



Surveying parental experiences of receiving a diagnosis of developmental coordination disorder (DCD)



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ABSTRACT

Receiving a diagnosis of a developmental disorder has a major impact on an individual and their family. However, little is known about parental experiences of having a child diagnosed with developmental coordination disorder (DCD). In this study, 228 parents completed an online survey about their experiences of obtaining a diagnosis of DCD for their child in the United Kingdom. Results demonstrated that, on average, a diagnosis was confirmed two and a half years after parents initially sought professional help in relation to their child's motor difficulties. Satisfaction with the overall diagnostic process was mixed: 45% of parents were dissatisfied (26% = very dissatisfied, 19% = quite dissatisfied) and 39% were satisfied (16% = very satisfied, 23% = quite satisfied). Four factors were predictive of parental satisfaction with the overall diagnostic process: the stress of the diagnostic process; the manner of the diagnosing professional; satisfaction with post-diagnostic support; and the time taken to get a diagnosis. Post-diagnostic provision was the area in which parents reported most dissatisfaction; an unsurprising finding given that 43% of parents were not offered any practical help or support during the diagnostic process or in follow up appointments (although there was an indication that this was improving). Based on these findings (as well as previous research), we propose three key areas in which improvements in the diagnostic process for DCD are needed: (1) greater awareness about DCD in order to facilitate earlier recognition; (2) implementation of clear referral pathways, to reduce the time taken to receive a diagnosis; and (3) increased post-diagnostic support within health and educational systems.

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1. Introduction

Developmental coordination disorder (DCD) is characterized by significant impairments in the acquisition of motor skills that interfere with activities of daily living (e.g., dressing, using utensils), and/or academic achievements (Zoia, Barnett, Wilson, & Hill, 2006). Although various labels have been applied to the condition, including 'clumsy child syndrome' (American Psychiatric Association, 1987), dyspraxia (Denckla, 1984) and Specific Developmental Disorder of Motor Function

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(World Health Organization, 1992), 'developmental coordination disorder' is now the term favoured internationally (American Psychiatric Association, 2013; Polatajko, Fox, & Missiuna, 1995; Sugden, 2006).

Generally, parents notice their child's motor difficulties from an early age (Maciver et al., 2011; Missiuna, Moll, King, King, & Law, 2007; Pless, Persson, Sundelin, & Carlsson, 2001; Rodger & Mandich, 2005). Yet these concerns are not always recognized by professionals (Missiuna, Moll, Law, King, & King, 2006) and parents are sometimes (incorrectly) reassured that their child will outgrow their difficulties (Zwicker, Missiuna, Harris, & Boyd, 2012). It is not until the child enters the school system that motor problems become more pronounced (Rodger & Mandich, 2005), and a diagnosis is normally received between the ages of five and seven (Novak, Lingam, Coad, & Emond, 2012). The routes to diagnosis vary from country to country but should always involve the collection of information, past and present, about the child from a range of perspectives (including input from a medical practitioner). Screening tools and assessment test batteries (such as the Movement ABC2; Barnett, Henderson, & Sugden, 2007) will also be used during the diagnostic journey. A consideration of information provided from all sources leads to a diagnosis.

Parents frequently experience relief once their child receives a diagnostic label, as they find it helpful in understanding their child's difficulties (Ahern, 2000). However, significant delays often trigger negative feelings such as fear, stress and disempowerment (Pless et al., 2001; Rodger & Mandich, 2005). Further, parents may feel angry and guilty, believing that their child has 'missed out' on treatment at a crucial time (Maciver et al., 2011). Indeed, delayed identification and intervention can cause long-term negative consequences (Hamilton, 2002). Such factors lead to dissatisfaction amongst parents and loss of confidence in the professionals involved (Maciver et al., 2011; Novak et al., 2012).

The issues surrounding the diagnosis and management of DCD have been aggravated by the lack of gold-standard tools for identifying DCD-related motor difficulties and a lack of agreed guidelines. In 2012, a Swiss-German guideline was published by the European Academy of Childhood Disability (EACD). This focused on the definition, diagnosis, assessment, and intervention appropriate for children with DCD (Blank, Smits-Engelsman, Polatajko, & Wilson, 2012). Expectations were: (1) greater awareness and recognition of the condition; (2) improved access to services; (3) establishment of clear diagnostic criteria and examinations; (4) better information about available therapies; and (5) data concerning the effectiveness of therapy in relation to improvement of motor difficulties, execution of daily activities and/or participation. The EACD recommendations were reached after a systematic evaluation of the literature and consensus from experts in the field, and have also been adapted for the UK to ensure their applicability for health and educational services in this country (Barnett, Hill, Kirby, & Sugden, 2012; Barnett, Hill, Kirby, & Sugden, 2014). This UK adaptation was coordinated by the UK umbrella organization *Movement Matters* and involved a broad range of stakeholders including medics, allied health professionals, teachers, educational psychologists, researchers, adults with DCD, and parents. In the short time since dissemination in the UK, via the professional organizations linked to the stakeholders involved, improved awareness is appearing. This is, in part, due to the agreement of a narrative definition of DCD that is adhered to and has been adopted by the UK's National Health Service. It is essential to continue consulting families to determine if the EACD recommendations are being acted on and to discover if the key areas for improvement that were identified match the concerns of parents in the UK.

The current research represents the first large-scale investigation exploring the experiences and opinions of parents receiving a diagnosis of DCD in the UK. This was achieved by adapting and extending a recent online survey exploring parental experiences of receiving an autism diagnosis (Crane, Chester, Goddard, Henry, & Hill, 2015). The aims of the present research were to: (1) examine the common ways that DCD presents (e.g., nature of initial concerns), and the journey that the parents go through to obtain a diagnosis for their child; (2) evaluate parents' satisfaction with different aspects of the diagnostic process, including support; (3) investigate which factors affect parental satisfaction (e.g., the knowledge of the professional at the first consultation, the child's age when help was sought, the time taken to get a diagnosis, the information given at diagnosis, the manner of the diagnosing professional, satisfaction with post-diagnostic support, and parental stress regarding the diagnostic process as a whole) in order to determine areas in which improvements would be beneficial.

2. Method

2.1. Participants

Parents/guardians who have a child/children diagnosed with DCD, or who fit the criteria for DCD (e.g., diagnosed with 'dyspraxia' or 'clumsy child syndrome') were invited to participate. To recruit the sample, an e-mail was sent to relevant services and organizations (e.g., charitable foundations, parent support groups) outlining the purpose of the project and providing suggestions to promote the research. Advertisements were distributed via websites, online support groups/forums and via social media, with which the target population was likely to engage with. Details were also circulated to an existing database of parents who participated in other DCD research at Goldsmiths, University of London.

Although 255 parents completed the survey, 27 cases were removed from the final sample: two cases were adults with DCD who completed the survey themselves; one respondent was diagnosed outside the UK; five cases described their child's age at various stages of the diagnostic processes inconsistently, making the process chronologically impossible; and

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