the burden of DCD on individuals and their families.

Associate Investigators

Dr Gail Alvares

Telethon Kids Institute
The University of Western Australia

Ms Charmaine Bernie

The Royal Children's Hospital
Murdoch Children's Research Institute
The University of Melbourne

Mr Wesley Billingham

Telethon Kids Institute

Dr Paola Chivers

The University of Notre Dame

Dr Matthew Cooper

Telethon Kids Institute

Ms Georgina Earl

The University of Western Australia

Associate Professor Jenny Downs

Telethon Kids Institute
Curtin University

Mr Brian Elbers

DCD Australia Inc.

Ms Samantha Elbers

DCD Australia Inc.

Professor Catherine Elliott

Telethon Kids Institute
Curtin University

Dr Kiah Evans

Telethon Kids Institute
Curtin University

Dr Tamika Heiden

Research Impact Academy

Dr Leanne Lester

The University of Western Australia

Associate Professor Fleur McIntyre

The University of Notre Dame

Associate Investigators (Continued)

Dr Sarah McIntyre
Cerebral Palsy Alliance
University of Sydney

Professor Jan Piek
Curtin University

Ms Sarah Pillar
Telethon Kids Institute

Dr Siobhan Reid
The University of Western Australia

Dr Jess Reynolds
Telethon Kids Institute

Professor Alicia Spittle
Murdoch Children’s Research Institute
The University of Melbourne

Ms Renee Teal
Telethon Kids Institute
The University of Western Australia

Dr Ashleigh Thornton
Paediatric Rehabilitation,
Perth Children’s Hospital

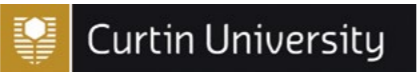
Professor Andrew Whitehouse
Telethon Kids Institute
The University of Western Australia

Artwork & Design

Ms Sarah Pillar
Telethon Kids Institute

Printing & Production

Printed by Vanguard Press
Design by Upside Content & Marketing



PARTICIPANTS

Who took part in this survey?

The eligibility criteria for people who participated included parents with a child aged 4-18 years with persistent movement difficulties not associated with another movement-related condition (e.g., cerebral palsy, muscular dystrophy) who were currently living in Australia.

Our study is the largest of its kind internationally, with responses received for 443 children (73.5% male) with movement difficulties from around Australia. The average age of children reported on was 9.2 years.

Location

Over a third of the participants were from New South Wales (36.1%), 20.8% from Victoria, 20.0% from Western Australia, 16.5% from Queensland, 3.1% from South Australia, 2.1% from Tasmania, 1.4% from the Australian Capital Territory and 0% from the Northern Territory (Figure 2).

Based on state population size, New South Wales and Western Australia were slightly over-represented in our study, while Victoria, the Northern Territory and South Australia were under represented.

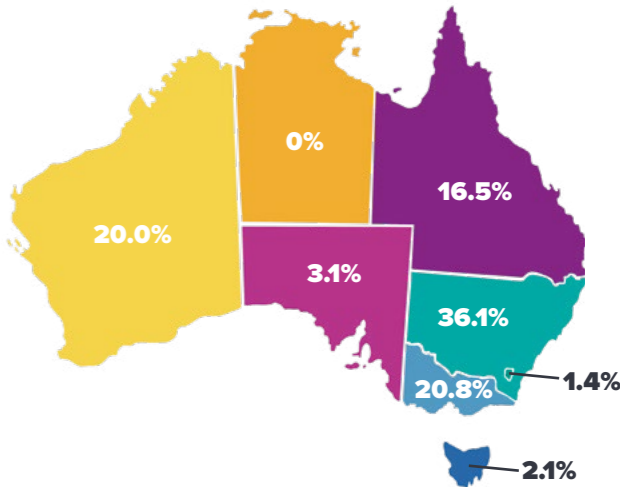


Figure 2. Distribution of responses by state

Figure 3 presents the distribution of responses by age. Overall, parents of children across most age groups were well represented, with 76.2% of responses received in relation to children aged 5-11 years.

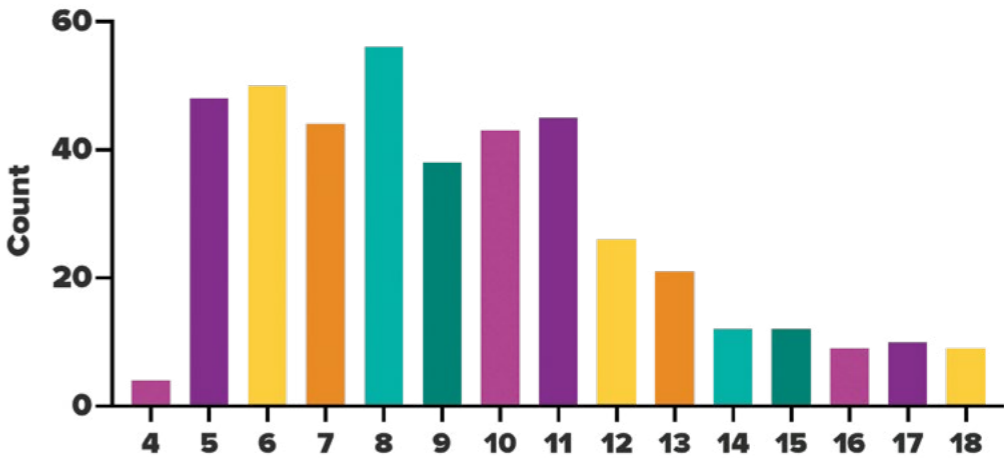


Figure 3. Distribution by age (years)



Key Findings

This is the largest international study on DCD and its *Impact* on children and families. Key findings comprise five domains: *Impact* of delayed and inconsistent diagnosis; *Impact* on function; *Impact* on education; *Impact* of cost of therapy and *Impact* on social and emotional health.

Impact of delayed and inconsistent diagnosis

Families were often (63%) the first to identify movement difficulties, usually in the third year of life. Over half (56%) of the families in this survey sought help within 12 months of their first concern, but **regularly experienced a prolonged diagnosis; 45% waited between two and four years.**

There was no clear diagnostic pathway, with diagnoses provided by a variety of medical and allied health professionals. Nine in ten families reported a diagnosis was helpful but were frustrated by inconsistent and inaccurate labelling. The survey found nine separate diagnostic terms used and more children were diagnosed with dyspraxia than with the correct clinical diagnosis of DCD.

Co-occurrence with other disorders was common (70%), and 40% of children had at least two co-occurring disorders. The most common was Childhood Apraxia of Speech, followed by ADHD and Autism.

Impact on function

The top five activities parents reported as being most difficult for their child were: dressing, eating using utensils, self-care, drawing and writing.

Most families (84%) reported that their child was more tired at the end of the day than other children. **Half the families reported that their child did not enjoy physical activity,** however, sedentary and screen-based activity time was on par with rates reported across the general paediatric population.

Almost two thirds of families were concerned about the impact movement difficulties are having on their child's overall health.

Impact on Education

Most parents (82%) felt that their child's movement difficulties were negatively impacting their education.

One in four parents reported that their child did not enjoy going to school and 62% said their child had difficulties making friends.

While many teachers were made aware of a child's movement difficulties, **only half of the children had an individual learning plan in place,** one in three children were provided with extra time

for tasks, and communication between teachers and therapists occurred in less than half the sample. Only one in five parents reported the school's physical education teacher speaking with them about their child's difficulties and how to support them. **Parents reported that their biggest challenge with schooling was a lack of teacher awareness of DCD.**

Due to learning needs not being met (i.e., social exclusion, bullying and mental health conditions) 5.3% of children were home-schooled, compared with only 0.3% of the general population.

Impact of cost of therapy

Most families had accessed therapy for their children, typically on a weekly or fortnightly basis. **Two out of three families reported that they did not feel the current level of therapy they were accessing was sufficient** to support their child.

Less than half had access to funding to support the cost of therapy. Additionally, much of the funding for families eligible to receive it was via the Early Child Early Intervention (ECEI) plans from the NDIS - however, these plans cease at age 7, leaving many families concerned as to how to meet ongoing costs.

Cost was the major limiting factor for families who had not accessed therapy for their child. Over 40% of families were spending more than \$4,000 per year (out of pocket therapy costs), causing families financial strain. On top of this, almost half of families reported regularly taking time off work to support their child's therapy and families travelled, on average, 45kms per week for therapy services. Time off work and travel are typically undocumented costs.

Impact on social and emotional health

Almost all families (92%) were concerned about the impact their child's movement difficulties were having on their social and emotional health and the majority were 'always' or 'very often' concerned about their child's future.

The top three concerns for parents were: 1) Friendships; 2) Anxiety and; 3) Poor self-esteem.

These concerns were reflected in scores for emotional function and peer relationships on the clinical Strengths and Difficulties Questionnaire (SDQ), where approximately **two thirds of children scored in clinically concerning ranges for emotional symptoms and peer relationship problems.** Positively, 76% fell into the normal range for pro-social behaviour. These difficulties were evident in children with a sole diagnosis of DCD, as well as those with comorbidities.

Some families reported that their child had expressed suicidal thoughts (8%), including some children as young as six years of age.

Over half of families reported that their child is 'always' or 'very often' anxious about learning or performing movement-related activities and that their child 'always' or 'very often' withdraws from such activity, raising significant long-term physical health concerns.

Almost three quarters of parents reported that their child's movement difficulties 'always' or 'very often' caused them emotional worry and concern. Two thirds of parents felt that their child's movement difficulties limited the time they have for their own needs and almost half said the difficulties limited the amount of activities they can do as a family.

Key Recommendations

Based on the findings of the *Impact for DCD survey* and considering the priority areas identified by families, the following key recommendations were developed in collaboration with both family and professional reference groups.



Reduce functional impact

- Support for research into ways to minimise the cognitive and physical fatigue experienced by individuals with DCD.
- Increased use of evidence-based strategies to improve functional outcomes.
- Increased community awareness of DCD, particularly in sporting clubs, along with strategies for making playing sport and physical activity more accessible for children with DCD.
- Awareness campaigns for the general public and professionals to highlight the impact of DCD on function more broadly, to counteract the often-held view that DCD just affects sporting abilities.



Increase screening and accurate diagnosis

- Develop and publish a clear diagnostic pathway. This will incorporate:
 - Identifying roles for various clinical experts;
 - Responding to early identification by parents, with evidence-based assessments for children under the age of five;
 - Identifying children as 'at risk' of DCD to enable early intervention prior to the formal diagnosis being made after age five;
 - Assessment of co-occurring conditions and mental health problems.
- Increased screening for DCD when diagnosing commonly co-occurring neurodevelopmental disorders.
- Widespread adoption of the correct clinical diagnostic term, being DCD.
- Awareness campaign and professional development offered for medical and allied health professionals to ensure the above.

“The impact of DCD should not be underestimated. More support and understanding is required. The diagnosis process is onerous and expensive. It is draining on finances and both child and family mental well-being.”



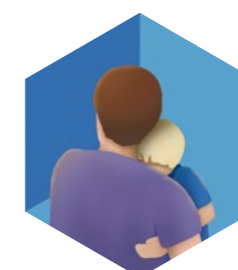
Decrease impact on education

- Awareness and education campaigns for teachers and educators about DCD.
- Development of resources to assist teachers and educators in making schooling more accessible and enjoyable for children with DCD.
- Education departments across Australia to recognise DCD as a disorder which affects a student's ability to reach their full potential and provide provisions that allow them to reach their potential (e.g. using a scribe or audio-to-text technology in examinations, providing breaks or additional working time to reduce fatigue).
- Schools funded to provide movement assessment of first year commencing students, in a similar way to the Victorian Department of Education and Training “Speech Pathology in Schools” program providing language assessment.



Increase evidence-based therapy options

- Delivery of evidence-based interventions that are based on comprehensive needs assessment.
- Development and evaluation of new interventions.



Decrease the social and emotional health impact

- Education of teachers and health professionals about the considerable impact motor impairment can have on social and emotional wellbeing, to ensure individuals with DCD, and their families, are appropriately monitored and supported.
- If required, children with DCD provided with a mental health plan to access sessions with a psychologist.
- Education for families about signs of poor mental health and the services available to support themselves and their child.
- Support for research into strategies to support the mental health of individuals with DCD and their families.

“With the correct supports and assistance I believe children with DCD would have a better chance at achieving their full potential. Early intervention is the key and more funding for teachers to identify and understand DCD would be beneficial.”

Diagnosis



History and Challenges of DCD Diagnosis

Over the past century, many terms have been used to describe impairments in the acquisition and development of movement skills emerging during early childhood and persisting throughout life. Diagnostic terms have included *childhood motor deficiency syndrome* (Dupre, 1911), *clumsy child syndrome* (Orton, 1937), *developmental dyspraxia* (Ayres, 1972), *perceptuo-motor dysfunction* (Laszlo et al., 1988), *developmental movement difficulties* (Sugden & Keogh, 1990), *developmental coordination disorder* (APA, DSM-III-R, 1987), and *developmental motor coordination disorder* (ICD, 2018). Developmental Coordination Disorder first appeared in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R, APA, 1987). However, the term dyspraxia is still used synonymously. Dyspraxia, by definition, means a partial impairment (-dys) of movement (-praxia). Whilst dyspraxia is a term generally used to describe the clinical presentation of movement difficulties, it is not currently recognised as a discrete diagnosis and does not appear in internationally recognised diagnostic manuals. Despite this, the term has been adopted as a 'diagnostic label' in some countries (e.g., United Kingdom, United States of America) and is used by many advocacy, charity and support groups around the world (e.g., in the United Kingdom: The Dyspraxia Foundation UK; in the United States of America: The Dyspraxia Foundation USA).

While there is ongoing debate surrounding terminology, with many

preferring the term dyspraxia, DCD was the diagnostic term accepted and recommended at an international consensus meeting in Canada in 1994. DCD has been recommended as the preferred diagnostic term by the European Academy of Childhood Disability (EACD) in their 2012 International Guidelines on the Definition, Diagnosis and Intervention of DCD, and again in the 2019 International Guidelines on the Definition, Diagnosis and Assessment of DCD (Blank et al., 2012, 2019). Even though DCD has appeared in the last three editions of the DSM (APA, 1987, 1994, 2013), the manual utilised by most diagnosticians in Australia, confusion surrounding diagnostic terminology remains. Differences in terminology likely reflects lack of dissemination and uptake of consensus diagnostic guidelines into clinical practice, resulting in individuals being provided with one or several of the labels that are used to refer to this disorder.

There are also challenges in understanding who is qualified to diagnose DCD. Since its first appearance in the DSM, it has generally been expected that diagnosis be made by a suitably trained medical professional. This is especially important when ruling out '*other explanations for the movement difficulties*' (e.g., cerebral palsy, a neuromuscular disorder), a criterion that has appeared in DSM-III-R, -IV and -5 (APA, 1987, 1994, 2013) and which can only be ruled out following detailed medication examination. Unfortunately, medical professionals appear to have limited knowledge of DCD, highlighted in a survey of family physicians (n=339) and paediatricians (n=255) in Canada by Wilson et al. (2013). The researchers

reported that 23% of family physicians and 41% of paediatricians were familiar with DCD and only 9% of family physicians and 23% of paediatricians had diagnosed DCD before. While family physicians had similar rates of familiarity with the label dyspraxia (22%), paediatricians were more familiar with the label dyspraxia (61%). When alerted to the incidence of the disorder (~5%), 94% of paediatricians and 89% of family physicians requested more education. While a study of this nature has not been conducted in Australia, it may be expected that knowledge of the disorder within the medical community would be similar.

One of the challenges in making a diagnosis of DCD is confirming that the movement difficulties are below that expected for the person's age and intellectual ability. Confirmation requires standardised assessment by a trained medical or allied health professional (i.e., occupational therapist or developmental

psychologist) with knowledge of the disorder and current guidelines. A recent survey by Karkling et al. (2017) evaluated occupational therapist knowledge of DCD in Canada (n = 165). While all occupational therapists surveyed were familiar with DCD, only 64% were familiar with the diagnostic guidelines. Canada has adopted several advocacy strategies to increase awareness and support.

It is expected that the development and dissemination of these resources through peak organisations across Canada has increased knowledge of DCD amongst medical and allied health professionals. To the authors best knowledge, these advocacy, awareness and training efforts do not exist in other jurisdictions, including Australia, so it is likely that knowledge and awareness of DCD and the diagnostic guidelines amongst the local medical and allied health professionals would be much less advanced.

Canada has adopted several advocacy strategies to increase awareness and support for DCD.

DCD featuring within content available on the CanChild website
www.canchild.ca/en/diagnoses/developmental-coordination-disorder

The development of the DCD Advocacy Toolkit by the Canadian Association of Occupational Therapists
www.childdevelopment.ca/DCDAdvocacyToolkit/DCDAdvocacyToolkitIntro

DCD being targeted through the national rollout of a new service delivery model within schools, called Partnering for Change
www.partneringforchange.ca

Diagnosis Results

In the *Impact for DCD survey*, parents answered questions relating to the age of their child when they first became concerned or aware of their child's movement difficulties, the age at which they first sought help and the age at which their child first received a diagnosis for their movement difficulties. The diagnostic labels that their child had been given in relation to their movement difficulties were collected, along with the medical and/or allied health profession who had provided the diagnosis. Given that movement difficulties commonly co-occur with other neurodevelopmental disorders and learning difficulties, comorbid conditions were also reported. Families were also asked if receiving a diagnosis for their movement difficulties had been helpful and what had been the major sources of information and support following their diagnosis.

The average age of first concern was 2.5 years. In most cases, concern was raised by parents observing their child in the home environment (63.2%). A smaller proportion of children were initially identified by their child health services (5.9%), early learning and childcare centres (6.1%), kindergarten (7.9%) or school (6.6%).

The average age families first sought help was 3.4 years. A large proportion (55.6%) of families reported seeking help less than a year after first experiencing concern.

The average age of diagnosis was 5.3 years, for the 87% of children who had received a diagnosis for their movement difficulties. The time between seeking help and diagnosis was comparatively large, with 2-4 years not uncommon.

Almost half (45.7%) of respondents who received a diagnosis waited over 2 years for a diagnosis after first seeking help, 29.3% waited between 1 and 2 years, and 25.0% of children were diagnosed less than a year after seeking help.

Those children seeking help at an older age were diagnosed within a slightly shorter timeframe, with children aged >6 years diagnosed within 1.6 years after first seeking help, compared to ~2 years in those first seeking help when <5 years of age. This is likely to reflect a combination of two clinical practices: the first, a 'watch and wait' approach commonly adopted in clinical practice for young children with developmental delays; and secondly, a diagnosis of DCD is currently not recommended until after 5 years of age (Blank et al., 2012). This age is when most children commence formal education in Australia, where complex motor skills are generally acquired (e.g., handwriting), and proficiency differences are noticeable when the child is observed in relation to their peers.

Family History

Nearly one-third (30.0%) of parents reported that there was a history of movement difficulties in their family, and 36.8% reported a family history of other disorders and disabilities. More specifically, 17.6% of families reported that they had a family history of ADHD, 17.6% ASD, and 14.4% dyslexia.

Diagnostic Label Received

Amongst children receiving a diagnosis for their movement difficulties (n=385), 38% had received one diagnostic label in relation to these, 31% had received two diagnostic labels, 16% had received three diagnostic labels, and 15% had received four or more diagnostic labels.

A diagnosis of dyspraxia was the most frequent diagnostic label received (64.7%), followed by DCD (48.8%), motor dyspraxia (28.4%) and sensory integration difficulties (17.6%). The most frequent diagnostic labels reported are presented in Figure 4.

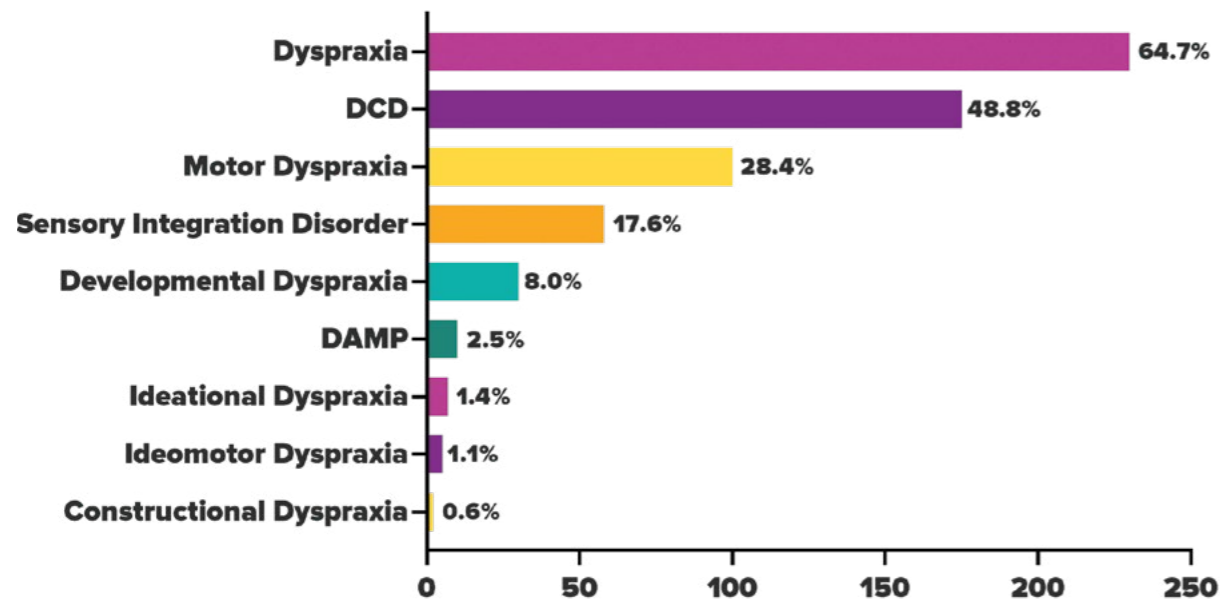


Figure 4. Count of diagnostic labels received for a child's movement difficulties

Most (87%) parents reported that receiving a diagnosis was helpful.

"It helped me understand why things can be more difficult for my child than other children [...] I am starting to appreciate why some things are harder, it's changed my attitude, and it's changed my parenting behaviours."

"It validated my concerns. Everyone from childcare to doctors were telling me that there was nothing wrong [...] I felt I was hitting my head against a brick wall."

"I'd like the condition be given one title, rather than the many that abound, preferably DCD as it is more explanatory, and many confuse dyspraxia with dyslexia and dysgraphia."

"It is such a relief to have a diagnosis but at the same time so disheartening that there is so little awareness of this condition."

"No-one seems to have heard of DCD or know how to diagnose it, so we still do not have a definite diagnosis for our son's movement difficulties, despite seeing multiple physios, speech therapists, general practitioners, orthopaedists, psychologists and an occupational therapist over the last 6 years."

Even though receiving a diagnosis was viewed favourably by most families, several families highlighted challenges surrounding the diagnostic terminology.

These challenges included the use of multiple labels to refer to their child's movement difficulties and a lack of awareness of movement-related diagnoses.

Professionals Providing the Diagnosis

Diagnosticians varied considerably, with 38.2% of children receiving their movement-related diagnosis from an

occupational therapist, 30.8% from a paediatrician, 10.8% from a speech therapist, 7.8% from a physiotherapist and 4.3% from a general practitioner (Figure 5).

Of the children who received a diagnosis of 'dyspraxia', 42.9% received this diagnosis from an occupational therapist, 31.2% from a paediatrician, 18.2% from a speech therapist, and 2.6% from a general practitioner. Of the children who received the diagnosis of 'DCD', 39.5% received this diagnosis from an occupational therapist, 39.5% from a paediatrician, 5.3% from a physiotherapist, 2.6% from a general practitioner, and 2.6% from a speech therapist.

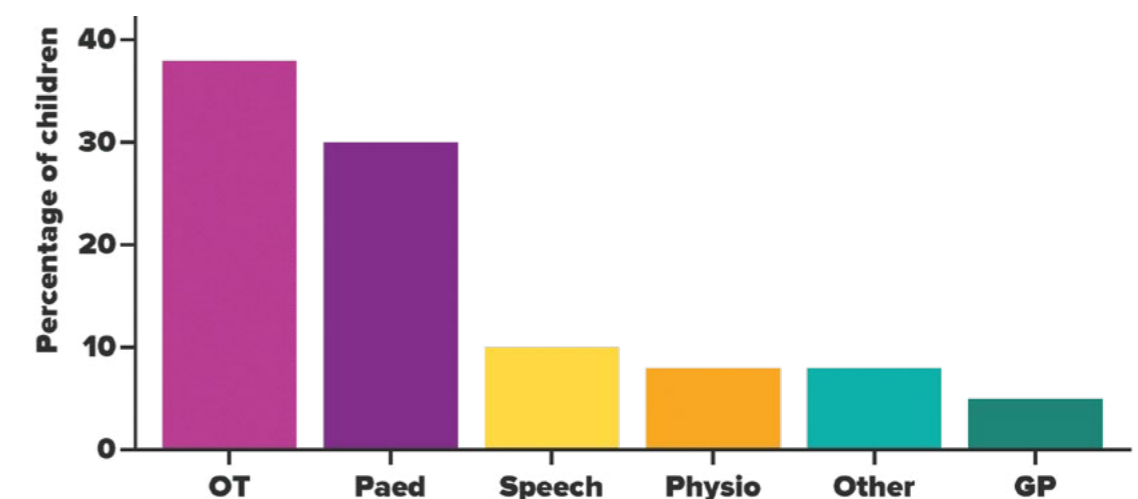


Figure 5. Professionals diagnosing

Major sources of information and support following diagnosis

Families were asked where they initially turned to for information and support following diagnosis. Most parents initially searched the internet (71%), followed by occupational therapists (57%) and Facebook support groups (21%). Many families highlighted the inconsistency in the information available.

The following source/s of information were reported as the most helpful:

- 1. CanChild
www.canchild.ca/en/diagnoses/developmental-coordination-disorder
- 2. Movement Matters
www.movementmattersuk.org
- 3. Dyspraxia Foundation UK
www.dyspraxiafoundation.org.uk
- 4. Dyspraxia Kids Australia (renamed to DCD Australia in 2018)
www.dcdaustralia.org.au

Comorbidity

Comorbidity refers to the co-occurrence of two or more disorders. The *Impact for DCD survey* asked about the co-occurrence of other neurodevelopmental disorders and language or learning

difficulties. Additionally, families were also asked to report if their child had any mental health conditions, including anxiety and depression.

Comorbidity was commonly reported for children in the study, with 69.8% (n=309) experiencing at least one co-occurring neurodevelopmental disorder, language or learning difficulty. Twenty-eight percent of children had one co-occurring diagnosis, 18.1% two, 12.1% three and 11.1% four or more co-occurring diagnoses. Co-occurring diagnoses reported in the study cohort are presented in Figure 6.

The most common co-occurring diagnosis was Childhood Apraxia of Speech (CAS) which was diagnosed in two out of every five children in the study sample (39.7%). CAS (also commonly referred to as verbal dyspraxia) impacts on the ability to produce the controlled production of speech sounds. Like DCD, CAS is a motor disorder, so it is not surprising that there was a high rate of co-occurrence. Diagnostically, the two disorders are viewed as two separate conditions; however, it is likely that they

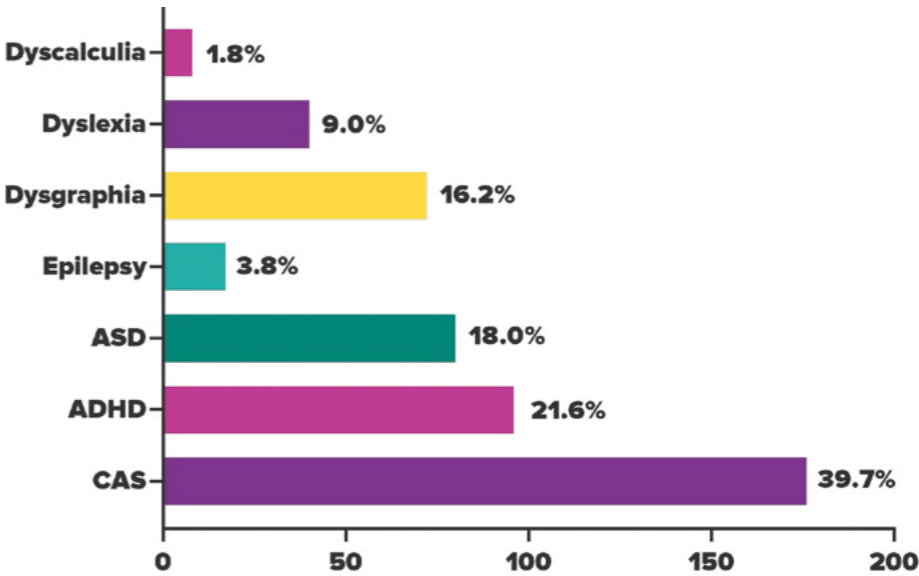


Figure 6. Count of conditions co-occurring in the study cohort

share similar aetiological mechanisms (Ho & Wilmut, 2010). One disorder involves the disruption of actions involved in the production of speech (i.e., strength of expiration, movements of the muscles in the jaw, tongue and lips), while the other involves disruption of actions coordinating movements in the rest of the body.

Other common co-occurring diagnoses included Attention Deficit Hyperactivity Disorder (ADHD, 21.6%) and Autism Spectrum Disorder (ASD, 18.0%). These two disorders have high rates of co-occurrence with DCD, with previous studies reporting that up to 50% of children with ADHD present with movement difficulties consistent with a DCD diagnosis (Pitcher, Piek & Hay, 2007) and close to 80% of children with ASD display movement difficulties (Green et al., 2009; Licari et al., 2019). The slightly lower rates of co-occurring ADHD and ASD in our sample likely reflects our recruitment strategy, with the study only advertised across media platforms specific to DCD.

Dysgraphia was also reported (16.2% of the sample). Dysgraphia is a learning

disorder that can impact on spelling and the ability to put words on paper. While there are different subtypes of dysgraphia, one subtype specifically relates to poor fine motor skills (motor dysgraphia) impacting on both legibility and output over time. It is likely that many children with DCD would meet the criteria for dysgraphia given the prevalence of fine movement difficulties. Dyslexia, a learning disorder characterised by difficulties with accurate word recognition and poor spelling and decoding, was also present in 9.0% of children. Dyscalculia, a learning disorder characterised by difficulties acquiring arithmetic skills, was present in a small percentage of children (1.8% of the sample).

The presence of mental health conditions (self-report of a health professional diagnosis) was also examined, specifically the number of families reporting their child had a diagnosis of anxiety or depression. A total of 43.8% of children (n=194) were reported to have at least one mental health condition. Most of these children presented with anxiety (n=191), with a smaller number also having both anxiety and depression (n=33).

“Some websites say DCD and dyspraxia are the same thing. Others describe DCD as a subtype of dyspraxia, with dyspraxia a broader disability affecting things like cognition, memory, emotion and behaviour. Some even say it affects the immune and gastrointestinal systems. I am still not quite sure what information is correct.”

“There was no one around who understood what this disorder is [...] It wasn’t until we found an occupational therapist knowledgeable in the disorder that our questions and concerns were finally addressed.”

“So much is misunderstood about DCD that you have to pick and choose what information you read.”

Activity & Participation



The movement difficulties experienced by individuals with DCD are highly variable. Some individuals have trouble learning and performing either fine motor skills (i.e., those involving smaller muscle groups in the hands) or gross motor skills (i.e., those involving larger muscle groups), or may have trouble with both. Previous studies examining activity limitations and participation restrictions in DCD have highlighted a wide range of difficulties. A systematic review of 44 articles identified participation in play-related activities as the most frequent activity limitation and participation restriction (reported in 72% of articles), followed by classroom activities (reported in 70% of articles) and self-care activities (reported in 48% of articles, Magalhaes et al., 2011).

The *Impact for DCD* survey included questions related to daily living activities that children found difficult in the home. There were several frequently engaged in activities listed, along with space for families to mention any additional activities their child found difficult. Families were asked to describe their child's movement, and also if their child took longer to accomplish tasks, became fatigued when performing tasks that were difficult, and whether they felt their child was more tired at the end of the day in comparison to other children of the same age.

Previous research has highlighted that children with movement difficulties are less likely to participate in tasks they find difficult (Izadi-Najafabadi, 2019) and are more likely to engage in sedentary activities. To examine this, families were asked what their child would do if they were given 30 minutes to themselves

at home. Additionally, families reported how many minutes on average their child engaged in screen-based activities (i.e., television, computer-based games and electronic gaming).

Physical activity was also examined, with families asked whether their child enjoyed participating in organised sport and physical activity, whether their child engaged in at least 60 minutes of moderate to vigorous activity per day, and an estimate of the number of minutes on average their child engaged in moderate to vigorous activity per day. To understand the sorts of sport, physical and leisure activities with which children with movement difficulties were engaged, families reported on the activities and the number of minutes per week in duration. Finally, families were asked if they had any concerns relating to their child's physical health and to provide information related to these concerns.



Daily Living & Play

When asked what areas their child had considerable difficulty with in relation to their movement at home, difficulties with dressing (71%), drawing and handwriting (67%), eating with utensils (63%), cutting with scissors (58%), and self-care activities (e.g., brushing teeth, brushing hair, 56%) were rated amongst the areas most challenging for children. A detailed list of activities is presented in Figure 7.

When asked how they would describe their child's movement when performing tasks, parents described them as uncoordinated (61.8%), awkward (58.2%), clumsy (55.3%), disorganised (51.0%), poorly timed (45.6%), slow (31.8%), unstable (29.1%), heavy (21.7%) and/or rushed (20.8%).

The majority of parents reported their child experienced considerable difficulty compared to other children, with:

- **97.2% of parents** reported that it takes longer for their child to accomplish movement tasks.
- **93.8% of parents** reported their child becomes fatigued performing tasks they find difficult.
- **83.8% of parents** reported their child was more tired at the end of the day when compared to other children.

Preferred Activities

When asked what their child would do if they were given 30 minutes to themselves at home, 57.3% of parents reported that their child would watch television, play computer-based games and other electronic gaming devices.

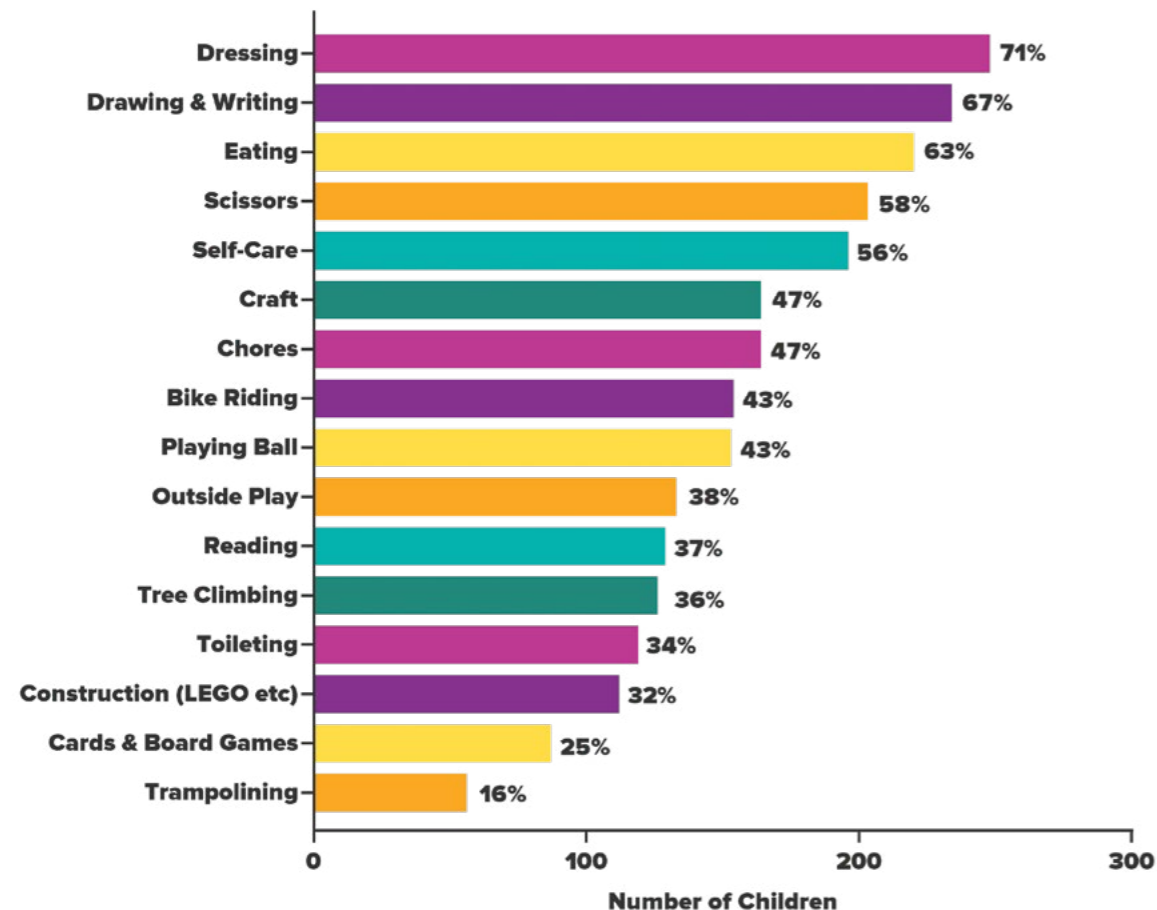


Figure 7. Percentage of children reporting difficulty in movement activities

“She is nearly 18 and we still must accompany her to a lot of places. She has had many near misses with cars crossing quiet roads. She struggles with domestic chores, such as using sharp knives, lifting saucepans, pegging out washing etc. It is unlikely she will be able to drive a vehicle because she finds multi-tasking very hard.”

“She just doesn't have the freedom of a normal teenager and it will be very hard for her to live independently.”

“We don't go out to other people's houses for dinner because he struggles with cutlery. It's little things that other people take for granted that really impact him.”

A smaller proportion (5.9%) reported their child would engage in outdoor or physical activity (e.g., trampolining, bike riding), while others reported their child would most likely read (5.2%) or play with Lego (4.1%).

Screen Time

On average, families reported their child engaged in 115±75 minutes of screen time per day. The distribution of screen time use by age is presented in Figure 8.

The Department of Health (Australian Government, 2017) currently recommends that children aged 2-5 years engage in no more than 60

minutes screen time, and children and youth aged 5-17 years recreationally engage in no more than 120 minutes screen time, per session.

On average, younger age groups in the surveyed sample met these recommendations. Children aged nine years and above slightly exceeded these recommendations, with children aged 15 years well above current recommendations.

These rates are not dissimilar to those reported in the general population, with a survey across Australia in 2017 (n=3797 children) revealing that the majority of children in Australia are exceeding

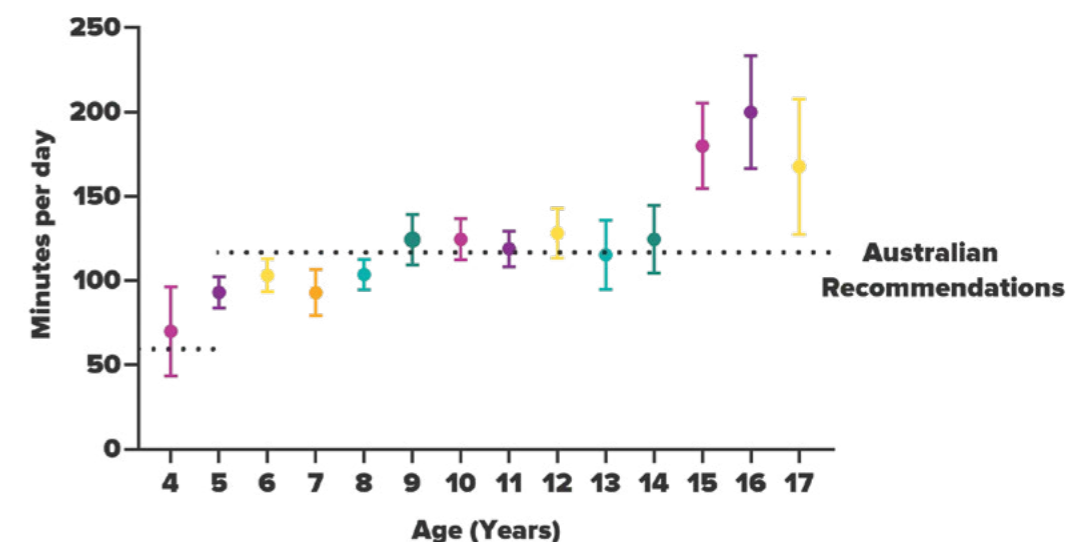


Figure 8. Average number of minutes per day engaged in screen-based activity by age

current recommendations, with highest usage seen in children aged 13-18 years of age (Australian Child Health Poll, 2017).

Physical Activity

More than half (52.6%) of families reported that their child did not engage in 60 minutes of moderate to vigorous physical activity per day. 28.6% of children engaged in <30 minutes and 5.0% of children were reported to be sedentary. Even though half of the children did not meet physical activity recommendations (Australian Government, 2017), this rate is slightly better than in the general population with 70% of children between the ages of 2-7 years not meeting current physical activity recommendations (Australian Institute of Health and Welfare, 2018).

49.3% of parents reported that their child did not enjoy participating in physical activity.

Enjoyment of activity decreased with age, with 38.1% of parents with a child aged 5-6 years reporting their child did not enjoy participating in physical activity, 51.2% with a child aged 7-8 years, 53.4% with a child aged 9-10 years, 51.6% with a child aged 11-12 years, and 57.6% with a child aged 13+ years.

Even though almost half of parents reported that their child did not enjoy physical activity, 75.1% of children were currently participating in at least one organised sport and/or leisure activity. Swimming was the most popular type of organised physical activity, with 52.6% of children currently actively engaged in swimming lessons.

Other types of physical activity children were engaged in included soccer (13.8%), martial arts (12.5%), dancing (9.5%), gymnastics (6.3%) trampolining (4.5%) and hockey (2.4%).

61.0% of parents were concerned about the impact their child's movement difficulties had on their physical health.

Areas they were most concerned about included their child's motivation to engage in physical activity, physical fitness, levels of fatigue and body weight.

Sleep

On average, most children (87.4%) met the recommended amount of sleep per night, with children <5 years of age sleeping on average 10.6 hours per night, 6-12-year-old children sleeping 9.7 hours per night and 13-18-year-old children 8.7 hours per night. Sleep disturbances were reported in 12.6% of children, with these children getting on average 1-2 hours below the recommended hours of sleep for their age per night.



“I have watched the gap between him and his peers continue to grow. The bigger the gap the more he avoids activity. He now avoids physical activity altogether and I worry about this leading to weight and related health issues later in life.”

“My son often says ‘I hate sport!’ He doesn’t hate it, he just hates that he can’t keep up and gets told off from more competitive boys for losing sports for them. This makes him have low confidence and increases his anxiety.”

“My son cannot play team sport. It is too competitive and there are no inclusion classes on offer. All of his physical activities are solo; aside from school physical education, which can be a tough thing for him (he is the slowest and teased). I worry about the social exclusion and lack of movement for fun. Weight is a constant struggle.”

“Because physical skills are lacking, it is easier for my child to avoid it. Any group based sport is traumatic with exclusion, unacceptance and frustration”.



School can be a particularly challenging time for children with movement difficulties. For many, it is often the first time the magnitude of a child's movement difficulties is realised when compared to their peers. When these difficulties are noticed by other children, some children with movement difficulties experience significant exclusion (especially in the playground) and bullying (in the most extreme cases).

Previous research has demonstrated poor awareness of movement difficulties within the education system, with a study in Canada revealing only 23% of teachers (n=202) were familiar with the term DCD and 21% with term dyspraxia (Wilson et al., 2013). This lack of familiarity is even more striking when compared to other neurodevelopmental conditions, with familiarity rates of 96% for ADHD, 92% for ASD and 88% for dyslexia. While there have been some recent efforts to make information about DCD available to teachers (e.g., Education Department in Victoria), information about DCD and how to support these children in the classroom is not currently included in most disability training modules for existing teachers or education courses at universities in Australia.

The *Impact for DCD survey* examined whether children's movement difficulties were evaluated on school entry. Parents were asked what recommendations were made by the school to those who were first notified of their child's movement difficulties on school entry. Information was collected on the type of school their child was currently attending (i.e., government, private or home schooling), including reasons for home schooling. Information was also collected on

whether the child had a delayed start to school or was repeating a school year, and the reasons for this.

Families were asked to report if their classroom teachers were made aware of their child's movement difficulties at the start of the current school year, if the classroom teacher met with families to discuss the child's needs, if an individual learning plan was put in place, and if there was any communication between the classroom teacher and any therapists the child was currently seeing. Families reported what supports or allowances their child was provided in the classroom, whether it took their child longer to accomplish tasks and if their child was provided with additional time to support them on tasks impacted by their movement difficulties at school.

Enjoyment of school was also examined, in addition to the biggest challenges families were experiencing at school, and perceptions related to the impacts of movement difficulties on a child's ability to demonstrate their knowledge and reach their potential at school.

Physical education is an area that is substantially impacted by movement difficulties, and an area sometimes taught by a specialist teacher. The survey examined whether specialist physical education teachers had consulted parents about their child's movement difficulties and the support their child may require in physical education at school.

Families also reported on whether their child was comfortable attending sports related events at school (e.g., sporting carnivals).

Evaluations on School Entry

In total, 42.7% of parents reported that their child completed a developmental evaluation on entry to the school system. While children's motor skills are not always examined as part of the school entry evaluation process, more than half of the children evaluated were identified with movement difficulties and their parents were subsequently contacted (61.8%). Approximately 1 in 4 families were notified that their child had difficulties in relation to their motor development and were either referred for an occupational therapy evaluation offered through their school or advised to seek support from an occupational therapist externally. Some parents were also recommended to seek support from a physiotherapist, speech therapist, paediatrician, or to generally seek medical advice. Some parents of children with fine motor issues were told that their child's difficulties would be supported through the school. Other parents were provided with no recommendations and advised that their child would likely catch up with time.

Type of School Attended

At the beginning of the current school year, 60.6% of children were attending government schools, 34.1% private schools, and 5.3% schooled at home (Figure 9). Based on the percentage of children enrolled in schools in 2018 (Schools Australia, Australian Bureau of Statistics, 2018) and taking into consideration the number of children registered for home schooling in Australia in 2018 (Home Schooling Australia, 2018), fewer children within our sample attended government schools compared to the general population (65.5%) and more children were home schooled compared to the general population (0.3%). Attendance at private schools was comparable to the general population (34.2%).

While there are many reasons that parents choose to educate their children at home (e.g., geographical location, religious and financial), the main reason families had chosen to home school within our sample included: 1. feeling that their child's diverse learning needs were not being met within government or private school settings, 2. difficulty keeping up in class, 3. social exclusion and bullying, and 4. mental health conditions (e.g., anxiety, depression).

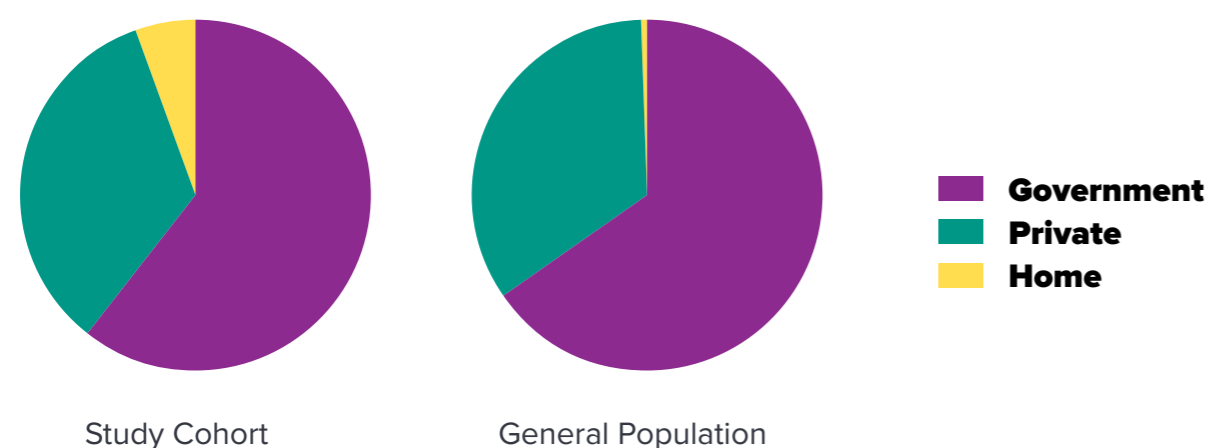


Figure 9. Percentage of children attending government, private and home schooling

“It’s sad that instead of knowing their child will thrive at school, parents often have to choose the path which is least damaging, depending on their personal circumstances. Systemic lack of awareness means a lack of support. We opted to home school both children at various points for the sake of their mental health, at an immense financial cost to our family.”

“He was being severely bullied at school. He was also very behind academically, and he was expected to be more organised than is possible for him, but without the added supports.”

“My child cannot keep up with the other children in the class. His teacher was very demanding. My son developed high anxiety in the classroom which caused him to externalise his frustrations.”

“He was struggling with the daily challenges of the school environment. It was bringing on too much anxiety and leading to depression, as well as regular meltdowns after school. Life is just such a struggle for him we hope that by home schooling we can remove some of the pressures and expectations he was struggling with.”

A small percentage of children in our study sample repeated a year at school (5.9%). The majority (84.6%) repeated within their first two years of schooling due to a combination of academic and social issues.

Parents reported that at the beginning of the current school year:

- 81% of classroom teachers were made aware of the child's movement difficulties.
- 67% of classroom teachers met with parents to discuss the child's needs.
- 56% of classroom teachers put an individual learning plan in place.
- 43% of classroom teachers communicated with a therapist/s the child was seeing.

Nearly three-quarters (72.7%) of parents reported their child was provided with additional provisions to support their learning at school. These provisions

included rest breaks, use of a laptop or tablet device to complete written tasks, slant/slope boards, more desk space, sit to stand desks, and alternative activities provided at recess and lunch breaks.

While most parents reported that it takes their child longer to accomplish tasks (97.2%), only 35.4% of parents reported that their child was provided with additional time to support them on tasks impacted by their movement difficulties at school.

82% of parents felt their child's movement difficulties are negatively impacting their ability to reach their academic potential at school.

62% of parents reported that their child had difficulty making friends at school.

1 in 4 parents reported their child did not enjoy going to school.

Greatest Challenges at School

The greatest challenges at school identified by parents included:

1. Teacher awareness of the condition.
2. Fatigue and keeping up in class.
3. Making friends and socialising.
4. Inclusion in the playground.
5. Bullying.

86.1% of parents were concerned about how their child's movement difficulties may impact on their ability to successfully complete their schooling.

Parents expressed concern that their child's movement difficulties were preventing them from demonstrating their knowledge at school and that the current system was not fairly assessing their abilities. Many parents stated that their child was unable to keep up with their peers and they were worried about the impact this would have on self-esteem and mental health over time.

52.4% of parents were concerned about their child's movement difficulties affecting their ability to gain employment in the future.

Physical Education Classes

Physical education is a specialist subject offered by most government and private schools around Australia. Some schools have classroom teachers deliver physical education lessons, while others have specialist physical education teachers. The focus of early physical education curriculums tends to be on the development of fundamental motor skills (e.g., running, jumping, hopping, throwing and catching).

"This is such a difficult diagnosis as so little is known and understood and it affects skills that we all just assume everyone has. People expect him to know and to be able to do. It has been a process educating teachers and I feel at times that they nod but don't seem to really understand. He is just another special needs child in an already overloaded classroom of needs. Many people dismiss it and focus on the ASD but in my opinion, DCD affects him in more ways than the ASD alone."

"I think the first step is educating the educators. I tell every teacher I meet about DCD, because if it wasn't for his year one teacher, I'd be on him every day for not trying, knowing he's smart but wondering why his grades don't reflect that. Feeling like somethings not right but getting frustrated and deciding he's being a lazy putz who doesn't want to work hard when in reality he's trying so hard it hurts. I shudder to think of how it all might have turned out if we didn't have that insight."

"My child has difficulty fitting in. He wants to play but can't keep up (always 'it' in tag and can't catch others). His teacher tells him he isn't trying. He has social problems, has received little help at school and is teased."

"He is a quiet, non-disruptive child who will fly under the radar and I'm afraid that his absence of learning won't be recognised. I also feel that he isn't receiving the support he requires to reach his full potential, dismissed by education staff that there is always going to be a gap between him and his peers."

"My biggest concern is that my child will fall through the gaps and not be supported at school appropriately due to lack of knowledge/awareness/acknowledgement of DCD. I am concerned that if she is not supported she will not only fail to reach her potential but could get left behind and really flounder both achievement wise and also the mental health repercussions of this."

A total of 57.3% of parents reported their child was taught by a specialist physical education teacher. Twenty-two percent reported that their child's physical education teacher had spoken to them about their child's movement difficulties and what support they may require during physical education lessons.

Fifty six percent of parents felt their child was not supported to engage in physical education lessons at school and 57.1% reported that their child did not feel comfortable attending the school's sports related events (i.e., school sports carnivals).



Therapy & Intervention



Occupational therapy is often considered a primary treatment for helping children gain the motor skills needed for school and everyday living. Physiotherapy is also considered an important area of therapy, especially for children who have issues with poor muscle tone, coordination and strength. Of increasing recognition in Australia is exercise physiology, with some accredited exercise physiologists (i.e., those with specialist training in paediatrics) providing therapy targeted towards the skills required for participation in playground and leisure activity.

Given that movement difficulties are often accompanied by difficulties in other developmental areas (especially in those with co-occurring diagnoses), other allied health professionals play a key role in supporting a child's development. For instance, speech therapists or pathologists may provide therapy to children with speech difficulties, feeding difficulties, social skills and literacy. Additionally, psychologists also play a key role in therapy provision, as many children with neurodevelopmental conditions often experience mental health and behavioural problems.

The *Impact for DCD survey* collected information on therapy attendance, both past and present, types of therapies accessed and duration of access. Age of those currently accessing therapy, the therapy type and regularity of attendance were also examined. Parents reported on whether they felt supported to maintain their child's therapy at home, and if they felt the therapy the child received was sufficient to support their movement difficulties.

Out of pocket costs of therapy and access to funding were also evaluated, along with the time off school or work and the distance travelled to attend therapy.

Therapy Attendance

Almost all (93.9%) of families had accessed therapy to assist their child's movement difficulties.

Occupational therapy had been attended by most families (79.5%), with children accessing therapy on average for three years. With the large number of children in the sample with co-occurring CAS, speech therapy was also a commonly accessed therapy (71.7%), attended on average for three years. Other therapists accessed by children on a regular basis were physiotherapists (45.5%) and specialised exercise physiologists (19.6%), each attended on average for two years.

Many children (42.7%) had accessed psychologists, with most children accessing this service on average for an 18-month period. Other professionals and types of therapy that had been accessed by families included optometrists (vision therapy), chiropractors, podiatrists and kinesiologists.

Of the small proportion of children who had not accessed therapy (6.1%), most parents stated that they were unable to afford therapy and that they did not qualify for funding to support access to services.

Current Therapy Attendance

The majority of children in this sample (63.9%) were currently receiving therapy for their movement difficulties. Most children accessing therapy were younger in age, with 76.7% of 4-6-year-old children and 72.6% of 7-9-year-old children currently receiving therapy for their movement difficulties (Figure 10).

The numbers attending therapy declined from 10 years of age, with 60.7% of

10-12-year-old children and 26.8% of 13+ year-old children currently receiving therapy for their movement difficulties.

Of those currently accessing therapeutic intervention services, 70.4% were seeing an occupational therapist (OT), 49.2% a speech therapist (Speech), 29.0% a physiotherapist (Physio), 29.0% a psychologist (Psych) and 21.8% an exercise specialist (Ex Phys) (Figure 11).

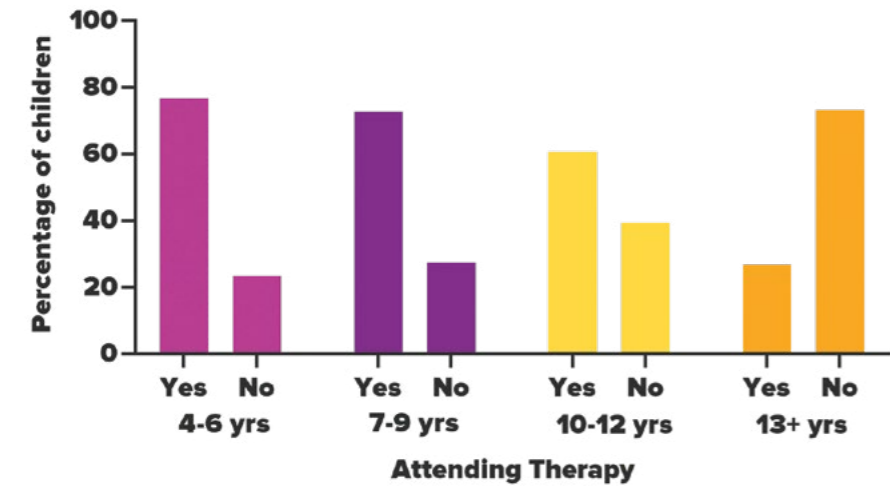


Figure 10. Therapy attendance by age of child

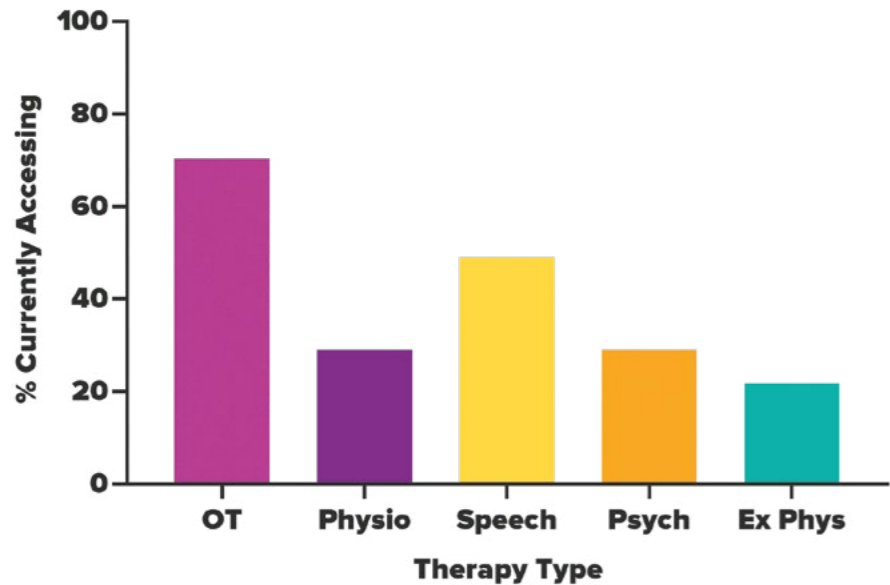


Figure 11. Current therapy services accessed

Regularity of attendance (weekly, fortnightly, monthly, yearly) is presented in Figure 12. Of those children using the service, most were attending occupational therapy, speech therapy and specialised exercise programs on a weekly basis. Physiotherapy and psychology services were less commonly accessed on a weekly basis.

68.5% of parents felt supported to maintain the progress that their child made in therapy at home, but two out of every three parents reported that

they felt the therapy received was not sufficient to support their child's movement difficulties.

Cost of Therapy

Annual out of pocket cost of therapy varied for families, with 29.9% of families spending <\$2000 per year, 26.5% of families spending \$2000-\$4000 and 18.6% of families spending \$4000-\$6000 (Figure 13). One in four families reported spending more than \$6,000 per year in out of pocket costs.

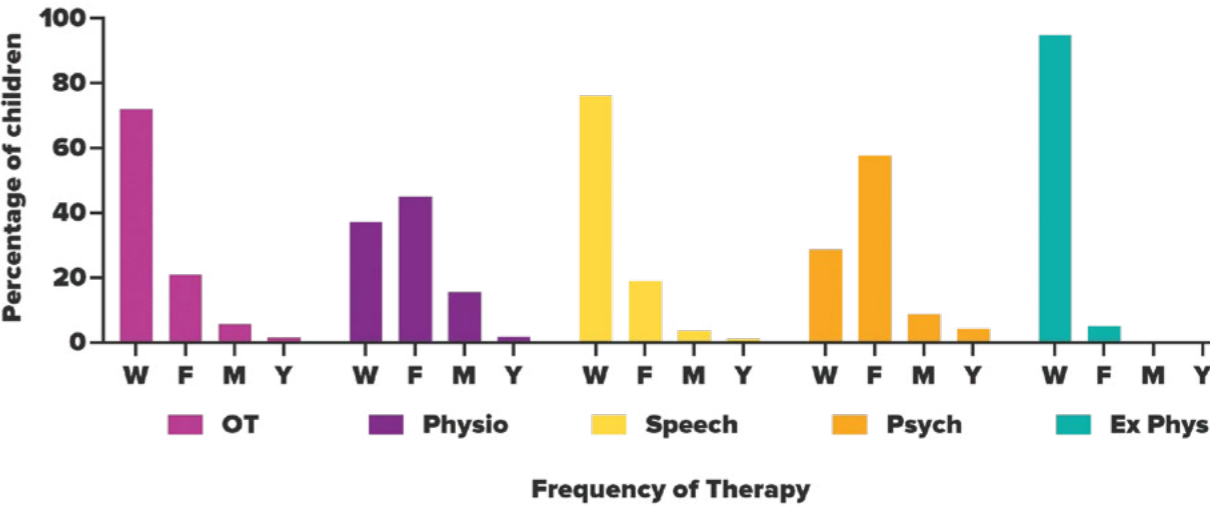


Figure 12. Regularity of attendance with allied health professionals

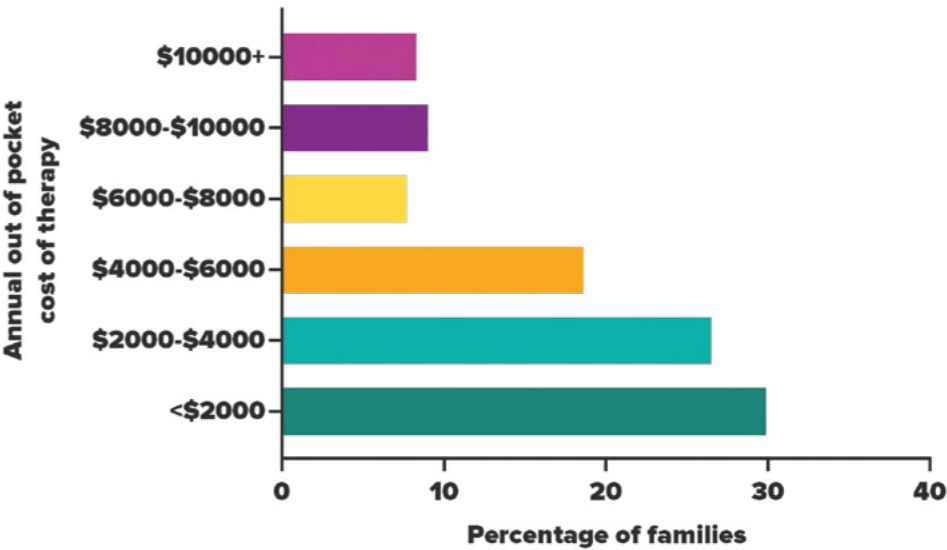


Figure 13. Annual out of pocket cost of therapy reported per year.

Funding for Therapy

Less than half of the families completing the survey (42.2%) reported that they had access to government funding to support therapy costs. As illustrated in Figure 14, access to funding marginally reduced the out of pocket cost to families, with a higher proportion of families with access to funding spending<\$2000 per year on therapy in comparison to those with no funding.

Almost half of the families with access to funding obtained it through the Australian National Disability Insurance Scheme (NDIS). The NDIS is a government scheme providing support and services for people with disabilities and was established in 2013. Age is currently a factor influencing access to funding, with children <7 years of age with ‘developmental delays’ eligible for Early Child Early Intervention (ECEI) plans. Children on an atypical trajectory

(regardless of their diagnostic pathway) may be eligible for support until they reach 7 years of age, after which access to funding is only available to those experiencing impairments deemed to ‘substantially’ reduce their functional capacity.

Of families with access to NDIS funding (n=61), a third had children <7 years of age (29.5%) and were accessing an ECEI plan. Children with access to these plans had a variety of diagnoses, including some with DCD only (38.9%) and other children with co-occurring CAS, ASD, ADHD, dyslexia or dysgraphia (61.1%). Funding was mainly used to support occupational therapy and speech therapy. Families commented on the enormous value of having access to this funding, but many also expressed concern about this access ceasing during their school years.

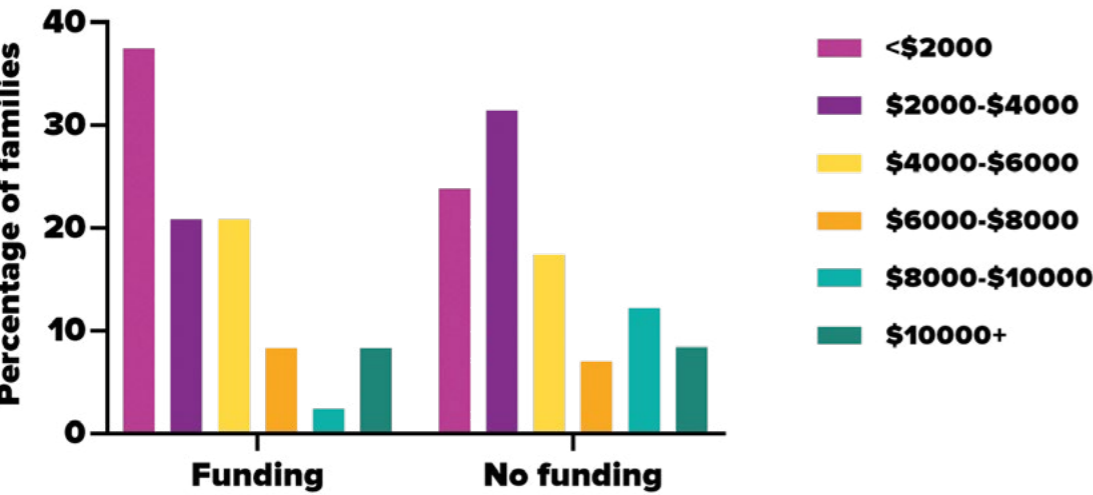


Figure 14. Annual out of pocket cost of therapy reported per year based on funding eligibility

“NDIS has been wonderful for my child. Unfortunately, funding will cease at the end of this plan as DCD and CAS are not recognised by the NDIS. He is currently funded under early intervention. His difficulties are still there. This will then put pressure on our family.”

“Children need access to affordable and effective treatment, but lack of providers and lack of funding options means they are falling through the cracks - sadly even for my son when I know what he needs I just can’t afford to get him the help yet.”

70.5% of children on NDIS plans were aged >7 years; 23 diagnosed with ASD, 13 with mental health conditions (e.g., anxiety and/or depression), 4 epilepsy, and 3 with unspecified learning difficulties.

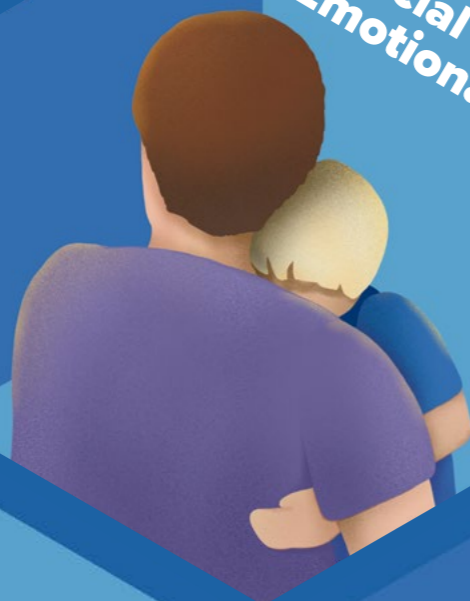
More than half of families (52.6%) reported that the costs specifically related to their child’s movement difficulties caused financial strain.

Other costs associated with therapy attendance

There were also families who reported accessing subsidies for therapy through Medicare, Australia’s publicly funded health care insurance scheme. These subsidies (offered through Chronic Disease Management Plans) were predominantly contributing to costs associated with occupational therapy and speech therapy services (subsidised funding available for up to 5 visits per year). Other families reported accessing Medicare for mental health care plans related to anxiety and depression (funding available for 8 visits per year). Finally, there were also families who qualified for rebates for therapy through private health insurers, however they highlighted that these rebates often only covered a fraction of therapy costs.

The majority (72.9%) of families travelled on average 44.5 kilometres per week (±46.0) to attend therapy sessions. A smaller proportion (13.7%) travelled >100km each week. Close to half of all parents (48.5%) took time off work to take their child to therapy sessions, equating to 12.5 hours per month (±12.0). Most (72.2%) children took time off school to attend therapy sessions, with children on average missing 86 minutes of school per week.

Social & Emotional



There is growing concern within the research and clinical community that the movement difficulties of DCD may also have broader impact on social and emotional health (Missiuna et al., 2008). Children with DCD often experience frustration in performing self-care activities (e.g., dressing) and educational activities reliant on movement (e.g., writing), and have less confidence in their ability to play with other children (Rodger & Mandich, 2005). Teachers report that school-aged children with DCD have fewer friends and are more socially isolated than their peers (Piek et al., 2005). These negative experiences in the classroom and playground then predispose individuals to a greater likelihood of experiencing mental health issues. Previous research has reported early movement difficulties to be a strong predictor of parent-reported anxiety and depression at 6 to 12 years of age (Piek et al., 2010). Additionally, some reports suggest that approximately one in five children with DCD are at risk of mental health issues (Lingam et al., 2012).

The *Impact for DCD* survey asked families if they were concerned about the impact of their child's movement difficulties on their social and emotional health, and to share their biggest concerns. Families also completed the Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997) which measures emotional symptoms, peer relationship problems and pro-social behaviour in children. In addition, families responded to a series of questions related to their child's avoidance of movement-related activities, anxiety in learning or performing movement-related activities, difficulty socialising with peers, difficulty making friends, and ratings of how often their child felt happy, sad and angry/mad.

The survey also evaluated the impact of the child's movement difficulties on family social and emotional health. Families were asked if their child's movement difficulties caused emotional worry or concern, limited the amount of time parents had for their own needs, limited the amount of activities they were able to do as a family, caused financial strain, and caused concern about their child's future.

92% of parents were concerned about the impact their child's movement difficulties are having on their social and emotional health.

The biggest concerns for parents ranked in order of frequency of endorsement included:

1. Friendships
2. Anxiety
3. Poor self-esteem
4. Exclusion by peers
5. Low confidence
6. Isolation and withdrawal
7. Depression
8. Bullying
9. Peer Acceptance
10. Suicidal Thoughts

One in three families reported that they were most concerned about the impact their child's movement difficulties had on their ability to establish and maintain friends. Many families reported that their child's physical limitations led to reduced social acceptance, exclusion and bullying by peers. These issues were reported to lead to social isolation, withdrawal and depression. Some families of children (as young as 6 years of age) reported that their child had expressed suicidal thoughts.

“He hates being the kid others laugh at. He hates anything that makes him different from his peers.”

“She has isolated herself from playing with peers because she is not as able as her peers. She says she’s too slow.”

“Motivating my child to get out of bed and go to school is a daily battle. I try to tell him that everything will be okay and today is going to be a better day, but I am not sure whether it will be. I dread school pick up, wondering if today is going to be another day my son gets into the car in tears wishing he was dead.”

Strengths and Difficulties Questionnaire

Findings from the SDQ (Figure 15) revealed that 65.6% of children fell into the abnormal range on the emotional symptoms scale and 64.9% fell into abnormal range on the peer relationship problems scale. When looking at pro-social behaviour, a large portion of children fell within the normative range (76.4%), with smaller numbers falling in the abnormal and borderline ranges (13.1% abnormal, 10.5% borderline).

These results indicate that children with movement difficulties experience social and emotional difficulties in the

same clinically concerning range as those with other neurodevelopmental conditions. Previous studies investigating the psychological profiles of children with cerebral palsy using the SDQ have reported fewer emotional difficulties (17-31% abnormal) and peer problems (36-38% abnormal) (Brossard-Racine et al., 2011; Parks et al., 2009) than the present findings. It is possible that because conditions like cerebral palsy are more observable (i.e., child may have orthoses, crutches, frame or wheelchair), the disability is more recognisable, and people are more generally accepting.

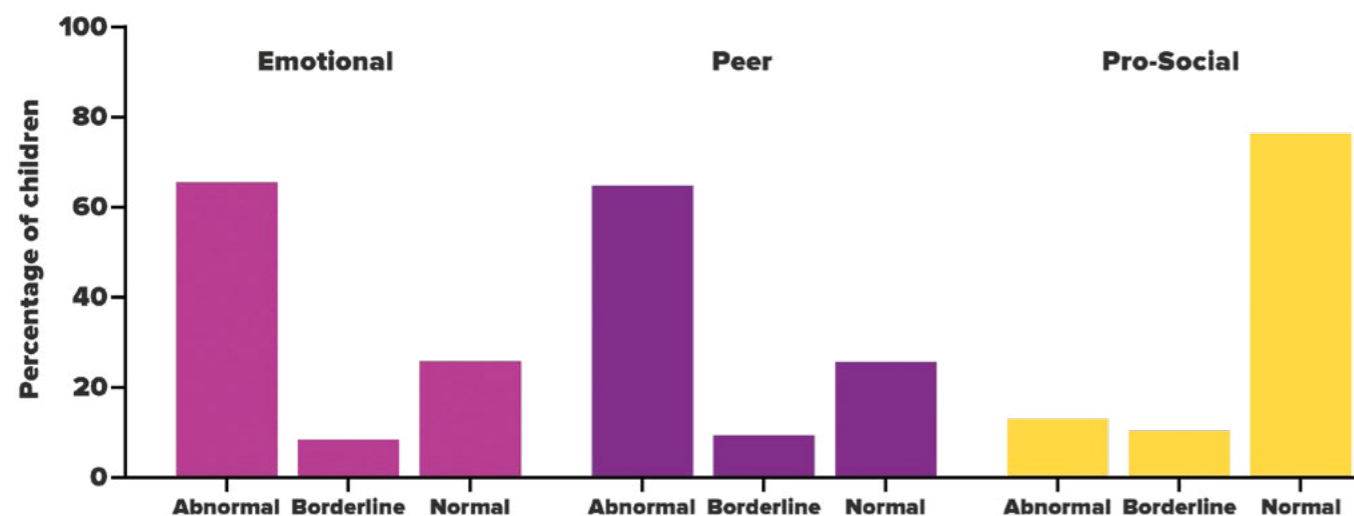


Figure 15. Percentage of children in the abnormal, borderline and normal ranges on the SDQ

Age Differences on the SDQ

As mental health issues become more prevalent during adolescence and young adulthood (Missiuna et al., 2007), each SDQ scale was evaluated by age categories (4-6 years, 7-9 years, 10-12 years, 13+ years) to determine if there were specific ages mental health issues were more prevalent. As illustrated in Figure 16, slightly more children aged 7-9 years (72.3%) and 10-12 years (68.9%)

scored in the abnormal range on the emotional difficulties scale compared to children aged 4-6 years (57.1%) and 13+ years (58.3%). Peer problems (Figure 17) were slightly more pronounced in those age 13+ years (70.8%) when compared to those aged 4-6 years (58.4%), 7-9 years (67.3%) and 10-12 years (62.2%).

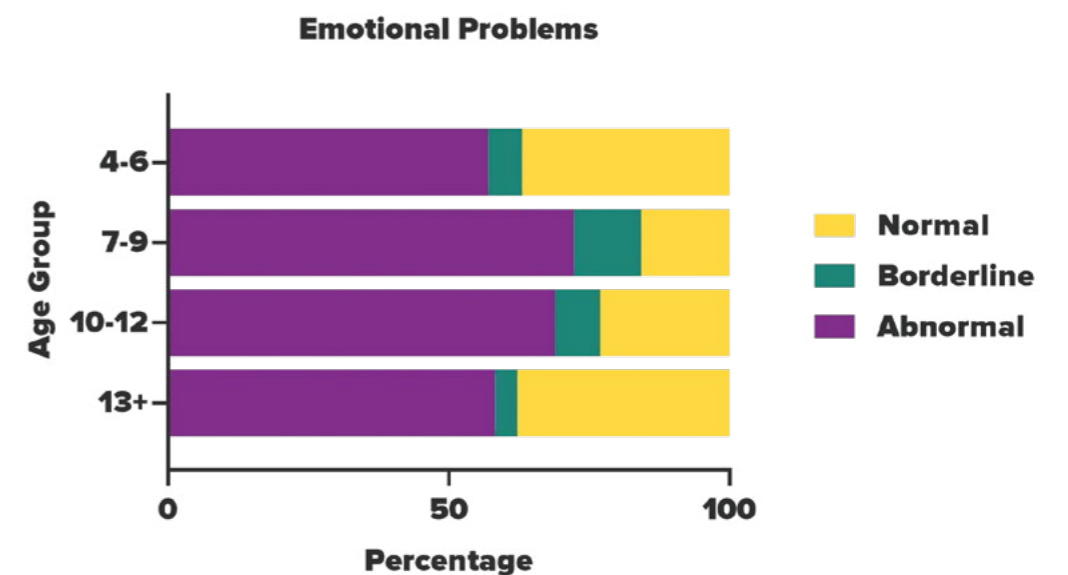


Figure 16. Percentage of children by age in the abnormal, borderline and normal ranges on the emotional problems scale of SDQ

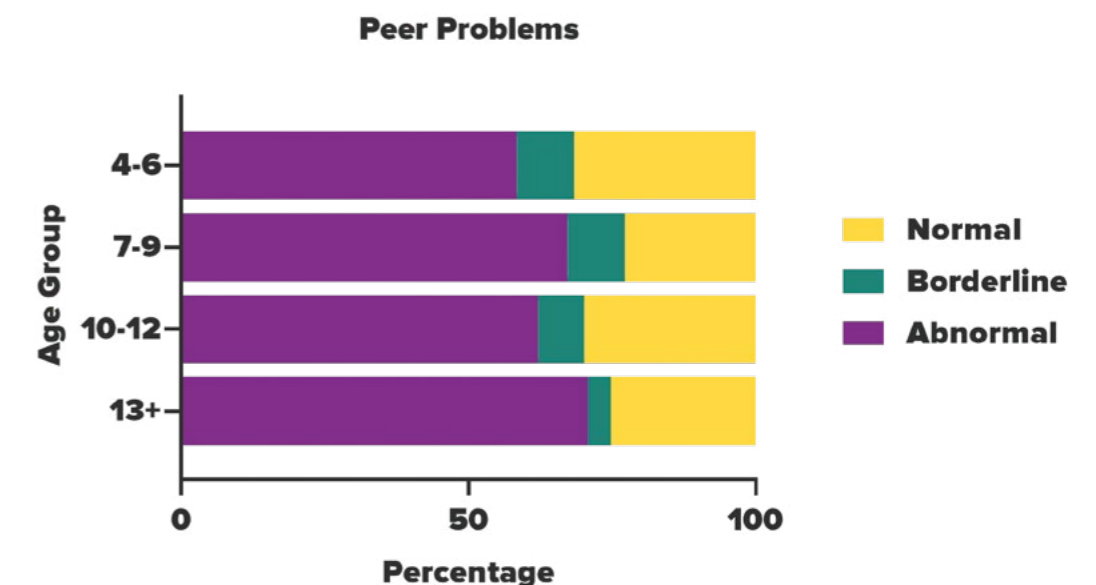


Figure 17. Percentage of children by age in the abnormal, borderline and normal ranges on the peer problems scale of the SDQ

While pro-social behaviour fell within the normative range for most children (Figure 18), slightly more children aged 4-6 years (26.0%) and 7-9 years (27.8%) fell into the abnormal and borderline ranges compared to those aged 10-12 years (18.9%) and 13+ years (18.7 years).

Diagnostic Differences on the SDQ

SDQ scores were also evaluated by diagnostic group, specifically children with DCD only (n=94) and those with co-occurring ASD (n=64), ADHD (n=73), CAS (n=150), dysgraphia (n=57) and dyslexia (n=31). The percentage of children in the

abnormal, borderline and normal range on the emotional, peer and pro-social scales are presented in Figures 19-21 respectively. While it was clear that all diagnostic groups had a high percentage of children in the abnormal range on the emotional and peer problems scales, slightly more children with co-occurring dyslexia (77.4%), ASD (76.6%) and ADHD (71.2%) had emotional difficulties and slightly more children with co-occurring ADHD (83.5%) and ASD (78.1%) had peer problems. Children with co-occurring ASD (29.6%) and ADHD (21.9%) were also more likely to score in the abnormal range for pro-social behaviour compared to the other diagnostic groups.

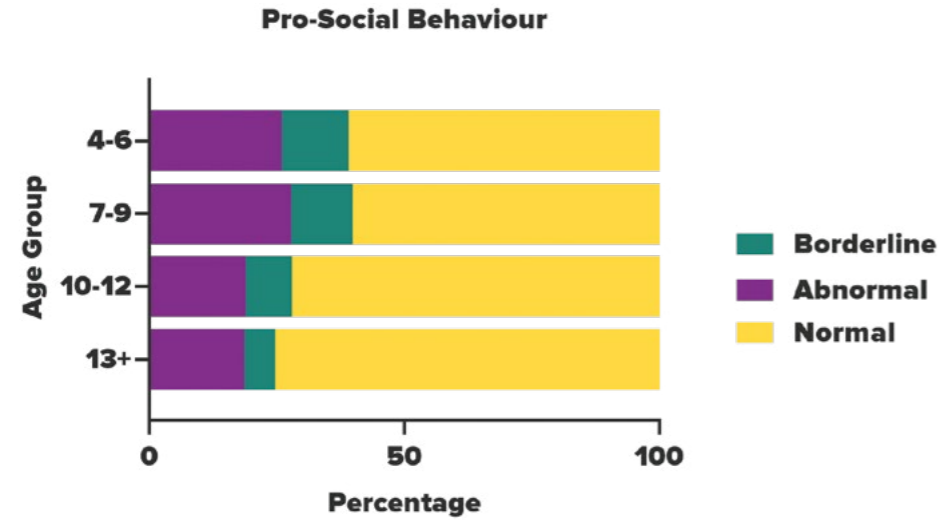


Figure 18. Percentage of children by age in the abnormal, borderline and normal ranges on the pro-social scale of the SDQ

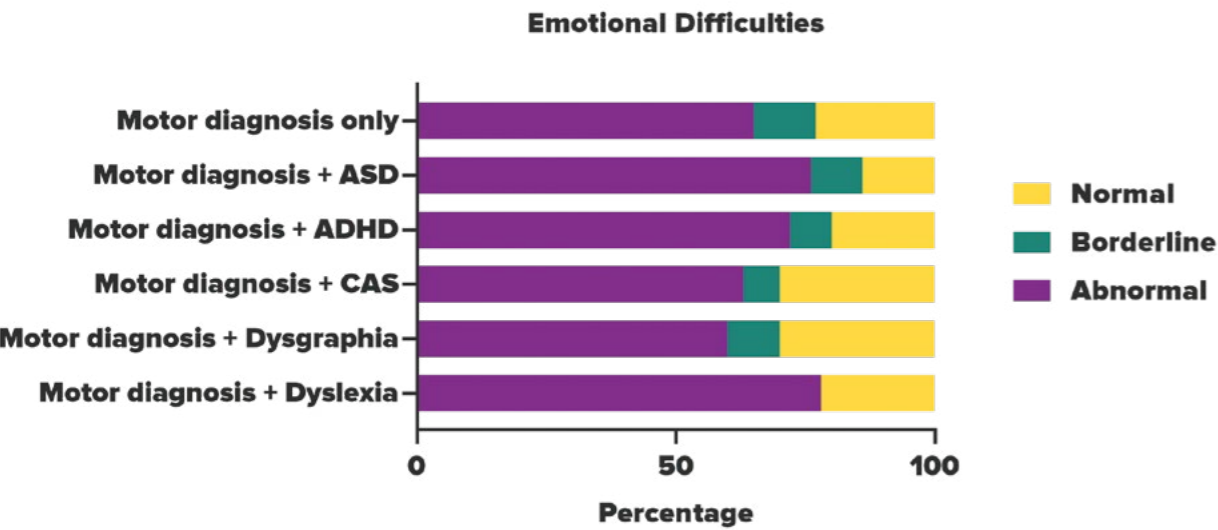


Figure 19. Percentage of children in the abnormal, borderline and normal ranges on the emotional scale of the SDQ based on the presence of co-occurring conditions

“She says she isn’t good enough and a rubbish person because she can’t join in.”

“Her difficulties make her feel inadequate and she thinks she’s a failure”

“Knowing how to support the movement difficulties alone is hard enough, but it is a struggle to know how to protect them from the cruelty that exists because they are different”.

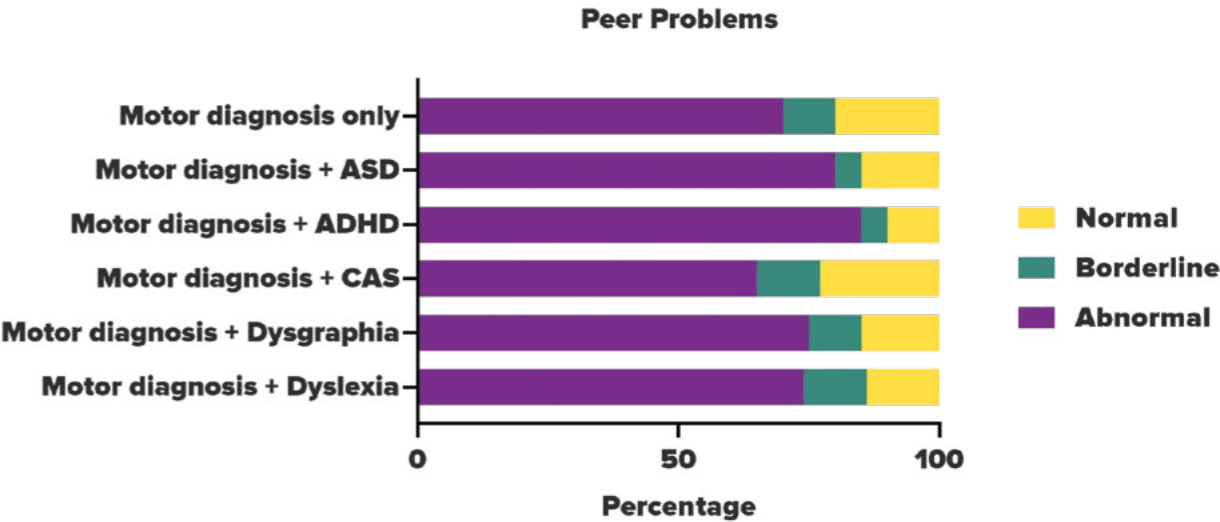


Figure 20. Percentage of children in the abnormal, borderline and normal ranges on the peer scale of the SDQ based on the presence of co-occurring conditions

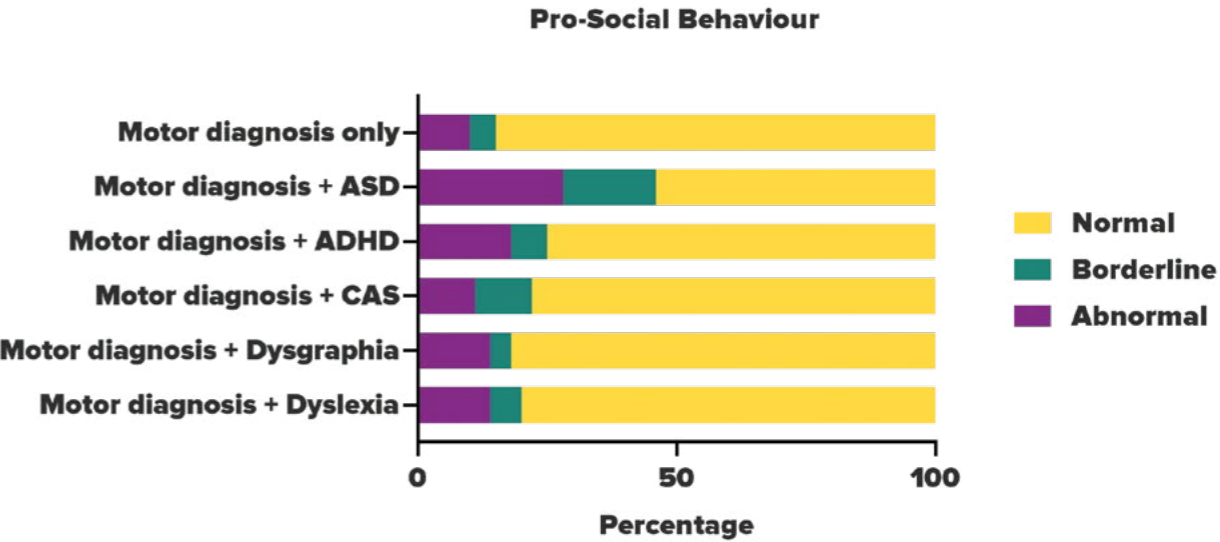


Figure 21. Percentage of children in the abnormal, borderline and normal ranges on the pro-social scale of the SDQ based on the presence of co-occurring conditions

Other features

Families were asked a series of questions related to their child’s emotions and behaviours in a number of contexts rated using a 5-point Likert scale (always, very often, sometimes, rarely and never); Figure 22.

59.3% of families reported that their child either always or very often is anxious learning or performing movement-related activities.

53.0 % of families reported that their child either always or very often withdraws or avoids participating in movement related activity.

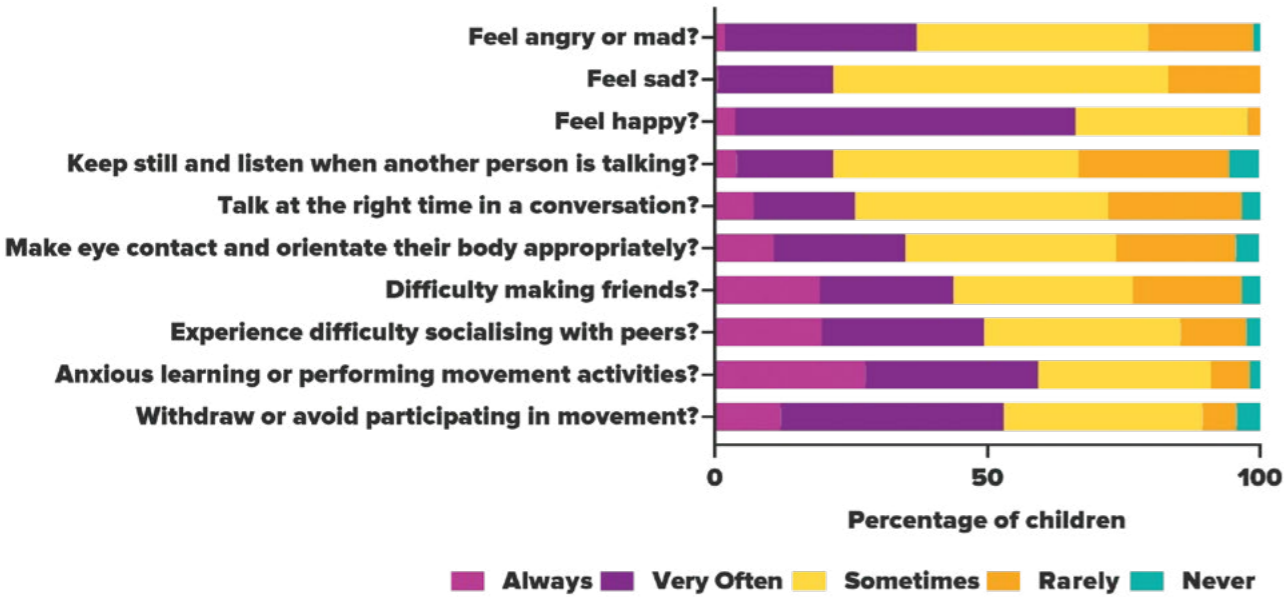


Figure 22. Other features of children with movement difficulties

Difficulties making friends and socialising was highlighted by families, with 49.4% of families reporting that their child either always or very often has trouble socialising with peers and 43.8% of families reported their child either always or very often has trouble making friends. While a large proportion of families (66.1%) reported that their child either always or very often felt happy, a third of families reported that their child either always or very often felt angry or mad.

Impact on the Family

Parents were also asked a series of questions related to the impact of their child’s movement difficulties on the family; Figure 23.

74.2% of families reported that their child’s movement difficulties either always or very often caused emotional worry or concern.

Families also reported that their child’s movement difficulties either always or very often limited the time that parents

have for their own needs (62.4%) and either always or very often limited the amount of activities they can do as a family (46.4%). More than half of families (52.6%) reported that supporting their child’s movement needs (i.e., through therapy) either always or very often caused financial strain.

77.7% of parents were either always or very often concerned about their child’s future.

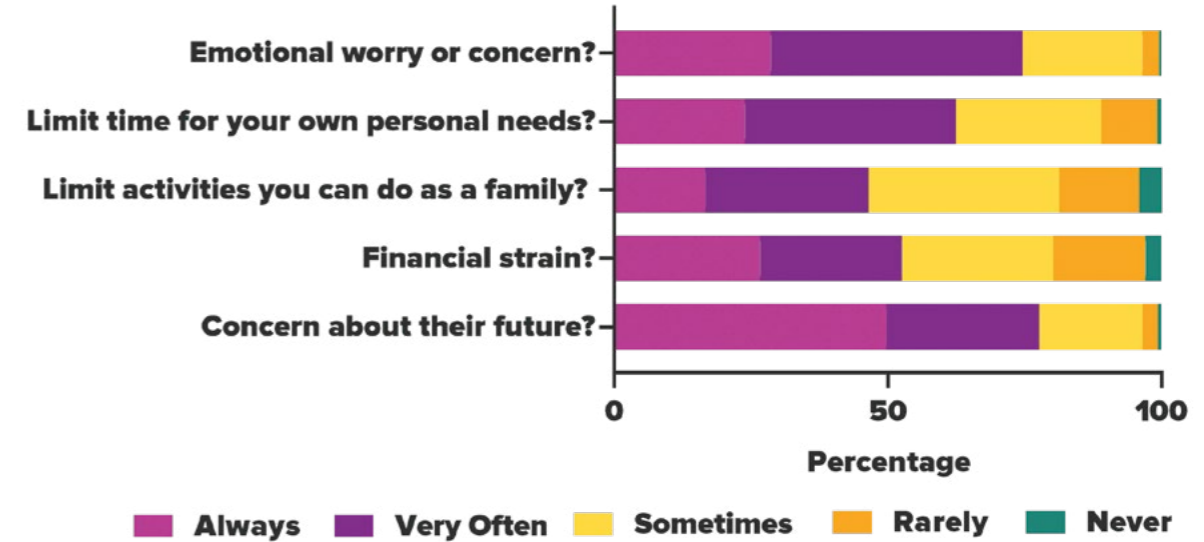


Figure 23. Impact of child’s movement difficulties on the family

“The mental fatigue I experience on a daily basis supporting my child is at times near breaking point. I feel for all the other parents out there suffering seemingly alone too.”

“Raising these kids, conducting therapy at home, [...] trying to get support at school and being brushed off, endless therapy appointments, talking to other parents that don’t get it, are all a source of stress, anxiety, fatigue for parents.”

Priority areas to improve support for all children with DCD

Families were asked to provide information on the areas they felt needed to be targeted to better support all children and families impacted by DCD in Australia.

These responses (n=278 families) were coded to identify **the top 10 target areas for change:**

1. Increased knowledge, awareness and support at school
2. Increased awareness and recognition of DCD in the community
3. Financial assistance to subsidise therapy costs
4. More resources and information about DCD for families
5. Increased knowledge and awareness by health care professionals
6. Improved access to therapy
7. Earlier identification and support in the early years
8. Support groups for children and families
9. Better consensus and coordination amongst health care professionals
10. More research to evaluate the efficacy of movement interventions

Increased awareness and support at school was the largest priority area identified by families, with 62.5% of families recommending it as an area they would like to see resources allocated to. Specifically, families would like to see teachers receive more training and resources, so they (i) know what the disorder is, (ii) can support the learning needs of children with movement difficulties, and (iii) make appropriate adjustments where required.

Increased awareness and better recognition of the disorder within the general community was also recommended by 25.2% of families. Families expressed concern that most people had never heard of DCD, despite the condition's prevalence. The lack of recognition was perceived by some as being overlooked as something "real".

Families (20.9%) would also like to see the costs associated with movement therapies subsidised, with some families feeling they cannot adequately meet their child's therapy needs.

Some families (13.7%) felt there was currently limited information and resources available in Australia. Currently, families are largely reliant on the information available from overseas websites which was not always relevant to the Australian context (e.g., medical and education systems).

Families would also like to see increased knowledge, awareness and consensus amongst health care professionals. They reported wanting to see better coordination of diagnostic and intervention pathways, and more specialists with expertise in the area, particularly within the early years.

Families also felt that support groups for children, adolescents and adults would help build friendships with people who have similar challenges, encourage social interaction and reduce mental health issues.

"I wish this road wasn't so tiring and difficult for our little people and parents. Acceptance and support for families struggling is needed and a system that is more user friendly!"

"There needs to be increased awareness so that when parents express concerns they are listened to. I feel like we have squandered critical early intervention years by being consistently reassured that he would grow out of it/catch up."

"There needs to be increased awareness in the community for DCD to be considered a disability and for it to be properly funded and recognised."

"I would welcome increased awareness amongst teachers so that parents don't need to start from scratch each year educating a new teacher."

"Right now, I feel there is no support. Major support needs to come from the school system."

"We need more resources, so we can understand and support our children."

"We need resources and advice on how to make our children's lives better."

"More resources for families would allow for better advocacy within the education system."



Parents also felt they would also benefit from support groups, to support one another through various stages of their child’s social and emotional development.

Finally, more research was identified by families as an area of unmet need, in particular, evidence related to the effectiveness of interventions for children with movement difficulties.

Priority areas for their child at present

To examine how family support needs may change over time (i.e., with age), families were also asked to identify the highest area of priority for them at present. Responses were coded and examined across the entire group (Figure 24) to identify the areas of highest priority at present.

Four key areas emerged;

- 1. Support and assistance at school,
- 2. Therapy,
- 3. Funding, and
- 4. Mental health.

These key areas were examined by age group (4-6 years, 7-9 years, 10-12 years, 13+ years) to identify if priority areas were more prominent at certain ages.

As illustrated in Figure 25, access to therapy and funding was a higher priority area for families with children aged 4-6 years when compared to those aged 7-9, 10-12, 13+ years. Those with children in older age groups were more likely to identify support at school and mental health as priority areas.

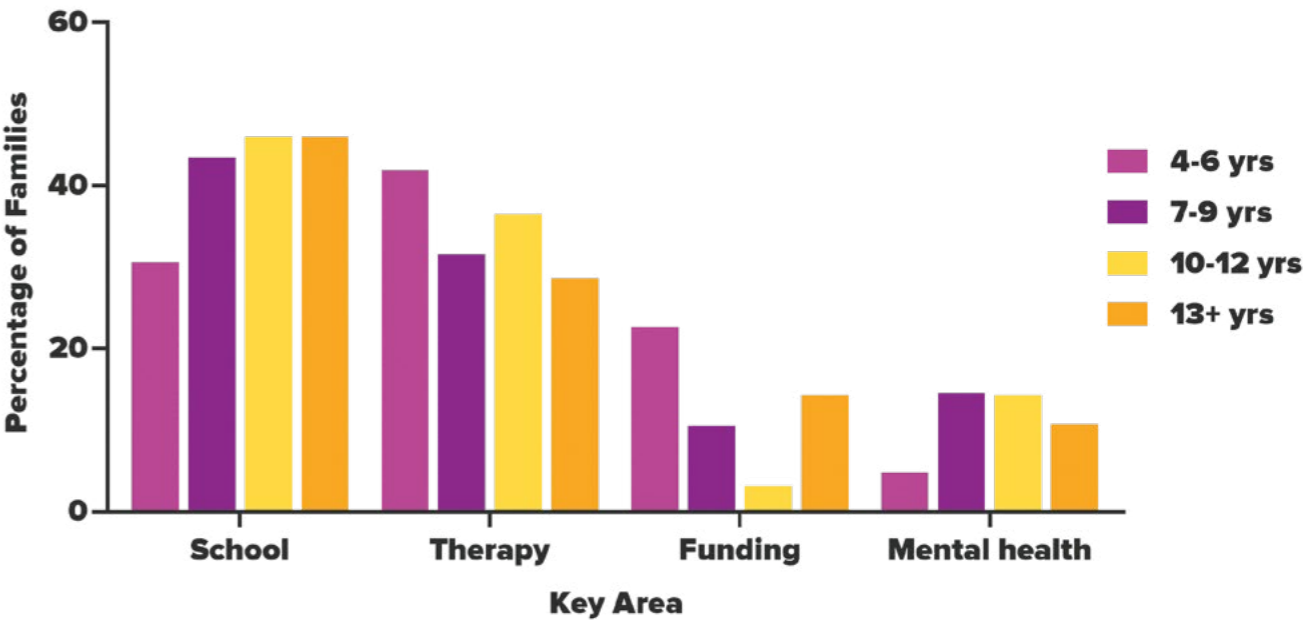


Figure 25. Key areas of priority across age groups

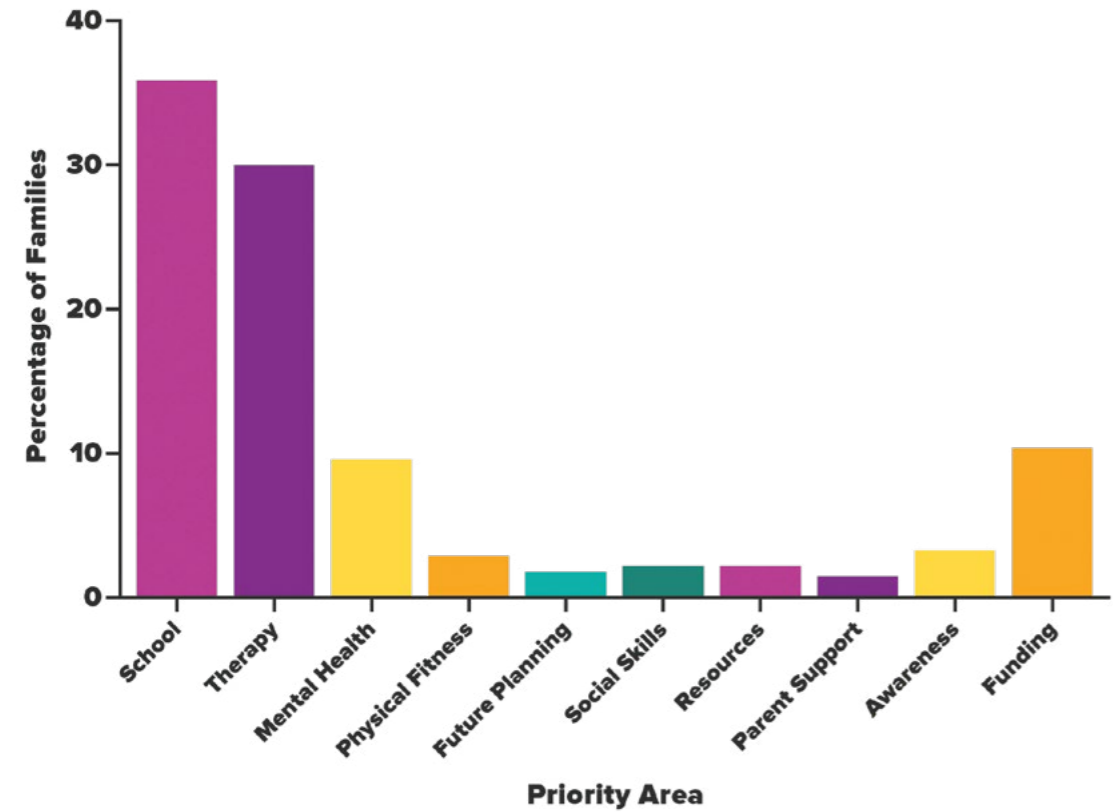


Figure 24. Priority areas identified by families at present

“DCD is just as life altering as other diagnoses but with no recognition or adequate help. We have been on such a long difficult road. The government doesn’t recognise it, a lot of teachers don’t know about it. People need to know what it is and how to help. I hate to think how many kids and their families are out there not knowing this is what their child has.”

“Please get the word out, people need to know about DCD and its effect on all aspects of everyday life, the government needs to start recognizing it as a real disability and schools and teachers need to know about it too, these kids are being left behind.”

“DCD is statistically very common, yet there is almost zero understanding, support or recognition. Just like people didn’t understand Autism and what it entails until it became more accepted and better understood, so too can DCD. When we tell people he has DCD, we need to go into great detail so that people can have some semblance of understanding”

“Teachers need to be trained to understand what our kids are going through. Schools also need to be appropriately resourced to provide extra help in the classroom and playground.”

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