

The Impact of Developmental Coordination Disorder: Parent Perspectives



Erin S. Klein OT^{1,2} Melissa Licari PhD³ Skye Barbic PhD, OT^{4,5,7} Jill G. Zwicker PhD, OT^{2,4,6}

¹Rehabilitation Sciences, University of British Columbia, Vancouver, Canada; ²BC Children's Hospital Research Institute, Vancouver, Canada; ³Telethon Kids Institute and University of Western Australia, Perth Australia; Departments of ⁴Occupational Science & Occupational Therapy, ⁵Psychiatry, and ⁶Pediatrics, University of British Columbia, Vancouver, Canada; ⁷Centre for Health Evaluation Outcomes Science, Vancouver, Canada

INTRODUCTION

- Early motor challenges lead to physical, social, emotional, cognitive, and psychological impairments¹
- No standard of care or funding system in British Columbia (BC) to access diagnosis and treatment for children with DCD
- To inform best practice, we need to understand parental perspectives on needs, supports, and services

OBJECTIVES

To determine:

- 1. how parents navigate the healthcare and school systems for children with DCD
- 2. which therapy services and supports benefit families
- 3. the potential barriers and facilitators to access diagnostic and therapeutic services and supports

METHODS

Study Design:

Cross-sectional study design

Participants:

 Parents of children ≤ 18 years living in BC with motor coordination challenges (confirmed or suspect diagnosis of DCD, with or without co-occurring conditions, such as autism or ADHD)

Data Collection:

- Adapted online impACT for DCD questionnaire from Western Australia²
- Multi-pronged sampling strategy included convenience, purposive and snowball sampling
- Qualtrics, an online survey platform, was used to host and distribute the survey

Data Analysis:

- Descriptive statistics, parametric and non-parametric tests for quantitative data
- Exploratory content analysis for open-ended questions



RESULTS

Response:

244/336 completed and partially completed questionnaires (67% completion rate)

Demographic Distribution:

- 98% of children had a DCD diagnosis
- 89% had 1 or more co-occurring conditions
- Respondents primarily from urban centres, median income ≥ \$80,000, university-educated, 2-parent households

1. DIAGNOSIS



- 3 out 4 families report long wait-times
- 39% of families pursued private testing
- Less than 25% of physicians identify children at risk for DCD

Parent-Priorities:

- ✓ Funded, coordinated, and timely diagnostic services
- ✓ Increased capacity for healthcare providers, school staff, and general public

2. REHABILITATION



- Inconsistent access to school-based therapy
- 3/4 paying out-of-pocket for therapy
- No dedicated funding for DCD
- Only 40% currently attending therapy
- No impact of geographic location and income on therapy access
- Older children less likely to be actively followed by a clinician
- Low satisfaction for social and emotional services and supports
- Parents of older children prioritize services and supports for social and emotional wellbeing

Parent-Priorities:

✓ Funded motor, social, & emotional health services and supports at school and in the community

RESULTS cont'd

3. EDUCATION



- 3 out of 4 children receive some support at school, but...
- Insufficient supports and services, with limited awareness and understanding of DCD
- Affects their child's well-being, mental health, and self-esteem

Parent-Priorities:

- ✓ School-based services and resources
- ✓ Curriculum accommodations and modifications
- ✓ Access to educational assistants and equipment
- ✓ Education for teachers about DCD

CONCLUSIONS

- Families in BC have identified gaps in the healthcare and school systems
- Standard of care and best practice need to include:
 - 1. Funded, streamlined diagnostic services with education campaign for early detection
 - 2. Funded, multi-disciplinary assessments and treatment at school and in the community
 - 3. Increased school-based services and supports with educator training

REFERENCES

- 1. Blank et al., International clinical practice recommendations for DCD. *Dev Med Child Neurol*, 2019;39 (3):242-285
- 2. Licari et al., impACT for DCD. Telethon Kids Institute, 2020.

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Contact: erink01@student.ubc.ca or jill.zwicker@ubc.ca

