Introduction & Acknowledgement

• The following study was conducted for a non-profit, volunteer group of professionals called the Multidisciplinary Team with a Vision (MTV). The members of this group include professionals that focus on the condition of Developmental Coordination Disorder (DCD) in their work, as well as parents of children with DCD. This group came together to raise awareness of DCD, support the identification of efficient diagnostic processes, and ultimately provide information to assist the development of service delivery models to support children with DCD. The ultimate goal of MTV is to achieve more positive psychological, health, and academic outcomes for children affected.

• All suppliers for this project have generously donated time and resources completely free of charge. They have done this in support of the Vision for helping children with DCD. For their commitment to this project and generous support, we earnestly thank them.
Background - What is DCD?

- Developmental Coordination Disorder (DCD) is a credible and well-researched condition that affects motor performance. DCD has been included in The Diagnostic and Statistical Manual of Mental Disorders (APA) from 1989 onwards.

- DCD becomes apparent in childhood and persists into adulthood.

- Coordination difficulties caused by DCD affect the person’s ability to perform every day tasks.
  - For example, individuals with DCD can find basic tasks difficult such as dressing, holding a pencil, riding a bicycle, or moving their mouths adequately to provide clear phonation when they speak.

- Developmental Coordination Disorder (DCD) is one of the most common disorders amongst school-aged children*. The ratio of boys to girls varies from 2:1 to 5:1†.

- DCD affects 5-6% of school-aged children‡, which represents roughly one child in every ‘average’ sized elementary school classroom all across Canada.

- To put this in perspective, that is 2 to 6 times as many as currently diagnosed with Autism Spectrum Disorder (ASD).

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The Diagnostic and Statistical Manual of Mental Disorders (APA, 2000) provides four criteria to classify DCD:

I. Performance in daily activities that require motor coordination is substantially below that expected given the person's chronological age and measured intelligence. This may be manifested by marked delays in achieving motor milestones (e.g., walking, crawling, sitting) dropping things, “clumsiness,” poor performance in sports, or poor handwriting.

II. The disturbance in criterion A significantly interferes with academic achievement or activities of daily living.

III. The disturbance is not due to a general medical condition (e.g., cerebral palsy, hemiplegia or muscular dystrophy) and does not meet criteria for a Pervasive Developmental Disorder.

IV. If mental retardation is present, the motor difficulties are in excess of those usually associated with it.
The Impact of DCD on Children

- While the **observable** characteristics of DCD involve physical performance, the diagnosis appears in the DSM IV due to the impact of DCD on children’s **psycho-social and emotional development**.

- Researchers have determined that **children, youth, and teens with DCD exhibit high levels of depression, learning disabilities, anxiety, and low self esteem***. As they increase in age the **rates of health problems and suicidal risk†** are higher than the norm.

- Although children with **DCD typically have normal intellectual capacity**, they struggle to perform academically due to the requirement for **written ‘output’** (printing, writing, doing math worksheets, responding quickly to spelling tests and other timed assignments, etc.).

- **DCD also affects** social interactions: uncoordinated movements affect one’s ability to play or keep up with others, **participate in sports**, and in some cases the **ability** to speak clearly.

  ➢ Because **children with DCD are acutely aware** of the fact that they can’t do things like other kids, it affects their self esteem.

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† Are impaired childhood motor skills a risk factor for adolescent anxiety? Results from the 1958 U.K. birth cohort and the National Child Development Study. Sigurdsson E, Van Os J, Fombonne E., Source Department of Psychiatry, Lausditali-University Hospital, Reykjavik, Iceland. engilbs@landspitali.


† Clumsiness in children--do they grow out of it? A 10-year follow-up study. Losse A, Henderson SE, Elliman D, Hall D, Knight E, Jongmans M
International studies in DCD have shown that children perceive themselves as less competent than their peers, not only in the domain of physical play (athletic competence), but also in several other domains including physical appearance and social acceptance. (Skinner and Piek, 2001)

Adolescents with DCD have also been shown to have psychiatric symptoms ranging from mood and anxiety disorders to social negativism and withdrawal (Sigurdsson et al, 2002).*

Recent research has also focused on the physical impact, increasing the risk of obesity associated with DCD, especially in boys (Cairney et al, 2005) and also of cardiovascular disease (Faught et al, 2005). *
The Impact of DCD on Communities

One of the primary difficulties for families with such children is obtaining the correct diagnosis — as awareness and knowledge of the condition is very low.

Parents of children with DCD face the challenge of navigating a lengthy, multi-year search for answers. The diagnostic ‘path’ for children with DCD typically involves more than a dozen individual tests (some repetitive), eight or more health care professionals, and a multi-year time-frame. Two Canadian examples:

Pathway traveled by one family to obtain care for their 6 year old child†:

“It took 6 speech tests, 3 OT assessments, 4 PT assessments, over a dozen psychological tests (including ASD etc.), a full cognitive/psychological evaluation, blood work x 3, MRIs, you name it. We also bounced between dozens of professionals before getting to the bottom of it. At the end of the day, the administrative costs versus the amount of funding that went towards actual therapy for [my son] is about a 95/5 split.” ††

The Impact of DCD on Communities

• Are multiple assessments the best use of the resources in the healthcare and school system?
  • What are the costs for physical and mental health related issues if DCD is undiagnosed, misdiagnosed, or unsupported?

• Does lack of a diagnosis of DCD hinder the work of educators and specialists, particularly given the high rate of incidence?

• How much emotional stress within the homes of children with DCD results from difficulties in obtaining a diagnosis and support?
  • ...over and above the increased social-emotional difficulties of the children themselves?

• Are adequate resources being dedicated to therapy and intervention compared to resources available for diagnostic testing?
  • Would this be better spent to support the child’s needs during the important, early stages of social/emotional development?
To address these concerns, the MTV team proposed a study to meet the following objectives:

1. To measure current awareness and knowledge of DCD among key stakeholder groups
2. Gather information from stakeholders on the experiences, perceptions, and opinions as to what is needed
3. Present the findings and stakeholder recommendations to decision makers and support providers
Those identified as ‘key stakeholders’ defined the targeted sample frame for this study:

**Those responsible for diagnosing children’s conditions**
- Family Doctors - physicians working in community practice with at least 15% of their patient load being children between the ages of 3 and 18.
- Pediatricians
- Psychologists*

**Those responsible for teaching, providing diagnostic information about, administering tests to, and providing professional support to children with special needs**
- Educators of children between the ages of 5 and 12
- Occupational, Physical and Speech and Language Therapists, and Psychologists*

**Parents**
- Individuals with children between the ages of 3 and 12. Note: For the purpose of this study, we included thoughts and opinions of all parents (the general public) and did not screen specifically for those with special needs children.

*Data from therapists (Occupational, Physical, Speech/Language) and Psychologists is still being collected, and therefore is not included in this report.
Methodology Overview

Methodology
An 8 question, online quantitative survey was developed and deployed through a number of online research panels. A total of 1,297 surveys were completed and collected.

Margin of Error

<table>
<thead>
<tr>
<th>Sample Group</th>
<th>Sample Size</th>
<th>Margin of Error (19 times out of 20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians</td>
<td>n=594</td>
<td>+/- 4.0%</td>
</tr>
<tr>
<td>Teachers</td>
<td>n=202</td>
<td>+/- 6.9%</td>
</tr>
<tr>
<td>Parents</td>
<td>n=501</td>
<td>+/- 4.4%</td>
</tr>
</tbody>
</table>

Sample Source
Canadian Parents and Teachers - Angus Reid Forum; Vision Critical’s proprietary, on-line panel of Canadian residents. The panel participation rate was 29%.

Demographic variables were pre-collected.

Professional healthcare panel sample was donated by the following companies; Health Surveys, Precision HMI, HealthViews, and All Global in Canada, the US and the UK

Field Dates
The study was launched December 10, 2010 and the data compiled as of February 28, 2011.
Sample Detail n=1,297

**Physician Profile n=594**

- Physician Title
  - Pediatrician: 43%
  - Family Doctor*: 57%

- Country
  - UK: 8%
  - Canada: 50%
  - USA: 42%

**Parents Profile n=501**

- Age of Children in Home
  - 19-24 years: 5%
  - 13-18 years: 30%
  - 6-12 years: 73%
  - 3-5 years: 44%
  - 0-2 years: 23%

**Teacher’s Profile n=202**

- Age of Students
  - 19-24 Years: 1%
  - 13-18 Years: 51%
  - 6-12 Years: 38%
  - 3-5 Years: 8%

**Region (Canadian Sample Only)**

- Ontario: 47%
  - East: 17%
  - West: 36%

- West: 39%
  - East: 14%

*Physicians working in community practice with at least 15% of their patient load being children between the ages of 3 and 18
Detailed Results

Current awareness and knowledge of DCD among key stakeholder groups
Key Finding: Awareness of DCD is very low

Anecdotal evidence of poor awareness and knowledge of DCD is supported:

- Only 23% of doctors and teachers and 6% of parents with school age children are familiar with the condition.
- Compared to 13 other common childhood conditions, DCD was the least well known (20% familiarity or less) even when other terminology such as motor learning disability, dyspraxia and clumsy child syndrome were included (25% familiarity by any description).

Why is a common condition which has been in the DSM for over 20 years relatively unknown?

Implication: Given the high incidence of DCD and low awareness levels, effective strategies to increase awareness among teachers, doctors and the general public need to be identified and implemented.
Less than 1/3 of respondents are familiar with DCD

Total Net Unfamiliar 80%

- Have not heard of this condition: 50%
  - Parents (n=501): 19%
  - Teachers (n=202): 17%
  - Physicians (n=594): 24%

Total Net Familiar 20%

- Very unfamiliar: 24%
  - Parents (n=501): 24%
  - Teachers (n=202): 26%
  - Physicians (n=594): 34%

- Somewhat unfamiliar: 34%
  - Parents (n=501): 34%
  - Teachers (n=202): 26%
  - Physicians (n=594): 17%

- Somewhat familiar: 16%
  - Parents (n=501): 5%
  - Teachers (n=202): 16%
  - Physicians (n=594): 22%

- Very familiar: 1%
  - Parents (n=501): 1%
  - Teachers (n=202): 6%
  - Physicians (n=594): 1%

Base: All respondents n=1,297
Q2. How familiar are you with the following conditions? Top 2 Box Summary “Very/Somewhat Familiar”
DCD is the least known condition among many others typically diagnosed during childhood.
Only 34% of Canadian Family Doctors are familiar with DCD - slightly higher than in the USA and UK

Q2. How familiar are you with the following conditions? *Caution: Small base size

- Very familiar
  - Canada (n=300): 10%
  - USA (n=248): 6%
  - UK (n=46): 9%

- Somewhat familiar
  - Canada (n=300): 24%
  - USA (n=248): 20%
  - UK (n=46): 17%

- Somewhat unfamiliar
  - Canada (n=300): 22%
  - USA (n=248): 31%
  - UK (n=46): 28%

- Very unfamiliar
  - Canada (n=300): 27%
  - USA (n=248): 26%
  - UK (n=46): 24%

- Have not heard of this condition at all
  - Canada (n=300): 16%
  - USA (n=248): 17%
  - UK (n=46): 22%
Familiarity of DCD is significantly* higher among Pediatricians than Family Doctors

% Response, Pediatricians (n=255)

Net Familiar 41%

Very familiar

Somewhat familiar

Somewhat unfamiliar

Very unfamiliar

Have not heard of this condition at all

% Response, Family Doctors (n=339)

Net Familiar 23%

Very familiar

Somewhat familiar

Somewhat unfamiliar

Very unfamiliar

Have not heard of this condition at all

*p < 0.05, pairwise comparisons using the Bonferroni correction.
Detailed Results
Knowledge and Diagnosis of DCD
Key Findings: Signs of DCD are visible, but the diagnosis infrequent and knowledge is limited

- Many of the typical signs of DCD are visible to physicians in their practice (particularly Pediatricians), and to teachers in their schools.
- Specifically, among those physicians and teachers familiar with DCD, 7 in 10 identified the common and observable **physical** characteristics of DCD such as motor learning difficulty, motor learning delay, and difficulty writing. However, less than 3 in 10 identified the **psychological** aspects of DCD such as anxiety, depression, social skills deficits, and difficulty making friends.
- It is suspected that many children are misdiagnosed with other issues such as generalized delay, ADHD, and ASDNOS among others*.
- A recent study by Missiuna et al (2011) with approximately 3,000 children found that 50% of those with ADHD also had DCD (28 of the 55 children)

**Implication:** With less than 1/3 of physicians familiar with DCD and less than 1/3 of those considering the psychological aspects of DCD, we can estimate there is a very large population of children that are misdiagnosed and left unsupported or at risk. This is concerning as studies have shown that those with DCD (and particularly DCD/ADHD combined) are at higher risk for psychological problems down the road.
Key Findings: Signs of DCD are visible, but the diagnosis is infrequent and knowledge is limited

- Diagnosis of DCD is not common; only 23% of Pediatricians and 9% of Family Doctors have ever made a diagnosis of DCD in their practice, in spite of the fact that DCD is two to six times more common than ASD as a comparison.

- Only 20 to 25% of the teachers reported observing children who had problems performing fine motor skills or keeping up with other kids in physical games or sports. However, some of these teachers recognize behavioural problems in these students (e.g., lazy, oppositional, or defiant).

Implication: If doctors are not making the necessary diagnosis of DCD, teachers may misunderstand the cause of the student’s difficulties in school and the student may be judged as having behavior problems rather than motor problems -- again, suggesting that there is a very large population of children that are misdiagnosed and/or left unsupported and at risk.
Of those Physicians and Teachers familiar with DCD, the physical attributes are better known than the psychological attributes.

% Responding that these are ‘are part of the condition of DCD’

- Motor learning difficulties: Physicians (79%), Teachers (74%)
- Difficulty printing and/or writing: Physicians (77%), Teachers (72%)
- Gross motor and/or fine motor skills delay: Physicians (74%), Teachers (70%)
- Low self esteem: Physicians (41%), Teachers (59%)
- Poor physical fitness: Physicians (49%), Teachers (43%)
- Sensory processing challenges: Physicians (30%), Teachers (42%)
- Anxiety: Physicians (30%), Teachers (40%)
- Difficulty making friends: Physicians (33%), Teachers (40%)
- Poor social skills: Physicians (22%), Teachers (37%)
- Depression: Physicians (11%), Teachers (28%)
- Poor academic performance: Physicians (28%), Teachers (41%)
- Average (or above average) cognitive ability: Physicians (30%), Teachers (48%)
- Below average cognitive ability: Physicians (11%), Teachers (16%)
- Higher than average risk for suicide: Physicians (7%), Teachers (20%)
- Obesity: Physicians (9%), Teachers (17%)
- Unsure: Physicians (4%), Teachers (11%)

Base: Indicated Very or Somewhat Familiar to DCD at Q2 “How familiar are you with each of the following condition? Q3. To your knowledge, which of the following do you think are part of the condition of Developmental Coordination Disorder (DCD)?
Some signs often seen in children with DCD that are visible to all Physicians in their practice

<table>
<thead>
<tr>
<th>Mean number of children that Physicians see in their practice showing the following characteristics:</th>
<th>Family Doctor (n=255)</th>
<th>Pediatrician (n=338)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has evidence of difficulty learning (learning disability)?</td>
<td>17</td>
<td>91</td>
</tr>
<tr>
<td>Demonstrates oppositional behavior?</td>
<td>11</td>
<td>53</td>
</tr>
<tr>
<td>Is self-conscious and stressed about his or her physical skills?</td>
<td>9</td>
<td>32</td>
</tr>
<tr>
<td>Has trouble ‘keeping up’ with other kids in physical games or sports?</td>
<td>9</td>
<td>44</td>
</tr>
<tr>
<td>Can not complete tasks such as writing, drawing, or handling small objects, in a way that’s adequate for their age?</td>
<td>8</td>
<td>44</td>
</tr>
<tr>
<td>Appears to be clumsy and accident prone when compared to their peers?</td>
<td>6</td>
<td>28</td>
</tr>
<tr>
<td>Has difficulty moving their mouth in such a way that their yet passes standard speech tests?</td>
<td>3</td>
<td>12</td>
</tr>
</tbody>
</table>

Base: All physicians, n=594

Q4. How many children do you have in your practice that would be described by the following conditions?
Characteristics visible to teachers in their schools that may warrant exploring a diagnosis of DCD

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Teachers (n=202)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has evidence of difficulty learning (learning disability)?</td>
<td>51</td>
</tr>
<tr>
<td>Is self-conscious and stressed about his or her physical skills?</td>
<td>26</td>
</tr>
<tr>
<td>Has trouble ‘keeping up’ with other kids in physical games or sports?</td>
<td>25</td>
</tr>
<tr>
<td>Can not complete tasks such as writing, drawing, or handling small objects, in a way that’s adequate for their age?</td>
<td>22</td>
</tr>
<tr>
<td>Demonstrates oppositional behavior?</td>
<td>19</td>
</tr>
<tr>
<td>Appears to be clumsy and accident prone when compared to their peers?</td>
<td>11</td>
</tr>
<tr>
<td>Has difficulty moving their mouth in such a way that their speech is easy to understand, yet passes standard speech tests?</td>
<td>4</td>
</tr>
</tbody>
</table>

Base: All Teachers, n=200. Q4A. How many children do you have in your school (that you are aware of) that would be described by the following conditions?
In spite of visible signs of DCD, diagnosis is rare: Only 23% of Pediatricians and 9% of Family Doctors have ever diagnosed a case of DCD.

Have you diagnosed a child with DCD?

**Pediatrician (n=225)**
- Yes: 23%
- No: 77%

**Family Doctor (n=339)**
- Yes: 9%
- No: 91%

Base: All Physicians n=594
Q7. Have you diagnosed a child with DCD?
Detailed Results

Key stakeholder perceptions and opinions: what is needed
Key Finding: There is clear, consistent opinion among stakeholders as to what’s needed to support children with DCD

1. A diagnosis (... early)
   - 9 in 10 Pediatricians see the benefit of early identification of DCD
   - Nearly 80% of teachers agree that children with DCD are sometimes labeled as lazy or defiant
   - 97% of teachers indicate an accurate diagnosis is critical for educators to know how to help
   - 70% of parents are confident that their child’s physician would accurately and quickly diagnosis a specific condition, however, only 3 in 10 physicians agree that a diagnosis of DCD would be relatively easy at this time
Key Finding: There is clear, consistent opinion among stakeholders as to what’s needed to support children with DCD

2. More information

- Almost all physicians (94%), want more education about DCD and only 38% believe the information in the DSM-IV is adequate
- 9 in 10 physicians agree that more research about DCD should be conducted
- 85% of Teachers feel that kids with DCD could not be adequately supported today due to a lack of awareness and knowledge about DCD
- Only 46 of 202 teachers admitted knowing anything about DCD. Nearly 80% of the few teachers who know about DCD agree that these children are sometimes labeled as lazy or defiant
- Although teachers rate themselves as knowing quite a bit about various conditions, and more than 50% report a high number of students with learning disabilities in their classes, they seem less aware of motor problems -- such as seeing clumsy and accident prone students in school -- admitting they know very little about (3%) DCD and clumsy children
Key Finding: There is clear, consistent opinion among stakeholders as to what’s needed to support children with DCD

3. **Collaboration between healthcare and education, and more professional support at school**

- More than 9 in 10 parents believe that children with special conditions should be supported by professionals *in the school environment*.
- 94% of parents believe healthcare and education should work together.
- Teachers are strongly aligned with parent opinion, 94% indicating educators should play a role in identifying early warning signs.
- About 30% of teachers recognize that students might feel self-conscious and stressed about their physical skills and 20% indicate that oppositional behaviours may have a motor basis to it (*Tables 41-47*)
Key Finding: There is clear, consistent opinion among stakeholders as to what’s needed to support children with DCD

Implication 1:
All stakeholder groups are both definite (90%+ agreement scores) and aligned in their opinions that;
• early diagnosis of DCD is critical
• more professional information is needed
• healthcare and education need to collaborate
• and children must be supported in schools

Implication 2:
The two critical success factors (diagnosis and diagnosis/information based in-school support) are not currently in place. This is a concern because children are at significant risk for not only poor self-esteem and academic performance, but other psychological issues as well as the families supporting them.
Parent Opinion: Education and healthcare must collaborate and support special needs at school

<table>
<thead>
<tr>
<th>% Disagree</th>
<th>% Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believe education and health care should work together to help identify early childhood conditions.</td>
<td>6% 94%</td>
</tr>
<tr>
<td>Children with special conditions should be supported by trained professionals in the school system.</td>
<td>10% 90%</td>
</tr>
<tr>
<td>I feel there should be more education for parents about the signs of DCD and other childhood conditions.</td>
<td>17% 83%</td>
</tr>
<tr>
<td>I feel confident that if my child had a specific condition, my child’s physician would be able to provide an accurate diagnosis in a timely manner.</td>
<td>29% 71%</td>
</tr>
<tr>
<td>I feel confident that if my child had a specific condition, I would be able to tell.</td>
<td>35% 65%</td>
</tr>
<tr>
<td>I believe there are adequate resources in place to support children with specific conditions.</td>
<td>52% 48%</td>
</tr>
<tr>
<td>I would hesitate to have my child diagnosed with because I wouldn’t want them to be ‘labeled’.</td>
<td>65% 35%</td>
</tr>
</tbody>
</table>
Q6. Please indicate how much you agree with the following

- Accurate diagnoses and classifications are critical for educators to know how to help children with special needs. 97%
- I believe educators should play a role in identifying early warning signs that can help to diagnose conditions. 94%
- Trying to manage children with special needs in the classroom is overwhelming. 87%
- There are too many conditions for educators to keep up with. 87%
- Currently, the education system would not be able to adequately support children with DCD due the lack of awareness and knowledge about the condition. 85%
- I believe there are children in the school system labeled as lazy or defiant that in fact have gross and/or fine motor skills impairments. 78%
- There are adequate support professionals for special needs children in the school system. 23%
Doctor Opinion: There are significant benefits to an early accurate diagnosis of DCD and more information is needed.

- **Further research is needed on DCD.**
  - % Disagree: 7%
  - % Agree: 93%

- **I feel I need more education/information regarding the condition of DCD.**
  - % Disagree: 6%
  - % Agree: 94%

- **I believe there are significant benefits to making an accurate diagnosis of DCD early.**
  - % Disagree: 9%
  - % Agree: 91%

- **Learning that the estimated incidence of DCD is between 5% and 6% in children would surprise me.**
  - % Disagree: 18%
  - % Agree: 82%

- **The DSM-IV contains enough information about DCD to make an accurate diagnosis.**
  - % Disagree: 35%
  - % Agree: 65%

- **DCD would be relatively easy to diagnose.**
  - % Disagree: 64%
  - % Agree: 24%
Critical factors to improving the Awareness and Knowledge of DCD are emerging:

- Physician education is necessary
- Improved school support is needed
- The impact on children with DCD who are unsupported must be addressed as well as the stress to families supporting them
Where to go for more information about Developmental Coordination Disorder (DCD)

1. CanChild – Centre for Childhood Disability Research  
   [www.canchild.ca](http://www.canchild.ca)
2. Research4Kids – Dr. Deborah Dewey  
   [http://www.ucalgary.ca/research4kids/members/dewey_full](http://www.ucalgary.ca/research4kids/members/dewey_full)
3. Learning Disabilities Association of Alberta –  
   [www.ldaa.ca](http://www.ldaa.ca)
4. The Family & Community Resource Centre  
   [http://fcrc.albertahealthservices.ca/](http://fcrc.albertahealthservices.ca/)  
   Phone: (403) 955-FCRC (3272) or  
   Toll Free 1-877-943-FCRC (3272)
5. DCD Parents Support Group Calgary  
   [dcdparentsupportgroup.ca](http://dcdparentsupportgroup.ca)
6. Child Psychologist & Author - Dr. Paulene Kamps  
   [www.drkamps.ca](http://www.drkamps.ca)
Thank you!
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