DEVELOPMENTAL
COORDINATION
DISORDER
AUSTRALIA INC.

Statement from DCD Australia Inc.

Developmental Coordination Disorder (DCD) Australia Inc. welcomes the opportunity to provide a submission to the Disability Royal Commission on behalf of the DCD community to outline systemic factors which have led to people with DCD experiencing abuse, neglect and violation of their rights.

DCD Australia was established in 2014 as the national peak organisation for children and adults with DCD in Australia. DCD Australia takes a human rights-based approach and works to:

- advocate on behalf of people with DCD to ensure they have access to the services and supports they need;
- provide community support to people and families affected by DCD;
- raise awareness in the community of the complex nature of DCD;
- develop strategies and teaching programs for educators and health professionals; and
- support research that will advance understanding of DCD.

DCD is a lifelong disability affecting approximately 1.2 million Australians but there is little community awareness of the disability and its impact on people with the condition. In 2020, DCD Australia partnered with researchers to deliver a national study to demonstrate the impact of DCD on families in Australia. Findings revealed that there are currently no clear diagnostic pathways for DCD in Australia, diagnostic labelling is inconsistent and inaccurate, and families are struggling to access therapy due to funding ineligibility. The report also highlighted a lack of support in the education system. Most teachers have no knowledge of the condition and therefore do not provide an appropriate level of accommodations to support learning in the classroom.

People with DCD struggle in school, work, and social situations and are not getting the support they need. We hear of children who experience suicidal ideation because of the exclusion they experience within the classroom; adults who never learn to drive and find their employment opportunities limited; and families who are struggling to pay for much needed therapies for their children, and often end up having to struggle with no formal support.

Given that DCD substantially impacts a person's ability to participate in daily activities at home, school and in the community, and, without the right support, reduces quality of life, we believe people with DCD are currently experiencing significant neglect in the current system. **This is an urgent call for systemic changes that will support the rights of people with DCD and their families in Australia**.

We consent for our submission to be published on the Royal Commission website.

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List of Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
CAS	Childhood Apraxia of Speech
DCD	Developmental Coordination Disorder
EACD	European Academy of Childhood Disability
ECEI	Early Child Early Intervention
ECP	Early Childhood Partners
GP	General Practitioner
LAC	Local Area Coordinator
MHCP	Mental Health Care Plan
NDIS	National Disability Insurance Scheme
OT	Occupational Therapist

1. Submission Overview

DCD Australia Inc. is pleased to have the opportunity to provide a submission to the Disability Royal Commission on behalf of our community. In this submission **we will present evidence demonstrating the significant neglect experienced by people with DCD** in Australia. Even though DCD has appeared in diagnostic manuals used in Australia for over 30 years, the disorder remains under-recognised and under-supported in this country.

Although Australia is a signatory to the United Nations Convention on the Rights of Persons with Disability (UNCRPD), people with DCD in Australia regularly experience violations of these rights. People with DCD experience discrimination across a range of settings and systems including:

- The health care system where they struggle to get access to a diagnosis or clear pathways to intervention.
- The education system where children are not given the support they need to be given full access to the curriculum within mainstream education.
- Limited opportunities and support to participate in community activities.
- Lack of funding from the National Disability Insurance Scheme (NDIS).
- No access to systemic or individual advocacy due to the complete lack of funding for the disability representative peak organisation.

Over the last decade, the National Disability Insurance Scheme (NDIS) has been implemented in Australia; the primary system of individualised access and support for people with disability. For children, access to the scheme changes across age groups, with children under 7 years of age able to receive support based on developmental delays and needs assessment, whilst those above 7 years access the scheme via diagnostic categorisation. To date, individuals above 7 years of age with DCD have not had defined access to the scheme, nor alternatively funded support or services. Given DCD is not typically diagnosed until children are school age, the vast majority of individuals with DCD do not receive funded support for intervention access.

Like all disabilities, change for people with DCD will only come through advocacy and awareness efforts. It was only 40 years ago that the autistic community encountered similar challenges to what the DCD community are experiencing today. It is the hard work of advocacy groups that leads to systemic changes that improves the lives of people with disabilities.

As the National representative organisation for people in Australia with DCD, we ask for the Royal Commission to consider how this population of people with disability are being discriminated against, marginalised and neglected in our communities. We request that the Commission consider making specific recommendations to address the inequities and discrimination experienced by our community.

In this submission we will:

- Provide an overview of DCD
- Present the major areas people with DCD and their families are currently experiencing discrimination and neglect, including:
    1. Diagnosis
    2. Education
    3. Recognition of the lifelong impact
    4. Access to services and supports
- Provide detailed recommendations of changes that are needed to address the neglect experienced by the DCD community in Australia.

Our submission is supported by evidence from the published research literature, statements from the DCD community (parents of children with DCD, adults with DCD, medical professionals, allied health professionals, educators), and findings from a national survey conducted in 2020 to evaluate the unmet needs of children with DCD in Australia (called *Impact for DCD*).

The *Impact for DCD* survey was conducted together with leading Australian researchers, in collaboration with parent, teacher and clinical service reference groups. The survey covered questions targeting five key impact domains identified during survey development: 1. diagnosis, 2. activity and participation, 3. education, 4. therapy and intervention, and 5. social and emotional impact. The *Impact for DCD* survey is the largest survey to be conducted on this condition in Australia, with responses received from the parents of 443 children with DCD (aged 4-18 years). The average age of children reported on was 9.2 years. A full copy of the *Impact for DCD* national survey can be viewed in Appendix 1.

1.1. What is Developmental Coordination Disorder (DCD)?

DCD is a neurodevelopmental disability characterised by marked impairments in learning and performing movement skills. 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). Challenges often extend beyond the motor domain to include secondary cognitive, mental and physical health issues. With an estimated prevalence of ~5% of the population, DCD is a lifelong disability affecting approximately 1.2 million Australians. It is estimated that on average one or two children in every Australian classroom has DCD.

DCD first appeared in the Diagnostic and Statistical Manual of Mental Disorders in 1987 (DSM-III, APA, 1987), and has appeared in all editions since (DSM-IV, 1994; DSM-5, 2013). Classed as a motor disorder, diagnosis currently requires meeting four diagnostic criteria (Table 1).

Table 1. Diagnostic Criteria for DCD (DSM-5, APA, 2013).

Criterion	**Description**
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.

Like most neurodevelopmental disorders, the cause of DCD is not well understood, but is attributed to alterations in brain development leading to atypical brain function. Several risk factors have been identified. DCD occurs in two out of five babies that are born early (<37 weeks) or with low-birth weight (Williams et al., 2010). DCD also runs in families, demonstrating genetic involvement (Licari et al., 2019). DCD can occur on its own, but frequently co-occurs with other neurodevelopmental conditions as altered brain development often disrupts more than one function (i.e., cognition, behaviour, motor, sensory). Conditions that frequently co-occur with DCD include autism (79% of autistic children also meet criteria for DCD, Licari et al., 2019), ADHD (50%, Goulardins et al., 2015), childhood apraxia of speech (CAS, verbal dyspraxia, 49%, Duchow et al., 2019), and other learning conditions.

1.2. The Impact of DCD

DCD impacts children and adults at every stage of their life and impacts on most aspects of daily living that involve movement. It is important to recognise that coordination is not only about sport and physical activity, but that movement skills are required for almost every activity we perform. Symptoms of DCD are present early in life, with infants (later diagnosed with DCD) often delayed in achievement of early motor milestones (e.g., walking, Faebo Larsen et al., 2013). Preschoolers 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 become most noticeable. It is at this age that children are expected to perform most movement skills relatively independently and movement differences then become much more prominent when observed next to peers. They often have difficulty learning to hold a pencil and draw/write, cut with scissors, open their bag and lunchbox items, and engage in activities in the playground. Movement appears 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 create significant challenges throughout schooling, especially keeping up with written work in the classroom. They also can have an impact on social relationships, as children are excluded due to their inability to 'keep up' with their peers (i.e., in the playground).

<u>DCD is a lifelong condition.</u> The movement difficulties experienced in early childhood continue to exert an impact throughout adolescence and adulthood. Poor fine motor skills associated with the disorder causes difficulty with handwriting, self-care, cooking, housework, and shopping. Poor gross motor skills affect balance, posture and ability to engage in leisure and physical activities. 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 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.

1.3. The Impact of DCD Beyond Movement

DCD is associated with secondary impacts on mental and physical health (Caçola, 2016). Because of movement differences, people with DCD struggle to keep up, experience exclusion, and are ridiculed and bullied because of their poor coordination. DCD can therefore have substantial impacts on a person's confidence and self-esteem, and leads to high rates of psychopathology. A recent systematic review examining mental health conditions in DCD revealed that 1 in 3 children with DCD are diagnosed with anxiety and 1 in 5 are diagnosed with depression (Draghi et al., 2020). In another recent study, parents and teachers were asked to rate the emotional and social health of children with DCD (Crane, Sumner & Hill, 2017). When their ratings were combined, 54% were considered to have elevated levels of emotional problems and 69% elevated levels of difficulty relating to their peers. Findings are similar in adults with DCD. One study found that 60% of employed and 83% of unemployed adults with DCD fell inside the depressed range on a self-report measure (Kirby et al., 2013). The same study also reported that 79% of employed and 73% of unemployed adults with DCD fell into 'borderline' or 'abnormal' ranges for anxiety (though more than double the number fell into the abnormal range compared with borderline). Studies have also shown adults with DCD have lowered participation, quality of life, and life satisfaction (Engel-Yeger, 2020, Tal-Saban et al., 2014).

Reduced ability to participate also leads to avoidance and withdrawal from physical activities, impacting on physical health and increasing the risk of developing adverse health effects such as obesity, cardiovascular disease and diabetes. A systematic review of studies looking in to the health consequences of DCD by Rivilis et al. (2011) found "overwhelming evidence" for an increased risk of elevated body fat, with studies reporting up to a 20% greater chance of children with DCD being overweight or obese. Reduced cardiorespiratory fitness was also commonly reported, with one study in the review demonstrating that 83% of children with DCD were classified as having low cardiorespiratory fitness (Tsiotra et al., 2006). Poor muscle strength in DCD was reported in all 14 studies that examined it, with 20 out of 21 studies reporting reduced levels of physical activity.

1.4. The Gaps in Support

As with many other disabilities, access to early intervention and ongoing support is critical to enable people with DCD to develop their movement skills and be included within their community. Findings from the Impact for DCD study have demonstrated there is no clear pathway for identifying children at risk of DCD and providing them with appropriate evidence-based interventions in Australia (Licari et al., 2020). While markers are evident early in life, children at risk for DCD are not prioritised for therapy, and rather, a 'watch and wait' approach is 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 or diagnostic/intervention services. Families are often left to navigate very challenging healthcare and education systems on their own, systems that are hindered by a general lack of knowledge about DCD.

Australians impacted by DCD experience neglect at many levels. They are neglected by a health system that regularly fails to recognise the disorder or the impact it has, with many people told that it "*doesn't really matter if you/your child is not good at sport*". They experience neglect within the education system, with limited accommodations provided, particularly as students get older. There is inconsistency in support offered from state to state and from school to school, creating further disadvantage to many students. Families also report lack of inclusivity in extra-curricular activities. Australians with DCD are neglected by the NDIS, receiving limited support for costly therapies which are often required across the lifespan and not just in the first 7 years of life. Neglect also occurs at a community level. Participation in community activities is significantly impacted by DCD and the lack of awareness of DCD, accommodations and support is reducing involvement. This is concerning given we know that involvement in the local community increases an individual's sense of belonging and can reduce incidences of poor mental health.

The following sections will present the major areas people with DCD and their families experience significant neglect.

2. Area of Neglect: Diagnosis

People with DCD struggle to get an accurate and timely diagnosis. This leads to delays accessing therapies and interventions. There are a range of issues that impact on access to diagnosis including:

1. Confusion about diagnostic terminology
2. Lack of awareness of DCD by health professionals
3. Lack of clarity about who can diagnose DCD

Over the past century, many different labels have been used to diagnose or describe impairments in the acquisition and development of movement skills, including clumsy child syndrome, perceptual motor dysfunction, and dyspraxia. DCD first appeared in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III, APA, 1987) in the late 1980's. However, the term dyspraxia (used in the early 1980s) is often used synonymously today. Dyspraxia, by definition, means 'partial impairment' (-dys) of 'movement' (-praxia). Whilst dyspraxia provides an accurate *description* of the core symptoms associated with the condition, it has never been formally recognised as a discrete diagnosis or appeared in diagnostic manuals, and it is also a term frequently used by neurologists to describe motor impairment in other neurological conditions (e.g., Parkinson's disease, multiple sclerosis). Despite this, dyspraxia is a label that has been adopted by many advocacy, charity and support groups around the world (e.g., in the United Kingdom: The Dyspraxia Foundation UK established in 1987; in the United States of America: The Dyspraxia Foundation USA established in 2006). Unfortunately, the descriptions of 'dyspraxia' provided by these organisations vary considerably and the lack of a formal consensus on the term as a diagnosis has caused a great deal of confusion both within and outside the community impacted by these differing terms.

DCD is the diagnostic term that has been accepted and endorsed internationally. DCD is the diagnostic term appearing in international diagnostic manuals, including the DSM (APA, 1987, 1994, 2013; the manual utilised by most diagnosticians in Australia) and the International Classification of Diseases (ICD, 2019; utilised in Europe). DCD is also the diagnostic term recommended in the International Guidelines on the Definition, Diagnosis and Intervention of DCD, endorsed by the European Academy of Childhood Disability (EACD, Blank et al., 2012, 2019, Appendix 2). Even though DCD has been recognised for over 30 years, continued use of the label dyspraxia, along with lack of dissemination and uptake of the consensus diagnostic guidelines, has resulted in confusion and limited knowledge of DCD within the health care sector.

Challenges in understanding who is qualified to diagnose DCD have also been reported. Since its first appearance in the DSM, it has generally been expected that diagnosis be made by a suitably trained medical professional (i.e., a paediatrician). This is particularly important to ensure other clinical explanations are ruled out (Criterion D in Table 1; e.g., cerebral palsy, muscular dystrophy). Unfortunately, with many medical professionals lacking familiarity with DCD or current diagnostic procedures, diagnosis is often not made by medical professionals. Lack of familiarity was highlighted in a survey of physicians (n=339) and paediatricians (n=255) in Canada by Wilson and colleagues in 2013. Only 23% of physicians and 41% of paediatricians were familiar with DCD and 9% of physicians and 23% of paediatricians had diagnosed DCD before.

The Impact for DCD study demonstrated that in spite of international diagnostic guidelines which recommend the involvement of a medical professional, more families report their diagnosis coming from an OT (38.2%) than a paediatrician (30.8%). This is problematic as the Impact for DCD study also found that OTs were more commonly using the descriptor ‘dyspraxia’ than paediatricians (42.9% vs 31.2% respectively). This may be because OTs feel that diagnosis is outside of their remit, given the diagnostic guidelines, but leads families to adopt this descriptive term ‘dyspraxia’ as the diagnostic label for their child.

Medical and allied health professionals have shared some of their thoughts on DCD diagnosis within Australia:

A paediatrician described their experience: *“The limited awareness of DCD is the basic issue among healthcare professionals…..not many clinicians are familiar or clear on how to diagnose this condition…..coordinating an OT or physio and sometimes a psychologist makes it hard.”*

An occupational therapist described their experience: *“The term DCD has been accepted for a long time. The biggest barriers to the use of the term DCD is that neonatologists (with preterm birth a primary origin of DCD) say that they don’t know what it is and they’re the ones referring to community paediatricians. So very skilled neonatologists say ‘DCD - what’s that?’ It’s still going on in this country and they are the ones offering follow-up and they are concerned about these same children but don’t know the label for them.”*

A physiotherapist described their experience: *“Over the years of treating children with DCD I have found there to be a reluctance to diagnose from the medical* *profession. I have often wondered if this has been due to lack of funding and support so they question what is the value or is it from a lack of awareness and understanding of the significant and lifelong impacts DCD can have."*

An occupational therapist described their experience: *"A significant barrier is challenges with accessing paediatrician services. Families are being told that there is a waitlist of at least 12 months to see a developmental paediatrician through the public sector due to the increasing need for these services. That is way too long considering how quickly children develop at a young age. Unfortunately, it is also very costly for some families to access a private paediatrician service and, even if they can afford this service, the high demand for services has resulted in long waitlists across clinics and sometimes families being turned away as clinics can no longer keep up with demand."*

An occupational therapist described their experience: *"As a clinician we see many children with flags for DCD who mostly never pursue a formal diagnosis due to the cost involved of going to a paediatrician as well as long waitlists. I would say this cohort of clients struggles with motor skills are comparable to those with autism but have no access to funding. The impact on academics is significant and due to the large volume of therapy sessions these children need, the majority of parents cannot afford it resulting in disjointed intervention that is not on a frequent enough basis or have large gaps between."*

An occupational therapist described their experience: *"There is a lack of awareness around DCD in the community and also other health professionals. I have written a number of reports recommending a possible DCD diagnosis, and while I have had some paediatricians confirm the diagnosis, there are some that don't even seem to look at the report/ acknowledge this. Some children are "lucky" enough to have other diagnoses which enable them to access funding but those that don't have to try fund therapy and supports privately which is often not sustainable. From what I have seen, DCD can be quite debilitating with its widespread impact on multiple areas of functioning. I find that it not only impacts function and ability in self-care tasks, sport participation and handwriting, but very often impacts on emotional regulation and self-esteem".*

An occupational therapist described their experience: *"A big issue in this area is diagnosis (or lack of diagnosis). The paediatrician is required to sign off, so a big problem when paediatricians are in limited supply. They are making the diagnosis based on the OT assessment anyway. This is an issue that causes a lot of confusion amongst families and therapists across the country and it comes up constantly on all the facebook pages where parents are asking each other for guidance. It is very inconsistent across the country. Can OT's at least provide a provisional diagnosis?"*

A physiotherapist described their experience: "*…many paediatricians don't know or understand DCD and despite carrying out a full assessment using the BOT2 [standardised motor assessment] and explaining the results in a detailed report for paediatricians to understand it, they will refuse to acknowledge the diagnosis and write a supporting letter to help families access NDIS funding so their child can access therapy."*

An NDIS planner described their experience: "*Personally, I feel that DCD is not a term commonly used in society (in comparison to more well known diagnoses such as autism) and, with limited exposure and understanding of this diagnosis, I would suspect that families would not know how to identify this in their children and seek appropriate support. Majority of the time, the families I work with rely heavily on their health professionals and schools to help them identify and link to appropriate services for assessments and for support (e.g., NDIA). Without the right knowledge and understanding of the system, many of these families will slip through the cracks and by then it would be too late to get the intervention support these families and their children require."*

Families have shared the challenges they have experienced obtaining a diagnosis; including delays in diagnosis, lack of diagnostic pathway, and the impact on accessing services.

A parent of a child with DCD described their experience: *"My son's OT suggested he had DCD and that we should see a paediatrician to confirm it. After waiting over a year on the waitlist in the public system we ended up seeing a paediatrician privately. The paediatrician told me that DCD is 'just a nice way of saying your child is clumsy' and that there really is 'no weight in the diagnosis'.*

A parent of a child with DCD described their experience: *"I noticed very early that he was not developing as expected. He was a floppy baby with very poor head control. He was late to sit, late to crawl and did not walk until almost 2 years of age. His speech was also delayed. We could clearly see he was lagging behind other children his age, but we were frequently told 'he's a boy, he's just lazy, he will catch up', but as time went by, it was obvious the gap between him and other children his age was growing. And so the journey of seeing medical professionals to find out why our child had so much difficulty with his movement began. We visited GPs, a paediatrician, a paediatric neurologist, clinical psychologist, physiotherapists, occupational therapists, speech therapist, rheumatologist, audiologist, optometrist, and a podiatrist. After countless* *medical and behavioural assessments, they were not able to identify a 'medical cause' for his movement challenges. They just said he was dyspraxic."*

A parent of a child with DCD described their experience: *"My son is 13….We need a doctor to sign off on the OT's findings to formalise his [DCD] diagnosis. His school requires this to be formalised. We have seen two GP's that want him to see a developmental paediatrician for this. In WA, no paediatrician is accepting patients…..I have been told he could be waiting 2 or 3 years. None of the private rooms will even take new referrals. He is in year 8 [at school] and can't afford to wait."*

A psychologist and parent of a child with DCD described their experience: *"Took me 3 and ½ years to get him diagnosed and I work in this industry and we had the financial means to go private….I started the process with my son when he was in year 4 and he is year 7 now."*

A parent of a child with DCD described their experience: "*Our experience with diagnosis was slow! We had to fight for our child's diagnosis to be confirmed. Our first paed would of happily diagnosed ASD or ADHD on the spot. We didn't feel it was the right fit……we happened to bump into a friend who is an OT but lives too far from us to be our son's regular OT. She watched him play and said I think he has DCD. We'd never heard the term! We mentioned this to our regular OT who did an assessment. This confirmed his mobility and coordination was very poor. But the OT could not provide an official diagnosis. We started physio straight away. In this time we were trying to afford OT through the use of EPC and MHCP [Mental Health Care Plan]. Our GP was also hard to deal with. He was adamant OT couldn't be accessed on a MHCP. We also got a referral to a diff paed. A well regarded male paed in the region. This new paed was diagnosis conservative. He believed our child had 'no diagnosis' - we just needed to discipline him more, not accept his emotional meltdowns, provide consequences and ensure he was getting enough outside time and physical activity. Our son, according to him, was just one of the 20% of clumsy people we have in society and "not everyone will play a sport". Unfortunately, this decision severely affected our application for ECEI [Early Child Early Intervention] NDIS [National Disability Insurance Scheme] and we were declined on the basis of being too close to 7 with no diagnosis."*

A parent of a child with DCD described their experience: *"Getting a diagnosis is a battle and there is no clear way of doing this. My speech therapist assumed my paediatrician had told me, they just said he needed speech therapy. It was only when we had behaviour issues and went to a child psychologist that it [DCD] was raised and then tested for along with tests for ADHD, autism etc. A clear way of diagnosis would be greatly helpful and save a lot of money in fees and stress in going backwards and* *forwards to many different therapists in trying to find support and help for your child. It is stressful enough having a child that needs help without the brick walls and roundabouts you get sent on trying to get an answer."*

Findings from the Impact for DCD report revealed that families are concerned about their child's movement difficulties early, with the average age of first concern 2.5 years. Families also seek help for these challenges early, with 3.4 years the average age help was first sought. While most children in the Impact for DCD study had received a diagnosis (87%), 75% of families waited more than 12 months to receive a diagnosis and 46% of families waited over 2 years to receive a diagnosis. There was inconsistency in diagnostic terminology, with children more likely to be diagnosed with 'dyspraxia' than DCD. Diagnosticians varied considerably, with 43% of families reporting that they received their child's diagnosis from an occupational therapist. While both medical and allied health professionals should be involved in the diagnostic process, it is essential that the medical diagnosis ultimately be made by a suitably qualified medical professional to ensure other potential explanations of motor impairment are ruled out (criterion D).

In the Impact for DCD report, 87% of families reported that receiving a diagnosis was helpful. It provided families with an understanding of why their child had significant movement challenges and a sense of relief.

Statements from parents involved in the Impact for DCD survey included:

Parent quote: *"It helped me understand why things are more difficult for my child….I am starting to appreciate why some things are harder, it's changed my attitude, and it's changed my parenting behaviours."*

Parent quote: *"It validated my concerns. Everyone from childcare to doctors were telling me there was nothing wrong….I felt I was hitting my head against a brick wall."*

Those families who reported that a diagnosis was not helpful (13%) were frustrated by the lack of recognition and understanding of DCD:

Parent quote: *"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".*

3. Area of Neglect: Education

Entry to school can be a particularly challenging time for children with DCD. For many, it is a time in which the magnitude of movement difficulties are first realised. Movement difficulties have a significant impact on learning within the classroom. Students with DCD have enormous difficulty processing, planning and executing movement, especially completing tasks at school requiring multiple steps. Trying to keep up in class is both cognitively and physically tiring for a student with DCD. Without adequate breaks for rest, they can become easily fatigued. Movement and learning difficulties are noticed by other children, which often results in significant exclusion (especially in the playground) and bullying (in the most extreme cases).

There is poor awareness of DCD within the education system, with research revealing only 23% of teachers are familiar with the term DCD (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.

Many parents report that teachers are not familiar with the condition and schools are not well equipped to provide additional educational support to their child. This lack of awareness and understanding means that appropriate accommodations are not made for the child's disability within the education setting. This can lead to the child experiencing both educational and social difficulties within the classroom.

Families and teachers have shared the challenges experienced at school:

A parent of a child with DCD described their experience: *"DCD is misunderstood, unheard of by many and dismissed. The current schooling system is hell for kids with DCD and a much higher awareness of the impact needs to be driven home to the education department."*

A parent of a child with DCD described their experience: "*My daughter is 8 years old and we live in Tasmania….The school system has been horrific. They have not provided the supports that she needs to succeed. Each year they suggest maybe she should repeat the year. They developed a plan for learning- but they never gave me a copy or let me have a say in it. They told me she needs just as much support as a kid with autism but they can't give it to her because she does not have autism as a diagnosis."*

A parent of a child with DCD described their experience: *“My son is 9 years old and we live in Brisbane. He is bullied at school and is having lots of trouble learning. No one seems to know what to do with a kid like him. He does not fit in. Each year his teacher has no idea what DCD is. I have to explain it again - and then they seem to not understand. We need more awareness. People need to know - DCD is just as common as autism. It can create similar problems. But no one knows what it is. It is like we have a hidden condition and our kids are just in the shadows.”*

A teacher and parent of a child with DCD described their experience: *“My husband and I are both school teachers in Perth and we had never heard of the condition until our son was diagnosed. Our son’s transition to school has been an enormous challenge. Like us, his teachers didn’t know what DCD is and have not received any training to know how to support a child with significant movement challenges. He has been ruled ineligible for an aide, told his condition is not recognised by the education department as one warranting funding or support. He cannot hold a pencil and draw, cut with scissors, open the zip on his school bag, or take his pants off fast enough to go to the toilet. Our greatest fear is that he is not going to be given an opportunity to show his potential at school. So much of schooling relies on being able to move and move well. I worry that he is just going to be viewed as the “clumsy”, “unco” or “lazy” kid, stuck in an educational system without the knowledge and skills needed to support him and others like him. It is hard enough now walking into a classroom and seeing all these beautiful pictures on the wall, and then you see your child’s indecipherable work. His peers already laugh at him (he is 6!) and ask what’s wrong with him - what is life going to be like in a couple of years time?”*

A teacher and parent of a child with DCD described their experience: *“I learnt about supporting students with a diagnosis of autism, dyslexia, ADHD, intellectual disability etc, but nothing about even the existence of DCD. I found out about DCD because my son was diagnosed, not because it was included in any of the content taught in tertiary teacher education.*
My son does not qualify for any funding or aide support through the Department of Education despite the challenges he faces at school, both inside and outside the classroom, because he doesn't meet the criteria. Why? Because he is gifted (so no intellectual disability) and he is extremely well behaved, resilient, and determined to succeed (so no 'severe behaviour').
I have held him while he has sobbed about the frustrations he feels when he can't produce work that is of a standard he is otherwise capable, when he is left out of fun games and activities by his peers in the playground because he can't climb, run, jump, throw, catch, kick with the other kids. When his teachers simply don't understand that his brain has to actually work so much harder than his peers with every task set.

My son will be going into Grade 5 next year, and he still struggles to hold a pencil. He fatigues quickly and then his handwriting gets even worse and he can see it happening, and that takes a toll on him, physically, mentally, and emotionally. And handwriting is one tiny challenge he faces. He is lucky that I am a teacher and I can support him to learn to advocate for himself with his teachers - he has seen me do it for years. So many other families of children with DCD are doing the same thing I have been doing for years, without the benefit of being a teacher - they understandably expect that teachers are able to support the individual learning needs of their child. As a parent, I am so frustrated that teachers don't 'get it'. As a teacher I am so saddened that we are letting down so many of our students because 'we' simply don't know what we don't know. When I had a meeting with a 'Program for Students with Disabilities (PSD) Coordinator' to discuss DCD Awareness Week, she had never even heard of it, and that's not good enough!

We need to work together to help teachers understand that kids with DCD are not lazy, and that while DCD has a significant impact on both fine and gross motor skills, it can also impact communication, organisation, and so many other aspects that are relevant to education.

My nearly 11 year old son can't ride a bike, he can't tie his shoelaces, he wears elastic-waist pants and shorts because he can't do (or un-do) ones with ties or buttons, he still often ends up with food on his face when he eats... it didn't bother him 'quite' as much when he was younger, but now he really notices the gap between what he can do, and what his peers can do.

Kids with DCD need adjustments made in the classroom. They may need tasks broken down into manageable and achievable steps. They may need to be allowed to produce smaller amounts of work that still demonstrate their knowledge and understanding of a concept. They may need to be able to complete some tasks verbally, or have an aide to scribe. They may need access to devices such as laptops for writing tasks. They may need more time to eat their snack and lunch, because otherwise they may end up simply going hungry, because they want to play too - even if it's alone. Kids with DCD may need a little compassion, support, and understanding when it comes to compulsory participation in school sports days. All of these accommodations are very achievable, teachers just need to know about and understand DCD, so they know to make them."

Findings from the Impact for DCD report revealed that 82% of parents felt their child's movement difficulties negatively impacted their child's ability to reach their potential at school, 62% reported that their child had difficulty making friends at school, and one in four parents reported that their child did not enjoy going to school. While approximately 1 in 300 children in the general population are home schooled, alarmingly, as many as 1 in 20 children with DCD are home schooled. Parents choosing to educate at home do so for many reasons, including: 1. their child's needs are not being met at school, 2. their child cannot keep up in class, 3. social exclusion and bullying, and 4. mental health conditions (e.g., anxiety, depression). Most families (97%) reported that it takes their child longer to accomplish movement related tasks at school, yet only 35% of children were provided with additional working time to support them on tasks impacted by their movement difficulties (e.g., handwriting).

When asked what the greatest challenge was for their child at school, the following responses were obtained in the Impact for DCD survey:

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

Australian law requires schools to make appropriate adjustments for students with a disability. The Impact for DCD study revealed that many children are experiencing discrimination and neglect as they are not receiving the appropriate and reasonable accommodations they require, such as receiving additional time, adjustments to their curriculum. This is in part due to a lack of awareness and understanding by teachers about DCD.

Statements from parents involved in the Impact for DCD survey included:

Parent quote: *“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. It has been such a process educating teachers and I feel at times that they nod but don’t really seem to 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.”*

Parent quote: *“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”.*

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

Parent quote: *“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 associated with this.”*

Findings from the Impact for DCD report were alarming in relation to mental health. With the core feature of DCD (i.e., movement difficulties) giving rise to a range of secondary stressors (i.e., poor academic performance, low self-competence, low self-esteem, low social support, peer conflict, peer victimisation, physical inactivity, obesity; Cairney et al., 2010), it is unsurprising that 92% of parents reported they were concerned about their child’s social and emotional health. When parents were asked what their greatest concerns were in relation to their child’s social and emotional health, many related to challenges experienced at school.

In the Impact for DCD survey, emotional symptoms, peer relationships and pro-social behaviour were evaluated using the Strengths and Difficulties Questionnaire (SDQ, Goodman, 1997), with 66% of children with DCD scoring within clinical ranges for emotional symptoms and 65% for peer relationships. A total of 44% of children in the Impact for DCD survey were diagnosed with at least one mental health condition and mental health issues (i.e., anxiety) were reported in children as young as 4 years of age.

Statements from parents involved in the Impact for DCD survey included:

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

Parent quote: *“I wouldn’t wish this condition on anyone. It is heart breaking to watch him always come last and to see others point and laugh at him (including other parents). He isn’t stupid. He sees them laughing. He sees them copying the way he runs. Do people not realise the impact this is having on him?”*

Parent quote: *“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.”*

The Impact for DCD report revealed that most families (86%) are concerned about how their child's movement difficulties may impact on their ability to successfully complete their schooling, and many families (52%) are concerned about their child's movement difficulties affecting their ability to gain employment in the future. These are valid concerns, with research in the UK showing that adolescents with DCD (n=284) scored poorly on their national General Certificate of Secondary Education (GCSE) exams when compared to children without DCD (n=5425), limiting future educational and vocational prospects (Harrowell et al., 2018).

4. Area of Neglect: Lifelong Impact

With 'developmental' appearing in the name, many assume that DCD is a condition potentially outgrown. However, within the context of DCD, the term developmental relates to the emergence of motor symptoms which change over time as a person grows and develops. Children with DCD do not outgrow their disability. Clear and significant motor difficulties remain through the lifespan for the majority (Hill & Brown, 2013). Poor fine motor skills cause difficulty with handwriting, self-care (e.g., dressing, shaving), cooking, housework, and shopping. While poor gross motor skills affect balance (e.g., stepping in/out of the shower, hanging washing), posture, safety when navigating oneself within the environment (e.g., road crossings), and ability to engage in physical activity. In a qualitative study by Scott-Roberts and Purcell (2018), all adults with DCD described in detail the less obvious impairments like fatigue and tiredness resulting from the effort to safely navigate their environments and how this created a vicious circle that placed them at greater risk of trips and falls.

Adults with DCD have shared some of the challenges experienced:

An adult with DCD described their experience: "*I have considerable difficulties with many self-care tasks. For example, my poor coordination makes cooking challenging. Preparing food takes me longer than other people and a lot of concentration. I find pouring, cutting and preparing ingredients difficult, so I often buy pre-cut vegetables and meat or pre-made meals. In addition, it is exhausting for me to stand for long periods. I usually take breaks or lean against the kitchen counter to rest between cooking tasks. My fine motor skills are poor; my lack of manual dexterity causes problems with holding and using cutlery. I often miss my mouth when I eat or drink, I drop cutlery, and I have trouble with cutting tough food. I am incredibly self-conscious about eating around other people. I have trouble getting dressed - especially with the fine motor challenges of buttons and shoelaces. So I generally opt for simple clothing and pull-on boots to make my life easier. I also have trouble with washing and brushing my hair.*

It took me seven years to get my driver's license; I thought I would never be able to drive. Learning to drive was so challenging because I found it difficult to coordinate both sides of my body. I had no understanding of the space I occupied, the size of the car and the distance between myself and other objects. I cannot drive when I am tired because my spatial awareness, coordination and response times are so significantly impacted by fatigue."

An adult with DCD described their experience: "*Speaking as someone who was diagnosed back in the days….it still makes life hard (I'm 48)....School sports typically made me cry - except for the time I got a concussion doing high jump - that made me vomit! I still don't enjoy playing sports and have even avoided practising my own children's sports with them because it's embarrassing and frustrating when your 7-year-old beats you when you are trying your best! (Maybe mine sound more condescending than other kids do when pitying their mother?!) It can actually be quite triggering - takes you right back to primary school and always being picked last and hearing the other kids groan when you got it wrong - Again! In Year 9, a new teacher decided to get us to stand in a circle around her. She'd throw the ball, the kid would catch it, say their name, and throw it back. She threw it at me so many times that I eventually couldn't catch it because I couldn't see it through my tears! I'm the one with so many bruises that people still ask me if I'm safe at home. The broken toes and frequent banging my head on things, especially when tired, is so frustrating - often, I'm actively trying to avoid what I just hit myself on (seriously - I frequently crash into walls while walking up the hallway at work. I worry my staff must think I'm drunk! But I literally struggle to walk and talk at the same time!) I remember being absolutely amazed at uni, when we learnt about teaching compensatory strategies to kids who struggled with motor skills! What a revelation that we could break skills down and part practice them! That we could do things like look at a particular spot on the wall to help us balance! This past year, I have tried to take up gardening as my version of physical activity that might be even slightly enjoyable. Yesterday, I noticed that I was more successful than usual throwing pebbles into a bucket as I dug them out of a garden bed. That means it's only taken me more than 20 years of practising compensatory strategies to get even close to average! It was a really odd feeling to be throwing pebbles and having them land where I wanted them to, without thinking really hard about how hard to throw! To watch them land pretty much exactly where I was aiming was strangely satisfying. I'm not sure it's one I'll get to feel very often - I noticed I missed a lot more pebble throws today. My poor brother is worse than me - he was in the E team for rugby. The first question we asked each other when we got a new girlfriend or boyfriend was, "how coordinated is she/he?" We didn't want our kids to go through what we have! Every time my DCD is on display at work, I emphasise to my team that "this is why it's important to treat the DCD kids while they are young!"*

An adult with DCD described their experience: “*DCD is an impairment of the processing of information in the brain and the transmission of messages to and from the body. In my case it also manifests in low muscle mass and hyper flexible joints. This greatly affects my ability to organise/execute movement and language, reducing the speed of fine and gross motor skills, processing information and speech. Greater concentration is required to coordinate movement such as writing and walking. This reduces my performance especially when tasks are completed simultaneously such as writing while listening. It can also mean I tire easily. As a result, I have tended to lead a sedentary lifestyle, which in my case has led to being overweight and suffering chronic pain.”*

An adult with DCD described their experience: *“...I found learning to drive a car so darn hard (got my automatic licence at 25), weird things like couldn't figure out how to turn left sometimes, the sequence of a manual car plus everything else being way too much. Telling time on an analogue clock, always having bruises because I have knocked into something, always have a scarf in my office desk drawer and or another top as chances are I will spill my coffee down the front of me at some point so best be prepared.”*

An adult with DCD described their experience: *“I am a 36 year old with autism and DCD. While having autism and not being able to read social cues and having sensitivities to the environment is a major challenge for me (e.g., noise in public places), my DCD is often a much greater challenge. When I go out with my friends it is hard to sit at a table in a restaurant and cut with a knife and fork. I always knock things over on the table. I also cannot do a lot of the activities my friends do. I cannot go to the beach because I am a bad swimmer….I cannot kick a ball to save my life.”*

An adult with DCD described their experience: *“I’m 72 and have lived with DCD all my life although, while aware of its effects daily, I did not know such a condition existed until age 50 when my young son was diagnosed. Not surprisingly I went to the internet to research and discovered all the regular symptoms I experienced were there – late walking, tying shoes, etc. My difficulties in childhood went effectively unrecognised - I was seen as a boy who was just less athletically talented than his brothers and peers. Not walking until 18 months of age just seen as an oddity and something for family legend. I struggled against all these symptoms as I believed it was the right thing to do to be ordinary; anything less than normal practice and achievement was possibly a moral fault. Anxiety about my physical difficulties then contributed to teenage onset of a separate, nasty mix of obsessive-compulsive disorder in religion (scruples) and major* *depression, all of which I still suffer from at 72. As with DCD, and despite a mental breakdown in teen years, I've been able to live a useful life but with this mental 'civil war' hidden within, even from close friends and siblings."*

Research has shown that employment opportunities for adults with DCD are limited by their physical capabilities and they are more likely to be unemployed (Kirby et al., 2013). Adults with DCD report lower levels of life satisfaction, general health and symptoms of anxiety and depression (Tal-Saban et al., 2012) and motor skill impairment consistent with DCD in adults has been shown to predict poor quality of life outcomes in physical, psychological, social and environmental domains (Engel-Yeger, 2020).

Adults with DCD have shared the impacts of this disability on their mental health:

An adult with DCD described their experience: *"I was diagnosed with DCD in year 11 of high school. An emotional roller coaster I am still dealing with as a 29 year old. My movements still embarrass me…..I isolated myself and developed anxiety and depression, which I still suffer from."*

An adult with DCD described their experience: *"The most deleterious effect of the characteristics of DCD was introducing serious anxiety to my life, even before school age, and for the rest of my life. The physical characteristics of DCD were and are the fuel that created and powered what was to become untreatable anxiety. A nervous breakdown, hospitalisation and shock treatment at 15 due to obsessive compulsive disorder (as you know, an anxiety disorder) ended my secondary school study (although I returned later as a young adult to secondary and university education). Inevitably the OCD led to untreatable (major) depression, what my psychiatrist calls 'masked' depression in that most family, friends and work colleagues don't notice the depression until it breaks out in an inability to look after oneself. Ironically, fear of losing work ensured that I was a hard worker (anxious perfectionist) but that fear then further fuelled the anxiety which, due to mental exhaustion, further stoked depression. Without DCD I might have suffered anxiety and depression anyway from other sources; But there is no doubt that DCD-induced anxiety in my case was/is a life-changing fact."*

An adult with DCD described their experience: *"High school was possibly one of the most traumatising experiences of my life. I was constantly picked on by other kids and called horrible names like 'retard'. I was always picked last at sports. I still remember the looks of disappointment and them saying "we are going to lose now" when placed in their team. I constantly had people's food scraps, spit balls and other items thrown at me. Kids thought it was funny trying to find ways to trip me over. The teachers were not* *much better. They called me lazy, said I wasn't trying and that my handwriting was terrible. They did this in front of other kids, and it was humiliating. I hated my life. I wanted to end it. I tried to end it. I ended up dropping out of school because I just couldn't take it anymore. The trauma of this shaped me in many ways. I lack confidence, and have struggled with low self-esteem and depression most of my life."*

5. Area of Neglect: Access to Evidence-Based Community Services and Supports
There is clear evidence that when people with DCD have access to the right community services and supports, positive changes can occur in their ability to participate in everyday activities in the home, school and community; such as selfcare, leisure/sports and school based activities (Izadi-Najafabadi, 2022). This in turn leads to positive self-efficacy, improved physical and mental health, and improved relationships (Smits-Engelsman & Verbecque, 2022). Unfortunately, access to effective support is currently limited by lack of funding (especially in those over the age of 7 years who are often unable to access NDIS services), lack of clear pathways to evidence-based interventions, and limited opportunities to participate in community activities.

Pathways following a diagnosis of DCD are highlighted in statements from health professionals:

A paediatrician described their experience: *"There may be thoughts around diagnosis, and a physio or OT might have done their assessments, and then of course a paediatrician to rule out other differentials and hence you make the diagnosis. But the issues I find is what then? What about it?...Does it mean anything for the NDIS? It is important to have a what then and what are we going to do about it. The reason is that I can see the trajectory for these children…….It is something that is real and a public health issue. So while early intervention is key, we need to think about (once we have made the diagnosis) what then?"*

An occupational therapist described their experience: *"A lot of a paediatricians in a very humble way would honestly say to us that they don't like giving a lifelong diagnosis when there's no treatment options and also, in this case, when there's not going to be any NDIS funding…..they want something they can give with a diagnosis rather than it just being bad news."*

A paediatrician described their experience: *"DCD servicing is a bit of a minefield…..Like other conditions, specialist servicing and clinics for DCD are needed in this country. Places people can go to access people with expertise to support the challenges associated with the disability. This inevitably requires funding."*

A physiotherapist described their experience: *"As a physiotherapist I have been working with children with DCD for over 15 years and over that time I have not seen the significant change in the level of awareness or the level of support given to these families that is required. The impact of DCD can be seen across various facets of a child's life and they can require extra support in order to participate meaningfully in various pursuits. Providing timely and effective support to a family can have a significant impact on a child's outcomes."*

Within Australia, the National Disability Insurance Scheme (NDIS) provides support to people with disability, their families, and carers. Currently there are 540,000 Australians receiving support through the NDIS. To be eligible to receive individualised support under the NDIS, a person must meet certain access requirements. This includes that the person must:

- Meet the residency requirement,
- Meet the disability or early intervention requirements, and
- Be under 65 years of age when the access request is made.

Many children with DCD or symptoms of motor impairment are able to access the NDIS under the early intervention requirements (7 years and under). These children are then able to access important interventions to assist with a range of symptoms associated with DCD including fine and gross motor impairment, speech delays, and difficulties with activities of daily living.

Unfortunately, **children with DCD over the age of 7 are often denied access to the NDIS**. Many NDIS planners and Early Childhood Partners (ECPs) have little experience or knowledge about DCD, and do not recognise the long-term support requirements. Families have shared with us many examples where therapists have written reports showing the need for further support and therapies, and NDIS access has still been denied. Reasons for denying support are varied, including claims that there is 'insufficient evidence to demonstrate that DCD is a lifelong disability', DCD being perceived to be a 'mild condition' and 'less functionally impactful', and 'DCD not being a disorder recognised by the NDIS'.

Without access to the NDIS it is impossible for people with DCD to access the level of support that is required unless it is self-funded. There is the option to access therapies and support through the Medicare system (with a max of 5 allied health sessions per year), but this is insufficient to get the support required for DCD which is a life-long condition with ongoing support requirements. This is particularly problematic given the delays in diagnosis.

Families have described their experiences with trying to access supports through the NDIS:

A parent of a child with DCD described their experience: "*The NDIS has recently cut us off as now that she is past 7 years of age apparently they think she does not need any support. What are we meant to do? We have an 8 year old who can not dress herself, who can not feed herself. Yet because no one knows about this condition- there is no public awareness of it- we find ourselves with no support. We can't get her help from a physio or an OT as we dont have the money to pay privately. The school won't help her with the support she needs to learn. I worry about her future."*

A parent of a child with DCD described their experience: "*NDIS has been a major disappointment. Even though he has a diagnosis I haven't reapplied as we simply cannot afford to get all the reports redone. They are more expensive than regular appointments. I also don't have the time or bandwidth for the admin side that comes with becoming an NDIS family. It shouldn't be this hard. Invisible disability families are just left behind. No one ever says oh yeah DCD I know what that is. Also DCD as a stand alone diagnosis should still get NDIS - we're seeing 2 allied therapists. Some families are also seeing speech. And yet there is no help. We feel like we've been to left float. We don't sink as we're not severely disabled but we also don't swim - we have a disability and we need help!! Our younger child misses out on so much as most of the family finances go into his therapies and good nutrition and sports for him*."

A parent of a child with DCD described their experience: "*We actually got denied NDIS on first application!! The LAC [local area coordinator] was hopeless. She kept saying, oh my sons like that, every time we had something to say about our daughter, and denied us, saying it wasn't high enough need!! I called her out on her bullshit and said perhaps your son needs assessing! Even though our daughter had tons of paperwork and multiple diagnoses by 2.9m of age, they still denied her and told us it's a health condition not a disability!"*

NDIS planners and health professionals have also shared their experience:

An NDIS planner described their experience: *"Even if a family is lucky enough to be linked to the NDIS to enable them to access funding for early intervention support, this support is only temporary as, once the child turns six year old, they will no longer meet the early intervention criteria to stay in the early childhood approach program under developmental delay. Unfortunately, DCD is currently not recognised as a disability that would enable an individual to permanently stay within the NDIS and many of these* *families, once transitioned out of the scheme, have limited options to continue the services they require to support their child's development."*

A physiotherapist described their experience: *"The intent of the NDIS is to not be diagnosis driven and be driven by functional impairments. I have seen many children with DCD who are grossly more functionally impaired than some NDIS participants I support with CP, intellectual impairment and ASD. They have however been denied support on the basis they have not exhausted all treatment options. The decision makers are clearly not understanding the lifelong impact of DCD and that we cannot treat or fix it but we support functional outcomes throughout the lifespan."*

A physiotherapist described their experience: "*Oh the battles I have had trying to have clients with DCD get access to NDIS funding past the age of 7!!! There is a lack of understanding about how this condition affects not only motor skills but has everyday life implications that are life long. I would love to see a wider audience have access to education about this condition and how it impacts them across their lifespan!"*

The Impact for DCD report found that less than half of families raising a child with DCD (42%) had access to government funding to support their therapy costs. Those with access to NDIS funding were either accessing it through ECEI plans (<7 years of age) or their child was diagnosed with other co-occurring conditions through which they have been able to access funding (including mental health conditions). More than half of families (53%) reported that supporting their child's movement needs through therapy either always or very often caused financial strain. Two out of three families also reported that the therapy their child was receiving was not sufficient to support their child's movement difficulties. This often reflected difficulty accessing therapy on a regular basis due to costs, including the financial cost, time off work and school, and travel.

Statements from parents involved in the Impact for DCD survey included:

Parent quote: *"Children need access to affordable and effective treatment, but lack of providers and lack of funding options mean 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."*

Parent quote: *"I have one son with DCD and one with autism. My son with autism has funding to help him learn the everyday skills he needs, but my son with DCD does not have funding and we just cannot afford the out of pocket costs for his therapy. His needs are much greater at this point. The system is really unfair."*

In addition to funding, access to healthcare professionals with expertise in DCD is another major challenge. Whilst evidence-based interventions have been established in the literature for individuals with DCD, access to assessments and interventions that are in line with the recommendations outlined in the International Guidelines for DCD (Blank et al., 2019, Appendix 2) have been historically limited (Jane et al., 2018).

Current evidence supports the use of task-oriented approaches to improve motor skills of people with DCD. A therapy called Cognitive orientation to daily Occupational Performance Approach (CO-OP) currently has the strongest evidence (Smits Engelsman et al., 2018). CO-OP is a client centred, performance-based, problem solving, approach that uses strategies, identified through guided discovery to enable skill acquisition (Polatajko et al., 2001). Occupational therapists, physiotherapists and exercise physiologists can access training to learn how to implement this approach effectively. Despite this intervention being available since the early 2000's, a research practice gap exists. Process oriented interventions (e.g., sensory integration therapy) are more likely to be delivered, despite the substantial evidence that now exists to demonstrate that process-oriented interventions are not effective in enabling participation in people with DCD (Novak & Honan, 2019; Smits Engelsman et al., 2018). Additionally, other debunked therapies (e.g., Brain Gym, neurofeedback therapy, chiropractic therapy) continue to be offered in both the public and private sector, taking advantage of people with DCD and families vulnerable and desperate for help. A major factor contributing to the slow rollout and uptake of evidence-based interventions is the additional training required by health professionals to become certified in these therapy approaches (i.e., time, costs attending professional development courses). People with DCD and their families are also not aware that different types of intervention approaches exist in Australia, with demand for evidence-based intervention potentially required to change practice.

Allied health professionals shared some of the challenges experienced in training and service provision:

An occupational therapist described their experience: *"A lot of OTs say they don't know enough [about DCD] and they want more education. In undergrad you get maybe one lecture on it and they don't hear the term much more than that unlike other diagnoses."*

A physiotherapist described their experience: *"Education on DCD varies at an undergraduate level….education must continue to be provided and when possible, I think inclusion of practical therapy skills during workshops is imperative."*

An exercise physiologist described their experience: *"Training in neurological conditions was limited in our course. The focus was on conditions like Parkinson's disease, multiple sclerosis and stroke. None of that training prepared me to work in my current workplace, delivering exercise programs to children with special needs. While I knew a little bit about autism, cerebral palsy and ADHD, I knew nothing about other conditions like DCD."*

An occupational therapist described their experience: *"PDs [to learn new therapy models] are not cheap, even when companies co-pay for some of them. Time is also a factor for me. It can be hard to take time off work and still maintain my caseload."*

Allied health professionals trained in CO-OP therapy shared their thoughts about this evidence-based approach:

An occupational therapist after completing CO-OP training described: *"After using bottom up approaches my whole career, this course has been transformative in achieving functional outcomes for the kids I'm working with in such a short length of time".*

An occupational therapist after completing CO-OP training described: *"CO-OP changed my way of thinking and the way that I practice. CO-OP certification should be compulsory for all OTs."*

An exercise physiologist after completing CO-OP training described: *"CO-OP training introduced me to an evidence-based model of therapy. I now understand and have seen the importance of using guided discovery to enable the individual to formulate their own motor plan rather than relying on direct instruction. It's a game changer."*

An occupational therapist after completing CO-OP training described: *"How powerful it is when you support the client to problem solve and find their own way of reaching their goal".*

In addition to challenges accessing healthcare professionals with knowledge and expertise in DCD, people with DCD and their families experience limited opportunities to participate in community activities. A study of community participation in DCD found that Canadian children with DCD participated in community settings less frequently, were less involved when they did participate, and participated in fewer activities than their typically developing peers (Izadi-Najafabadi et al., 2019). Fifty-eight percent of parents wished their child with DCD could be more involved in the community. Some of the biggest discrepancies in participation were activities that children with DCD in the study *never* participate in. Fifteen percent of children with DCD had *never* got together with children in the community (compared to 2.7% of typically developing children); 21% have *never* participated in organised physical activities (compared with 8% of typically developing children) and 73% had *never* participated in an organisation/group/club or leadership activity (compared with 36% of typically developing children). This data is currently being replicated in Australia (by researchers at Victoria and La Trobe Universities in the study 'Participation and quality of life in an Australian sample of families affected by DCD'), with preliminary findings showing high levels of similarity. Australian parents report that the biggest barriers to participation in community activities are the physical, cognitive and social demands of tasks. This includes, for example, not having the strength or endurance to participate (physical barriers), mental fatigue making concentration and problem-solving difficult (cognitive barriers) and poor peer relationships and the attitudes of other members of the community toward children with DCD (social barriers).

Adults with DCD have described similar barriers to participation in leisure and community activities, demonstrating this is a lifelong issue. When interviewed by Scott-Roberts and Purcell (2018), adults with DCD detailed how colleagues often viewed them as anti-social as they found it difficult to participate in those activities that helped to consolidate workplace relationships; how they had to concentrate so hard when participating in social and physical activities that it made them less enjoyable; and how active leisure activities were carefully considered when they involved people outside of their direct families.

Statements from parents involved in the eHealth for Mental Health in DCD study, led by researchers at Victoria University, included:

Parent quote: ***"****We've tried accessing disability activities in the community but that has pros and cons. My daughter seems to do better in some ways when she has more able children around that can drag her along - sometimes we might find someone kind who would run back to grab her and pull her along and encourage her to keep going. But then when she didn't want to participate and was refusing, there was less flexibility there. Which she does get in disability activities - there is more flexibility and a relaxed atmosphere and someone will always try to engage her on the side and keep things going or change up the activity for her. I just wish there was more of that in the mainstream as I think she'd benefit more in that space."*

Parent quote: *"The main issue for my son is that when he plays with his friends, and he is very social and has good friends, he gets left behind in the physical games they play* *and at his age, he is nine years old, it's boys playing and being very physical. He struggles with that, quite a lot. So he's got really nice friends but they love to play tag and they love to climb trees and he just can't, he can't keep up and that's probably my biggest worry for him in terms of mental health, is how he is excluded from play and social physical activities".*

Parent quote: *"I don't want my child to miss out on participating in things. It's super important. Mainly just because of the social interaction and the confidence. If you've got all the other kids in the playground going out and kicking a ball or it's in the park and the kids are all climbing ladders on the playground, and they are missing out…. It's where you build a relationship and build your confidence so it's hard when they can't find a way to be involved."*

Parent quote: *"At swimming lessons one day, my son had a different teacher to usual. This guy was trying to push and push him to swim and I got so upset that I had to take him out of the water. So I tried to tell them, this swim school, "look, he's got this disorder that's impeding him" and they just said "oh, every kid's got something nowadays". I had to find another swim school that would modify expectations and focus on encouragement".*

Parent quote: **"***It's a challenge to find people who are trained to look outside the box. At swimming, she was struggling to swim on top of the water. But she was loving trying to dive down and grab the sink toys from the bottom. And to me, that's progress, her diving down. But they have to force her to swim on top because that's their program and they aren't trained to just go with the flow and look for where kids are making progress or what their strengths are. To get that, you need to find someone who is more accommodating and then pay for them to help privately and that's too much on top of all the therapy costs".*

6. Summary and Recommendations

In this submission, we have demonstrated that people with DCD and their families are currently being denied access to basic human rights in Australia. People with DCD are experiencing discrimination and neglect across the health care system, education, and community inclusion. While many people with disabilities struggle to get access to appropriate accommodations and support, this is further exacerbated for people with DCD due to the poor level of awareness and understanding of this condition.

We request that the Royal Commission specifically consider the issues experienced by people with DCD and how they are being failed by mainstream systems across health, education, and community. Until people with DCD are appropriately recognised, diagnosed, and provided with support, they will continue to experience neglect and experience significant (and avoidable) physical, educational and emotional impacts. These problems are further complicated by the fact that there is no funded peak representative organisation for people with DCD.

Based on the evidence we have presented and in consultation with leading experts in DCD from around Australia, we present the following recommendations:

1. Improved awareness and support for people with DCD in the healthcare system

- Adoption and promotion of the correct diagnostic term (Developmental Coordination Disorder, DCD) that appears within the diagnostic manual that is utilised in Australia (DSM-5, APA, 2013).
- Accurate assessment and diagnosis, conforming to the procedures outlined in the International Guidelines on the diagnosis of DCD.
- Routine screening for DCD in at-risk groups, including infants born preterm, infants with motor delay, children with conditions that commonly co-occur with DCD, and those with a family history of DCD. Screening measures include the Little DCD Questionnaire (3-4 years) and the DCD Questionnaire (5+ years).
- Pathways to access services following diagnosis.
- To achieve the above, there needs to be increased tailored education about DCD for medical and health professionals. The most effective strategy identified involves the development and dissemination of an advocacy toolkit to raise awareness and improve evidence-based practice within Australia. This approach has been successfully delivered in Canada: https://caot.ca/site/rc/caot-bc/practiceresources/dcdcadvocacytoolkit

2. Improved access to funding and services

- People with DCD with demonstrable functional need should be able to access intervention through NDIS beyond 7 years of age to access services and support within their community to improve their participation and quality of life.
- NDIS Planners/LAC's/ECEI partners should receive training in DCD, its lifelong impact and the potential disability associated with the condition.
- There needs to be promotion and prioritisation of evidence-based interventions for people with DCD, including CO-OP therapy.
- The NDIS should collect data on people with DCD who are NDIS participants. Currently, the NDIA Customer Relationship Management (CRM) system does not provide an option of coding a participant as having DCD and instead they categorise children with DCD as 'developmental delay' or 'other physical disability'.

3. Increased awareness and support for people with DCD in the educational system

- Awareness and education campaigns for teachers and educators about DCD. The most effective strategy identified would involve a mass media communication campaign to influence audiences, increase awareness and encourage changes to educational practices.
- Primary, secondary, and tertiary education systems across Australia to recognise DCD as a disability affecting a student's ability to reach their full potential and to provide appropriate accommodations and support based on functional need. These provisions are likely to include modified instruction, additional working time, rest breaks, alternative assessment items, use of devices, and appropriate support within the classroom (including specialist classroom setting, e.g., physical education, art, music, science, languages). Accommodations also need to be provided for ATAR exams that are administered under separate authorising bodies (e.g., School Curriculum and Standards Authority).
- Development of resources to assist teachers and educators making schooling more accessible and enjoyable for children with DCD.
- Improvement of systems to allow for improved communication between class and specialist teachers, and teachers from year to year, to decrease the burden on families, who report starting from scratch with each new academic year.
- DCD to be included in tertiary education and TAFE courses around Australia as part of existing disability modules, especially courses training medical, allied health and education professionals.

4. Improved awareness and advocacy for people with DCD in the community

- DCD Australia should be funded as part of the Department of Social Services National Disability Representative Organisations to provide systemic advocacy for people with DCD. It should be noted that the current Government has made a budget commitment to doubling funding for systemic disability advocacy. This should include expanding the funded organisations to ensure appropriate representation of disability types including DCD Australia Inc.
- People with DCD should be included in any Government awareness campaigns about disability (as part of the implementation of the National Disability Strategy).
- There needs to be community awareness campaigns to ensure widespread understanding of the disability (including early signs), promotion of the correct diagnostic term, and its impact as a lifelong condition.
- Information about DCD should be covered in workplace disability and inclusion programs like Job Access. Additionally, resources need to be developed for people with DCD to help them advocate for their own support needs with their employer/s.
- Resources and training opportunities need to be developed for community sporting and leisure organisations to improve their knowledge of DCD and strategies that can be employed to support inclusion and participation.

For too long people with DCD have been neglected by the very systems that are meant to be providing them with support. They have struggled to get diagnosed, been unable to access therapy support, and then not given the accommodations they need to succeed at school. It is time for DCD to be recognised in Australia and for people with DCD and their families to get the support they need to lead happy, healthy lives. It is time for people with this disability to stop falling through the gaps and to be heard.

To conclude this submission, we would like to include some final statements from the DCD community which highlight the struggles experienced by these families. We ask the Royal Commission to acknowledge the neglect experienced by the DCD community and include specific recommendations in their final report to ensure that DCD does not continue to be the most ignored and hidden disability in Australia.

A parent of a child with DCD shared their experience: *“DCD is often seen as a catchall for kids that don’t fit another box. It seems to be easily dismissed by professionals as ‘nothing really wrong’. I’d like people to come and live with me for a week just to see how much it impacts our family. Our son is a superhero but he also has major difficulties with everyday tasks. It creates chaos and it’s sad. I’ve watched him fall over 100s of times and not get his hands down to protect himself. He’s had a multitudes* *of bruises cuts and abrasions on his body - particularly his head - and it is distressing. We don't go out to other people's houses for dinner because it's like eating time at the zoo given he struggles with cutlery. It's little things that other people take for granted that really impact our family."*

A parent of a child with DCD shared their experience: *"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 is DCD. When we tell people he has DCD or Dyspraxia is used more commonly, we need to go into great detail so that people can have some semblance of understanding so they don't think he is dumb or naughty."*

A parent of a children with DCD shared their experience: *"Raising these kids, conducting therapy at home, providing assistance with self-care, helping them manage their emotions, limiting your weekend activities and food choices, trying to encourage more physical activities, 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."*

An adult with DCD shared their thoughts: *"People with DCD don't outgrow coordination and motor planning issues; their challenges change as their lives do. Therefore, we desperately need government agencies and communities to understand and support people with DCD throughout different stages of their lives."*

A parent of a child with DCD shared their thoughts: "*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 recognising it as a real disability and schools and teachers need to know about it too. These kids are being left behind and treated as the naughty kids because no one understands them."*

An adult with DCD shared their thoughts: "*There is a lot that Australia could do for people with DCD from setting up specialist clinics to training medical practitioners and academic staff in how to diagnose a child with DCD. Early diagnosis and treatment are the best tools Australia could provide for people with DCD. For adults like me who are diagnosed too late, a support system of specialists that know and understand the disorder should be set in place. Enabling workplaces and schools to be able to accommodate and understand neurodevelopmental differences, specifically DCD. This all starts though from knowing that this condition exists."*

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