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Participation and needs of children with developmental coordination disorder at home and in the community: Perceptions of children and parents

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ABSTRACT

Background: The existing literature provides only a partial understanding of the viewpoints of elementary school-aged children with developmental coordination disorder (DCD) regarding their participation and needs. In order to plan and develop health and social services driven by a personalized approach, it is essential to further document their perceptions with those of their parents.

Aims: The aim of the study was to explore the participation and needs of school-aged children with DCD at home and in the community, as perceived by children and parents.

Methods: Participants were ten school-aged children with DCD, from 6 to 13 years old, and their parents, including one couple ($n = 11$). Individual semi-structured interviews were conducted with each participant, except the couple who were interviewed together.

Results: Most children and all parents perceived some difficulties at home but few in the community. However, participation and needs varied for each child. Children rarely expressed the same expectations as their parents. While most children did not want more support, parents requested training on DCD.

Conclusions: When planning health and social services for children with DCD, it is recommended to consult all stakeholders, including children, as well as offer indirect interventions, such as training and coaching for parents.

What this paper adds?

This study sheds light on the perceptions of school-aged children with DCD and their parents regarding the children's participation and needs at home and in the community. It adds to our understanding of their needs in their living environment for optimal participation, as perceived by both children and parents. Play and sports were the main significant activities for the children at home and in the community, so it is important to consider them in order to foster full participation and positive mental health. Most children and all parents perceived some challenges with participation at home but few in the community. Parents' expectations tended to differ from and be greater than the children's. Some children had concerns related to relationships with siblings and

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contextual factors affecting their participation in leisure, while most parents wanted to improve their child's autonomy in ADL and participation in physical activities. However, the findings indicate that some aspects of participation and needs were specific to each child, revealing the unique and complex relationships between the child with DCD, his/her environments, and his/her participation or occupations. Most children did not want more help than they already received whereas parents asked for training on DCD so they could help their child to learn and participate. Consulting all stakeholders, including children, is recommended in order to plan personalized health and social services. Diversified services, such as training and coaching for parents and adapted leisure activities, may be required to respond better to the children's and families' varied needs.

1. Introduction

According to the [American Psychiatric Association \(2013\)](#), approximately 6% of school-aged children present with developmental coordination disorder (DCD). This neurodevelopmental condition is characterized by the presence of motor coordination difficulties, which disrupt participation in activities of daily living (ADL), academic activities, play and leisure. DCD also affects self-esteem and social inclusion ([Mandich, Polatajko, & Rodger, 2003](#); [Missiuna, Pollock, Egan, DeLaat, Gaines, & Soucie, 2008](#)). Over the long term, poor psychosocial outcomes are reported, especially when the individual also presents with Attention Deficit Hyperactivity Disorder (ADHD), which is the most common co-occurring condition ([Rasmussen & Gillberg, 2000](#); [Zwicker, Missiuna, Harris, & Boyd, 2012](#)). Considering this situation, it is essential to recognize the needs of these children in order to meet them properly and intervene appropriately.

In the literature, two needs assessments for children with DCD have been published ([Forsyth, Maciver, Howden, Owen, & Shepherd, 2008](#); [Jasmin, Tétreault, & Joly, 2014](#)). A needs assessment is defined as a systematic evaluation describing a social problem and determining what services are needed to address it ([Rossi, Lipsey, & Freeman, 2004](#)). It helps service providers, managers and politicians to prioritize the needs of a specific population and target the services to offer them ([Massé, 2009](#)). Therefore, a needs assessment is a recommended first step before planning and developing services ([Massé, 2009](#); [Rossi et al., 2004](#)).

The first published needs assessment for children with DCD aimed to develop a practice framework for allied health professionals in Scotland ([Forsyth et al., 2008](#)). General principles were proposed to guide the organization of services for these children. However, the paper did not detail the needs of children with DCD across their life span and in different social contexts or the relevant variables to consider to plan an intervention program. To address this, the second assessment undertaken in Quebec (Canada) explored the needs of children with DCD from an ecosystemic viewpoint, using a multiple case study design ([Jasmin et al., 2014](#)). A profile of the participation and needs of children with DCD in different life and social contexts was developed, which led to a proposed intervention program based on theory-driven evaluations. However, since the results combined different viewpoints (children, parents, teachers and significant service providers) and measures (children's records, validated questionnaires and interviews) and covered all the life and social contexts to provide an integrated vision, they did not identify the specific perceptions of children with DCD and their parents regarding their needs in their living environment.

Since children with DCD and their parents must be considered stakeholders, it is important to understand their respective points of view in their real life situations in order to plan appropriate services to meet their needs ([Massé, 2009](#); [Rossi et al., 2004](#)). Moreover, offering services based on a client-centered approach, as recommended with children with DCD ([Blank, Smits-Engelsman, Polatajko, Wilson, & European Academy for Childhood Disability, 2011](#); [Forsyth et al., 2008](#)), implies consulting the child and his/her family to understand their needs and involve them in identifying meaningful goals, services and interventions ([Polatajko & Mandich, 2004](#)). To facilitate this practice, the organization of health and social services for children with DCD should also be driven by a personalized approach, which means recognizing and valuing the experiential knowledge of the individuals needing services ([Social Care Institute for Excellence, 2013](#)). Thus, it is relevant to conduct qualitative studies to document the perspectives of children with DCD and their parents.

Most qualitative studies have focused on the perceptions of parents, mainly mothers, with children with DCD ([Ahern, 2000](#); [Chesson et al., 1991](#); [Chia, 1997](#); [Green & Wilson, 2008](#); [Mandich et al., 2003](#); [Missiuna, Moll, King, King, & Law, 2006](#); [Missiuna, Moll, Law, King, & King, 2006](#); [Missiuna, Moll, King, King, & Law, 2007](#); [Pless, Persson, Sundelin, & Carlsson, 2001](#); [Rodger & Mandich, 2005](#); [Stephenson et al., 1991](#)). Basically, it appears that parents, and especially mothers, are competent to identify and describe their child's difficulties ([Green & Wilson, 2008](#); [Pless et al., 2001](#); [Rodger & Mandich, 2005](#); [Stephenson et al., 1991](#)). However, their relatives as well as teachers and service providers tend to disregard their concerns ([Chesson et al., 1991](#); [Mandich et al., 2003](#); [Missiuna, Moll, Law et al., 2006](#); [Rodger & Mandich, 2005](#)). Parents also have difficulty getting a diagnosis and accessing services for their child ([Ahern, 2000](#); [Mandich et al., 2003](#); [Rodger & Mandich, 2005](#); [Stephenson & Chesson, 2008](#)).

Work suggests that most parents begin to worry about their child's motor skills at age four ([Ahern, 2000](#); [Missiuna et al., 2007](#)). Parents become more aware of their child's difficulties when they observe other children and compare them with their own ([Missiuna et al., 2007](#)). Their concerns generally increase after the beginning of school ([Missiuna, Moll, Law et al., 2006](#); [Missiuna et al., 2007](#)). Their child's difficulties become more evident to them as the school's expectations increase ([Missiuna, Moll, Law et al., 2006](#)). Parents report reduced performance of their child in ADL such as dressing, academic activities like handwriting, as well as physical activities and sports ([Mandich et al., 2003](#); [Missiuna, Moll, King et al., 2006](#); [Missiuna, Moll, Law et al., 2006](#); [Missiuna et al., 2007](#); [Rodger & Mandich, 2005](#); [Summers, Larkin, & Dewey, 2008a, 2008b](#)). At school age, parents are more concerned about their child's self-esteem, mental health and socialization ([Ahern, 2000](#); [Mandich et al., 2003](#); [Missiuna, Moll, King et al., 2006](#); [Missiuna et al., 2007](#)).

Some studies have investigated the perceptions of school-aged children with DCD using self-report tools ([Cocks, Barton, & Donnelly, 2009](#); [Dunford, Missiuna, Street, & Sibert, 2005](#); [Green & Wilson, 2008](#); [Missiuna & Pollock, 2000](#); [Missiuna, Pollock, Law, Walter, & Cavey, 2006](#); [Pless, Carlsson, Sundelin, & Persson, 2001](#); [Poulsen, Ziviani, & Cuskelly, 2008](#)). The emphasis has been on

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