Published in final edited form as:

Res Dev Disabil. 2024 February; 145: 104658. doi:10.1016/j.ridd.2023.104658.

The impact for DCD – USA study: The current state of Developmental Coordination Disorder (DCD) in the United States of America

Priscila Tamplain^{a,*}, Haylie L. Miller^b, Derrick Peavy^c, Sharon Cermak^d, Jacqueline Williams^e, Melissa Licari^f

^aUniversity of Texas at Arlington, USA

^bUniversity of Michigan, USA

^cPerson with Lived Experience, USA

^dUniversity of Southern California, USA

eVictoria University, USA

^fTelethon Kids Institute, USA

Abstract

Background: Developmental Coordination Disorder (DCD) is among the most under-recognized and under-supported disorders worldwide.

Aims: To present a preliminary national study that evaluated the unmet needs of children with DCD in the USA using the Impact for DCD survey.

Methods and procedures: 232 parents of individuals aged 5–18 years provided responses from 36 items in five domains (diagnosis, activity/participation, education, therapy, and social/emotional health).

Outcomes and results: Most children (81.9%) had a formal diagnosis for movement difficulties, and 91.6% of parents reported that receiving a diagnosis was helpful, but most had not heard of the diagnosis before. The most common co-occurring diagnoses were childhood apraxia of speech and other speech-language disorders (24.6%), ADHD (23.1%), and anxiety (18.8%). Most parents reported that their children withdrew from or avoided movement-related activities (53%), and nearly all (94.8%) were concerned about the impact of motor difficulties on their children's social and emotional health. Only 37% of parents reported feeling that their child received sufficient therapy.

Conclusions and implications: Generally, parents reported feeling frustrated with others' understanding and awareness of the condition and with therapy services. The results shown here

^{*}Correspondence to: Department of Kinesiology, University of Texas at Arlington, USA. priscila.tamplain@uta.edu (P. Tamplain). CRediT authorship contribution statement

Priscila Tamplain: Conceptualization, Investigation, Formal analysis, Writing, Supervision. Haylie L. Miller: Resources, Writing. Derrick Peavy: Resources, Writing. Sharon Cermak: Validation, Resources, Writing. Jacqueline Williams: Conceptualization, Methodology, Writing. Melissa Licari: Conceptualization, Methodology, Writing.

provide timely data that can support efforts for increased awareness, improved diagnosis, and increased availability of services for DCD in the USA.

Keywords

Developmental coordination disorder; Dyspraxia; Motor skills; Children; Motor development; USA

1. Introduction

Developmental Coordination Disorder (DCD) is a neurodevelopmental disorder characterized by the following criteria: (1) acquisition and execution of coordinated motor skills is far below the expected level for age, given opportunity for skill learning; (2) motor skill difficulties significantly interfere with ADL and impact academic/school productivity, prevocational and vocational activities, leisure and play; (3) onset is in the early developmental period; and (4) motor skill difficulties are not better explained by intellectual delay, visual impairment, or other neurological conditions that affect movement (DSM-5; APA, 2013). The condition has appeared in diagnostic manuals for over 30 years, and is highly prevalent, with estimates between ranging from 2% to 20% of children, with 5% to 6% being the most frequently quoted percentage in the literature (Blank et al., 2019). Despite the long-time recognition as a diagnosis and its high prevalence, DCD remains one of the most under-recognized and under-supported neurodevelopmental conditions in the world (Licari et al., 2021).

There is evidence that DCD persists well into adolescence and adulthood (Cantell et al., 1994; Hellgren et al., 1993; Tal-Saban et al., 2014), with 50% to 70% of individuals continuing to have motor difficulties. Children with DCD exhibit slower, less accurate, and more varied motor performance than their peers and score lower on motor assessments than expected for their age and intelligence level (Brown-Lum & Zwicker, 2015). The movement abilities of children with DCD frequently lead to performance difficulties in activities of daily living and physical tasks that typically developing children easily perform. In addition, DCD frequently co-occurs with other disorders, including speech and language disorders; specific learning disorder (especially reading and writing); including Attention Deficit Hyperactivity Disorder [ADHD]; disruptive and emotional behavior problems; and joint hypermobility syndrome (APA, 2013). This may be because motor evaluation is not typically part of the diagnostic process for conditions historically characterized by social, cognitive, or communication features.

Despite the high prevalence of DCD, it remains among the least understood and recognized in medical and educational systems. Individuals with DCD have impaired motor abilities, but the impact of the condition extends to a wide range of psychological, cognitive, physical and social differences (Zwicker et al., 2013). The Impact for DCD study, developed in Australia, was the first of its kind to collect survey data on the wide range of areas of ability affected by DCD (Licari et al., 2020). The resulting dataset was the largest in the world specifically characterizing the multifactorial challenges experienced by children with DCD and their families. The results of the survey revealed that families in Australia

were experiencing enormous challenges, especially in relation to obtaining a diagnosis for their child's movement difficulties, receiving recognition and support, and managing the considerable impact that DCD has on everyday life (Licari et al., 2020).

While the results of the Australian study were extremely informative for the field, it is unknown whether families in other countries have similar lived experiences. Particularly given the differences in the structure of healthcare and education systems, geographically-targeted follow-up studies are needed to determine whether these results hold in other regions. Specifically in the United States of America (USA), families may experience greater barriers to diagnosis related to lower overall awareness of DCD. For example, one study of medical professionals in Canada, the USA and UK found that only about 20% were aware of DCD, and of those, less than 30% were aware of the secondary consequences in non-motor domains of ability (Wilson et al., 2012). In the DSM-5 (handbook published by the American Psychiatric Association and widely used by clinicians in the USA), there is little research on the condition and despite a clear presentation of the diagnostic criteria, there is no description of an uniform clinical pathway for assessment, diagnosis, and intervention in the USA.

Only a handful of researchers have conducted studies with DCD in the USA, and very little grant funding and public attention at the national level has been allocated to DCD relative to other neurodevelopmental conditions (e.g., autism), despite prior work showing that it has a considerable impact on families (Cleaton et al., 2019). For this reason, the present study examines the present state of DCD in the USA by reporting the main quantitative findings of the *Impact for DCD: USA* study, conducted between 2021 and 2022. The purpose of the present study was to present the first preliminary national study to evaluate the unmet needs of children with DCD between 5- and 18 years of age living in the USA. To that, we summarized the main quantitative findings of the *Impact for DCD: USA* survey in five areas (diagnosis, activity and participation, school, therapy, and social and emotional impact), which created a report of the present state of the disorder in this country.

2. Methods

2.1. Participants

A total of 232 parents or caregivers of children and adolescents (62.5% male) with movement difficulties consistent with a diagnosis of DCD and related labels participated in the study. The survey was open to parents of children between ages 5 and 18 living in the USA, and the mean age of the children was 10.10 ± 3.69 years. Participants were recruited primarily through social media with the support of some DCD/dyspraxia support groups. Parents consented to the study prior to answering the online survey. All procedures were approved by the Institutional Review Board at the University of Texas at Arlington.

2.2. Measure/procedures

The original *Impact for DCD* survey was developed by Licari, Williams and colleagues (2020) in collaboration with parent, educator, and clinician consultation groups in Australia. The questionnaire involved 95 multiple-choice and open-ended questions. With consent

of the Australian group, the survey underwent minor adaptations for American English language and culture to be distributed in the USA as part of the *Impact for DCD: USA* study. Otherwise, the format was the same as the original. All questions were divided into five impact domains: 1) diagnosis; 2) therapy/intervention; 3) activity/participation; 4) school/education; and 5) social-emotional issues. The survey was launched online via QuestionPro in January 2021 and data for this study were collected until June 2022. The three states with the highest number of responses were Texas (n = 41, 17.5%), New York (n = 21, 9.05%), and California (n = 21, 9.05%). A total of 40 states were included in the sample. Sixteen participants did not report their state. A table including the regions of the US, age groups (5–12 years: children; 13–18 years: adolescents), and gender is included to display a general demographics of the study sample..

After a conversation with stakeholders (families of children participating in the study), the authors decided to present a summary of the findings in all domains to create a "state-of-the-art" overview of DCD in the USA. To that, we reported the answers to a total of 36 items, with 6 from Diagnosis, 5 from Therapy/intervention, 6 from Activity/participation, 12 from School/education, and 7 from the Social-emotional issues domains of the survey. These 36 items summarized the main points of the survey and built a clear overview of the major findings in the USA.

2.3. Analyses

Frequency and descriptive data were computed for each item. Percentages are reported for all items; for items where multiple responses were possible, percentages may have exceeded 100% (i.e., diagnosis received – a child may have received multiple diagnoses, such as DCD and dyspraxia at the same time, therefore the number of responses and percentages exceeded 100%). On the other hand, not every question required a response, so some items do not have a total number of responses that equal to 232. Because of that, the total number of responses for each question is reported.

3. Results

The results are grouped into five domains: 1) diagnosis; 2) therapy/intervention; 3) activity/participation; 4) school/education; and 5) social/emotional issues.

3.1. Diagnosis

190 children had a formal diagnosis for their movement difficulties (81.9%). 142 children were diagnosed with DCD (37.93%), and 88 children were diagnosed with dyspraxia (23.53%). Fig. 1 shows the frequency and percentage of each diagnosis reported by parents.

The average age for diagnosis was 4.86 ± 2.6 years (n = 184). Most parents had not heard of DCD prior to receiving their child's diagnosis (n = 138, 72.6%, total = 190), and most agreed that receiving a diagnosis was helpful (n = 173, 91.05%, total = 190). Fig. 2 shows the frequency and percentage of each co-occurring diagnosis. The three most common co-occurring conditions were Childhood Apraxia of Speech and other speech/language problems (n = 17, 24.6%), attention deficit hyperactivity disorder (ADHD; n = 16; 23.19%), and anxiety (n = 13, 18.84%), total = 69.

3.2. Activity/participation

Most parents reported that it took their child longer than other children to accomplish movement tasks (n = 226, 97.4%, total = 232). Parents also reported that their child became fatigued when performing movement tasks they found difficult (n = 219, 94.8%, total = 231), and that their child was more tired at the end of the day compared to other children (n = 173, 74.5%, total = 232). Most parents reported that their children did not enjoy participating in organized sport and physical activity (n = 145, 62.5%, total = 232), and that they did not engage in at least 60 min of moderate-to-vigorous physical activity per day (n = 141, 61.04%, total = 231). Parents also reported concerns about the impact of their child's movement difficulties on their physical health (n = 148, 64.07%, total = 231).

3.3. School/education

Most children were reported to have movement difficulties upon entering the school system (n = 142, 71.23%, total = 146). At the beginning of the school year, most parents reported that classroom teachers were aware of the child's movement difficulties (n = 170, 75.56%, total = 225), and met with parents to discuss the child's needs (n = 146, 64.89%, total = 225). Most children had an individual learning plan (n = 166, 73.78%, total = 225), and received support from a teacher/education aid to assist tasks impacted by their movement difficulties (e.g., handwriting) (n = 167, 72.93%, total = 229). In addition, the majority received additional time to complete tasks that were impacted by movement difficulties (e.g. tests/exams) (n = 163, 71.18%, total = 229).

In physical education, most parents reported that teachers never communicated with the parent on supporting their child in classes (n = 132, 72.53%, total = 182), but a little over half of the parents felt their child was supported to engage in physical education classes at school (n = 102, 56.04%, total = 182). Most parents reported that their child enjoyed going to school (n = 161, 70.93%, total = 227), despite most having difficulty making friends at school (n = 136, 60.44%, total = 225). Most parents were concerned about the child's movement difficulties negatively impacting their ability to reach their potential at school (n = 179, 78.51%, total = 228), completing schooling to the best of their potential (n = 184, 80.35%, total = 229), and the child's ability to gain employment in the future (n = 155, 66.81%, total = 232).

3.4. Therapy/Intervention

Most parents had accessed therapy to assist their child with movement difficulties (n = 207, 89.22%, total = 232), but only one in three children were currently accessing therapy services for this reason (n = 83, 35.78%, total = 232). More than half of families felt supported to maintain the progress the child made during therapy at home (n = 132, 60.55%, total = 218), but the majority of parents did not feel that their child received sufficient therapy to support their movement difficulties (n = 139, 62.33%, total = 232). Table 2 presents a list of therapy services currently accessed for children.

3.5. Social-emotional issues

Most parents are concerned about the impact of their child's movement difficulties on their social and emotional health (n = 220, 94.83%, total = 232). Table 3 presents the frequency of children's participation in movement-related activities.

4. Discussion

The purpose of the present study was to present the first preliminary national study to evaluate the unmet needs of children with DCD in the US. To that, we summarized the main quantitative findings of the *Impact for DCD: USA* survey in five areas (diagnosis, activity/participation, school/education, therapy/intervention, and social/emotional issues). Ultimately, these results provide an overview of the current state of DCD in the USA and offer insight into the difficulties that families encounter in each of the 5 areas. The findings are discussed separately for each of the areas.

4.1. Diagnosis

While it was encouraging to see that 3 out 5 children (61%) in the sample had received a diagnosis of the globally accepted diagnostic label DCD, there were at least 10 other diagnostic labels provided to families. This is comparable to the Australian sample, which reported 9 other diagnoses (Licari et al., 2021). In addition, a total of 88 children were diagnosed with dyspraxia (38%). The issue of how clinicians, researchers, and community members use the terms dyspraxia and DCD, among other terms, is a complex one. While many use the two terms interchangeably, many also separate the two as distinct conditions. Given that DCD is: 1. the preferred diagnostic term recommended by the European Academy of Childhood Disability in their 2012 and 2019 International Guidelines (Blank et al., 2012, 2019), and 2. the term appearing in both national (DSM-5; APA, 2023) and international (ICD-11; WHO, 2021) diagnostic manuals used, there needs to be increased utilization of this term within diagnostic practice. Perhaps it is reasonable for dyspraxia to be used as a descriptor, since there are no clear diagnostic criteria for it, or the other related labels. Sometimes, the term dyspraxia is used to refer to a deficit of "praxis", as in a decreased ability to learn simply by observation and practice (Sanger et al., 2006). Problems with praxis can also be a symptom of other motor-related conditions, such as cerebral palsy, stroke, etc. (Sanger, 2015). Therefore, the recommendation is to use the term DCD for a consensus. However, it also appears that many individuals prefer to use the term dyspraxia for several reasons (including the fact that it allows for first-person identity, e.g., dyspraxic), and that should be taken into consideration. More needs to be done in this area from both perspectives – it is essential to improve diagnostic practice and terminology and to also attend the needs of individuals and families with lived experience of the condition.

In the USA, there is no national clear pathway or guidance for diagnosis, which may discourage families from pursuing one. Without a clear diagnosis, it is hard to provide the right accommodations and interventions for children, and frustration and stress associated with the secondary consequences of DCD are likely to happen (i.e. anxiety, depression; Draghi et al., 2019). The International recommendations for DCD state that DCD should be diagnosed by a multidisciplinary team of professionals qualified to examine the specific

DSM-5 criteria for the disorder (Blank et al., 2019). Ideally, the team should include a physician (e.g., child psychiatrist, developmental pediatrician, child neurologist) and both an occupational and physical therapist trained in the standardized motor tools used to assess children suspected of having the disorder (Blank et al., 2019). One way to provide a pipeline for an evaluation of DCD criteria is through assessment of motor skills for children diagnosed with the most common co-occurring conditions. For example, speech and language issues are typically identified early in life, and a pipeline for assessment and intervention for motor skills for these children is strongly recommended (for more on this topic, see Iuzzini-Seigel et al., 2022). Childhood Apraxia of Speech was the most common co-occurring disorder in both the USA and Australian surveys (Licari et al., 2021). ADHD and Autism also frequently co-occur with DCD (Kaiser et al., 2015; Miller et al., 2021), and a pipeline from these diagnoses would likely increase DCD diagnosis and treatment.

Almost three out of every four families reported not knowing about DCD prior to the diagnosis – this reinforces the paramount importance of increasing general knowledge and awareness of DCD in the USA. If there is low community awareness of DCD, caregivers are limited in their ability to recognize early signs and seek appropriate assessment for children with significant motor problems. Similarly, professionals who have limited knowledge of the core features of DCD, or who have little experience with their assessment and management, may not effectively address caregivers' concerns. Motor difficulties are often overshadowed by other difficulties, such as learning and social problems, particularly for children with multiple co-occurring neurodevelopmental conditions. It is crucial to ensure that community members in the USA have timely, direct access to knowledgeable professionals who understand the complex presentation of DCD.

4.2. Therapy/intervention

While most parents sought therapy for their children, only a few were currently receiving it at the time of our study (36%). This is a significantly lower number than the Australian sample (64%), at a similar age (USA: 10.1 years, Australia: 9.2 years). There is no clear guideline for motor intervention for DCD in the USA, leading to uncertainty among caregivers and clinicians and delays in the pipeline from first concern to therapy. Evidence-based motor intervention is necessary for a child to improve motor skills, and both occupational and physical therapy are recommended for children with DCD (Smits-Engelsman et al., 2018). In the USA, accessing physical and occupational therapy is a complicated, time-consuming process often heavily dependent on the efficiency and appropriateness of referrals and the payer status of the family (e.g., insured vs. paying out-of-pocket). Therapy can also be accessed through schools (generally) - however, the cut-off for receiving services can be relatively high (only severe cases may qualify), and the duration/frequency of sessions may not be enough to make a significant difference.

While sensory integration therapy seems to be common for children with movement difficulties/DCD in the USA, only 39 participants reported having that as a "disorder", and only 14 of those were in occupational therapy (35%). Interestingly, it has been suggested that at best, sensory integration is as effective as any other intervention in improving motor skills (Mandich et al., 2021). Generally, research shows that certain types

of interventions can be effective for motor skill improvement: activity-oriented approaches, body function-oriented when combined with activities, active video games, and small group programs (Smits-Engelsman et al., 2018). One example of a specific approach that shows overall effectiveness for children with DCD is the Cognitive Orientation to daily Occupational Performance (CO-OP). CO-OP is an individualized, task-specific (activity-oriented), cognitive-based, problem--solving approach for individuals experiencing difficulties performing the skills they want or need to do (Izadi-Najafabadi et al., 2022). CO-OP was initially developed for treatment of DCD. In the USA, only a small number of individuals is certified for CO-OP practice, according to the website (https://icancoop.org/). Providing access to therapies with high scientific evidence is fundamental for professionals and families These data contribute to the need for the development and implementation of a well-defined pathway for intervention for DCD in the USA.

4.3. Activity/participation

Participation is recognized as one of the priority areas for children with disabilities (O'Dea et al., 2020). In general, parents reported that children with DCD were slower, more easily tired, and did not enjoy participating in motor activities compared to other children. The issues with speed and effort are important because they are often not visible or clear to other people. Children that move slower or have to put more effort into tasks may be perceived as "lazy" or "inattentive", which is unproductive and does not support their needs.

Enjoying and participating in physical activities is an important component of a healthy childhood. Most children in the USA do not participate in at least 60 min of moderate to vigorous PA/day as recommended by the Centers for Disease Control and Prevention (CDC, 2018), and this was similar in this study. Despite a wide variety of physical activity options for school-age children, these tend to be mostly associated with sports and most tend incur medium to high fees for participation. Inclusive and low-cost programs, and programs specifically designed for children with DCD, should be part of the remediation of low physical activity among children with DCD in the USA.

4.4. School/education

The present study showed an overall level of support and understanding of children's motor difficulties in schools. This is potentially due to the fact that most children already had difficulties when starting school (71.23%). We do not know if these accommodations and supports were put in place easily or if parents had to "fight" for them, as it is often mentioned by parents. In addition, there is anecdotal evidence that many families that leave formal education for homeschooling make that choice because their child did not have the understanding and supports needed in the school environment. Overall, about 20–30% of families did not report understanding and support from schools. Without a system in place for diagnosis and intervention via general health settings, schools can be a great place for general testing and some intervention for children with DCD. In physical education classes, most teachers never communicated with parents, and only about half of the parents felt that their child was supported in PE classes. PE is an important part of developing general motor proficiency, therefore special consideration to children with low motor ability such as

DCD should be provided. Teacher and school education on the topic could be beneficial to improve these numbers.

While parents reported that most children enjoyed going to school, most were thought to have difficulties making friends, and parents were generally worried about the impact of motor problems in reaching full potential at school and future employment. Interestingly, a study showed that peer problems mediated the relationship between DCD and internalizing/externalizing problems in school-aged children (Wagner et al., 2012). In addition, a recent systematic review demonstrated high frequency and severity of academic difficulties in children with DCD, especially in math (Dionne et al., 2023). These data show that it is reasonable for parents to be concerned about their children in schools, and that supports should be put in place related to general socialization and academic performance. In the USA, there is a high focus on academic performance overall (as evidenced by the amount of standardized testing in school districts, for example). Therefore, it is important to provide knowledge and promote awareness of DCD throughout school districts, and foster understanding of how to provide better provisions for children with DCD.

4.5. Social-emotional issues

Not surprisingly, most parents were concerned about the impact of their child's movement difficulties on their social and emotional health. The data presented here is aligned with a higher prevalence of mental health problems in this population (Lingam et al., 2012). The findings show that most children avoid motor activities, are anxious when learning motor activities, and experience difficulties making friends and socializing with peers, all of which are precursors to poor mental health. We speculate that these concerns may be even higher in countries with relatively low knowledge and awareness of DCD, like the USA. Proper intervention and accommodation can improve the mental health of children with DCD (see Tamplain & Miller, 2021 for a detailed review). However, recognizing and understanding the condition is crucial for that to happen. Children with DCD tend to "fall through the cracks" of school and healthcare systems, which causes families considerable stress (Jijon & Leonard, 2020).

4.6. General discussion

These findings highlight the present status of DCD in the USA by presenting evidence in five areas of concern associated with the disorder. Our results revealed that families in the USA experience enormous challenges, from obtaining a diagnosis for their child all the way to receiving accommodations and intervention. In addition, the responses showed a considerable impact of DCD in everyday life, especially in social and emotional skills. The findings are similar to those found in Australia (Licari et al., 2021) and provide important insights into potential priorities for the field. Overall, as discussed by Licari and colleagues (2021), there is a clear need for targeted awareness campaigns and professional development opportunities for allied health and education professionals. In addition, it is necessary to develop and promote guidelines for practice in the USA in order to strengthen understanding and create a clear pathway for diagnosis and treatment of DCD. The international clinical recommendations by Blank et al. (2019) provide a starting point for such guidelines, which should also include input from self-advocates and other stakeholders in the DCD

community. Based on the main results of our study, we recommend four key priorities for DCD in the USA: 1) raise awareness and understanding of DCD, especially for professionals and general public, 2) standardize the diagnostic process, 3) increase opportunities for physical activity both in and out of schools, 4) improve access and continuation of therapy/intervention, and 5) recognize and address social-emotional difficulties. The data support a push for change, and we urge the authorities to use them to inform the development and delivery of national implementation strategies in the USA.

There are several limitations in this study. First, we used a convenience sample and state representation was not equal. Future studies that include a large, nationally representative sample can inform the prevalence and provide data for a better understanding of the state of DCD in the USA. For comparison purposes, the Australian Impact for DCD study had a sample size of 435 individuals, almost twice as much as the one represented in the US (with a much smaller country). However, it is important to mention that they had the support of a strong organization that serves the DCD community in their country, and awareness/education there is infinitely better the one we have in the USA. It is complex to achieve a larger sample size with such low awareness of the condition.

Lack of further demographic information such as ethnicity, family income, and other factors are also limitations to the current study. In addition, parents that chose to answer the survey were aware of the disorder and may have had different experiences compared to others. The results presented here only represent a snapshot of parents' perceptions about their children's diagnosis of DCD. Most importantly, co-occurrence of other disorders in the sample makes it difficult to determine which barriers during the diagnostic and care process were directly related to DCD versus to other conditions. It is important to mention that the present study was conducted generally during a time of COVID-19 restrictions. We are not able to infer if the "low" number of individuals receiving intervention is due to those restrictions or not, but that is a reasonable speculation. A further study would have to be performed to understand the reasons why the numbers were low and if this was due to COVID-19 restrictions. Nevertheless, this study is the first to use an exclusive American sample, and it highlights actionable issues specific for American families.

Based on the main quantitative findings of the *Impact for DCD: USA* study in five areas (diagnosis, activity/participation, school/education, therapy/intervention, and social/emotional issues), we conclude that there are several challenges related to the disorder in the USA. The results shown here are the first to provide a clear picture of the current state of DCD in the USA and provide timely, preliminary data that can support efforts for increased awareness, improved diagnosis, and increased availability of services.

Acknowledgements

The authors are immensely grateful to all the families that answered the survey and hope that this article helps support their efforts in advocacy for DCD in the USA. We are also grateful to several individuals and communities that helped advertise the study, especially the Facebook group "DCD/Dyspraxia: One Step Forward", Jenny Hollander, and the organization Apraxia Kids. One important organization is emerging in the USA and we are hopeful that it will help elevate awareness, understanding, and family support for those with DCD - they are called Dyspraxia DCD America: www.dyspraxiadcdamerica.org. NIH K01-MH107774.

Data Availability

Data will be made available on request.

References

Blank R, et al. (2019). International clinical practice recommendations on the definition, diagnosis, assessment, intervention, and psychosocial aspects of developmental coordination disorder. Developmental Medicine & Child Neurology, 61, 242–285. [PubMed: 30671947]

- Blank R, et al. (2012). International clinical practice recommendations on the definition, diagnosis, assessment, intervention, and psychosocial aspects of developmental coordination disorder. Developmental Medicine & Child Neurology, 54, 54–93. [PubMed: 22171930]
- Brown-Lum M, & Zwicker JG (2015). Brain imaging increases our understanding of developmental coordination disorder: a review of literature and future directions. Current Developmental Disorders Reports, 2, 131–140.
- Cantell M, Smyth MM, & Ahonen T (1994). Clumsiness in adolescence: Educational, motor and social outcomes of motor delay detected at 5 years. Adapted Physical Activity Quarterly, 11, 115–129.
- Cleaton MAM, Lorgelly PK, & Kirby A (2019). Developmental coordination disorder: the impact on the family. Quality of Life Research, 28, 925–934. [PubMed: 30536221]
- Dionne E, Bolduc M, Majnemer A, Beauchamp MH, & Brossard-Racine M (2023). Academic challenges in developmental coordination disorder: a systematic review and meta-analysis. Physical & Occupational Therapy in Pediatrics, 43(1), 34–57. [PubMed: 35611495]
- Draghi TTG, Cavalcante Neto JL, Rohr LA, Jelsma LD, & Tudella E (2019). Symptoms of anxiety and depression in children with developmental coordination disorder: a systematic review. Journal of Pediatrics, 96(1), 8–19.
- Hellgren L, Gillberg C, Gillberg IC, & Enerskog I (1993). Children with deficits in attention, motor control and perception (DAMP) almost grown up: general health at 16 years. Developmental Medicine & Child Neurology, 35, 881–892. [PubMed: 8405717]
- Izadi-Najafabadi S, Gunton C, Dureno Z, & Zwicker JG (2022). Effectiveness of cognitive orientation to occupational performance intervention in improving motor skills of children with developmental coordination disorder: A randomized waitlist-control trial. Clinical Rehabilitation, 36(6), 776–788. [PubMed: 35466705]
- Jijon AM, & Leonard HC (2020). Parenting stress in parents of children with developmental coordination disorder. Research in Developmental Disabilities, 104, Article 103695. [PubMed: 32474232]
- Licari M, Alvares GA, Bernie C, Elliott C, Evans KL, McIntyre S, Pillar SV, Reynolds JE, Reid SL, Spittle AJ, Whitehouse AJO, Zwicker JG, & Williams J (2021). The unmet clinical needs of children with developmental coordination disorder. Pediatric Research, 90, 826–831. [PubMed: 33504966]
- Licari MK & Williams J, Impact for DCD Team., 2020. National survey evaluating the Impact of developmental coordination disorder in Australia: summary of results. https://www.telethonkids.org.au/globalassets/media/documents/projects/impact-for-dcd-report.pdf).
- Lingam R, Jongmans MJ, Ellis M, Hunt LP, Golding J, & Emond A (2012). Mental health difficulties in children with developmental coordination disorder. Pediatrics, 129(4), e882–e891. [PubMed: 22451706]
- Mandich AD, Polatajko HJ, Macnab JJ, & Miller LT (2021). Treatment of children with developmental coordination disorder: What is the evidence? Physical & Occupational Therapy in Pediatrics, 20(2–3), 51–68.
- O'Dea A, Robinson K, & Coote S (2020). Effectiveness of interventions to improve participation outcomes for children with developmental coordination disorder: a systematic review. British Journal of Occupational Therapy, 83(4), 256–273.
- Sanger TD (2015). Movement disorders in cerebral palsy. Journal of Pediatric Neurology, 13(4), 198–207.

Sanger TD, Chen D, Delgado MR, Gaebler-Spira D, Hallett M, & Mink JW (2006). definition and classification of negative motor signs in childhood. Pediatrics, 118(5), 2159–2167. [PubMed: 17079590]

- Smits-Engelsman B, Vinçon S, Blank R, Quadrado VH, Polatajko H, & Wilson PH (2018).
 Evaluating the evidence for motor-based interventions in developmental coordination disorder:
 A systematic review and meta-analysis. Research in Developmental Disabilities, 74, 72–102.
 [PubMed: 29413431]
- Tal-Saban M, Ornoy A, & Parush S (2014). Young adults with developmental coordination disorder: A longitudinal study. American Journal of Occupational Therapy, 68, 307–316.
- Tamplain P, & Miller H (2021). What can we do to promote mental health among individuals with Developmental Coordination Disorder? Current Developmental Disorders Report, 8, 24–31. DOI: 10.1007/s40474-020-00209-7.
- Zwicker JG, Harris SR, & Klassen AF (2013). Quality of life domains affected in children with developmental coordination disorder: A systematic review. Child: Care, Health & Development, 39(4), 562–580. [PubMed: 22515477]
- Wagner MO, Bos K, Jascenoka J, Jekauc D, & Petermann F (2012). Peer problems mediate the relationship between developmental coordination disorder and behavioral problems in school-aged children. Research in Developmental Disabilities, 33(6), 2072–2079. [PubMed: 22750362]
- Wilson BN, Neil K, Kamps PH, & Babcock S (2012). Awareness and knowledge of developmental coordination disorder among physicians, teachers and parents. Child: Care Health and Development, 39(2), 296. [PubMed: 22823542]

What this paper adds?

Developmental Coordination Disorder (DCD) is a disorder where individuals have poor motor coordination and low motor skills, which affects daily living. Specifically in the United States of America (USA), families may experience barriers to diagnosis and intervention related to lower overall awareness of DCD. This study aimed to understand the unmet needs of children with DCD living in the USA by using the "Impact for DCD" survey. We summarized the main findings of 5 domains (diagnosis, activity/participation, education, therapy, and social/emotional health). 232 parents of children and adolescents aged 5- to 18 years of age participated. 3 out of 5 children had a diagnosis of DCD, but 9 other diagnoses were reported. Almost three out of every four families reported not knowing about DCD prior to the diagnosis. While most parents sought therapy for their children, only a few were currently receiving it at the time of our study. In general, parents reported that children with DCD were slower, more easily tired, and did not enjoy participating in motor activities compared to other children. However, there seemed to be a reasonable level of support and understanding of children's motor difficulties in schools. Not surprisingly, most parents are concerned about the impact of their child's movement difficulties on their social and emotional health. The results shown here provide support for more awareness, improved diagnosis, and better availability of services for DCD in the USA.

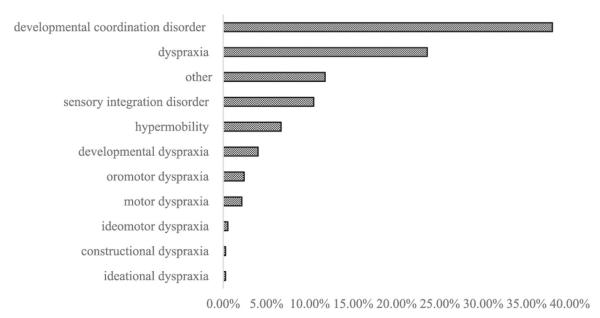


Fig. 1. Diagnoses received for children's motor difficulties.

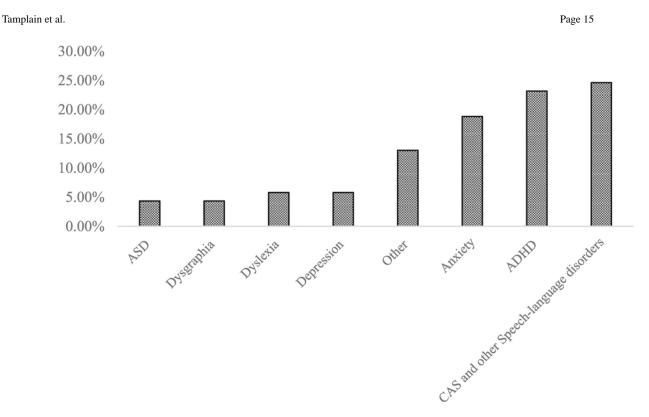


Fig. 2. Co-occurring conditions to motor difficulties.

Table 1

Sample demographic information.

Geographical region		Midwest	Northeast	Southeast	Southwest	West	Unknown	Total
Males	Children	20	27	8	16	22	9	102
	Adolescents	9	5	8	12	4	3	41
	Unknown	1	0	0	1	0	0	2
Females	Children	7	17	11	9	9	4	57
	Adolescents	5	7	3	9	2	0	26
	Unknown	1	0	0	0	0	0	1
Total		43	56	30	47	37	16	229

^{*} no report for age (n = 3), no report for gender (n = 3)

Table 2

Types of therapy received.

Types of therapy	Daily	Weekly	Every 2 weeks	Monthly	Yearly
Occupational therapy (n = 63)	1.59%	87.3%	7.94%	3.7%	0%
Physical therapy $(n = 33)$	6.06%	78.79%	12.12%	3.03%	0%
Speech therapy $(n = 43)$	9.3%	81.4%	9.3%	0%	0%
Specialized exercise programs (n = 13)	23.08%	61.54%	0%	7.69%	7.69%
Psychologist (n = 18)	0%	55.56%	22.22%	16.67%	5.56%

Table 3 Social-emotional issues.

	Always	Very often	Sometimes	Rarely	Never
Does your child withdraw or avoid participating in movement-related activity? (n = 232)	11.64%	41.38%	34.91%	9.48%	2.59%
Is your child anxious learning or performing movement-related activities? (n = 232) $$	26.29%	34.05%	31.47%	6.47%	1.72%
Does your child experience difficulty socializing with peers? (n = 231)	15.15%	34.20%	31.17%	13.85%	5.63%
Does your child have difficulty making friends? (n = 232)	15.52%	27.16%	31.47%	18.97%	6.90%
How often does your child feel sad? (n = 232)	0.43%	20.26%	59.48%	18.53%	1.29%
How often does your child's movement difficulties cause the following impact on the family? Emotional worry or concern? $(n=231)$	25.11%	38.53%	29.00%	4.76%	2.60%