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

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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.

Key words: Developmental Coordination Disorder, dyspraxia, diagnosis, parents, experiences, satisfaction

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

1. 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 19 respondents had not received an official diagnosis of a motor difficulty for their child. This resulted in a final sample of 228.

The mean age of the parents (97% mothers) at the time of the survey was 42.58 years (SD = 6.50, range 28-64). Although 6% of these parents were diagnosed with DCD, it was not established whether the parent who did not complete the survey had a

diagnosed motor difficulty. The sample was geographically diverse (see Appendix), but not ethnically diverse (with 96% of parents describing themselves as White).

The average age of the children (73% male) at the time of the survey was 11.13 years (SD = 5.25, range 2-33): 14% < 6 years; 53% = 6-12 years; 25% = 12-18 years; 7% > 18 years. Co-occurring disorders were observed in 61% of the sample, most commonly learning (16%) and physical (10%) disabilities, and autism spectrum disorder (10%) In relation to their experiences and views on the diagnostic process for DCD, only one significant difference was found between the parents whose children had another diagnosis besides DCD and those with only a DCD diagnosis: parents whose children had been diagnosed only with DCD (16.3%) were more likely to seek help privately (i.e., outside the UK's National Health Service) than parents whose children had DCD and at least one other co-occurring disorder (7.1%) (χ^2 (1) = 4.11, p = .04).

2.2 Materials

The online survey comprised a number of sections:

2.2.1 Information about the parents: This section, which comprised a number of closed questions, collected: demographic details (age, gender, ethnicity); whether the parent was diagnosed with DCD/dyspraxia; and their location at the time seeking a DCD diagnosis.

2.2.2 Information about the children: Data on the child's age, gender and co-occurring diagnoses (if any) were collected via a series of closed-questions.

2.2.3 Diagnostic process: This section examined the pathway from when parents noticed their child's difficulties to when they were given a formal diagnosis. Specifically, data were gathered (via a series of closed-questions) on: the child's age when help was first sought; the role of the professional(s) seen (e.g., paediatrician, psychologist, physiotherapist); and the outcome of the consultation (i.e., received a diagnosis, referred to another professional, referred for tests, told not to worry, told to return if problems did not improve, or another outcome [specified by the parents]). Comparable questions were included for each subsequent referral (up to three), including the appointment at which the child was given the DCD/dyspraxia diagnosis.

2.2.4 Alternative routes: This section included a free text box that allowed respondents to explain the process leading to their child's diagnosis in greater detail (e.g., if they experienced a long or unusual diagnostic pathway). Other aspects explored were whether parents chose to seek private help (i.e., outside of the UK's National Health Service); and details of any reassessments for the movement difficulties. If a reassessment occurred, parents were asked whether the reassessment changed the diagnostic label, and how old their child was at the time of this reassessment.

2.2.5 Satisfaction with the diagnostic process: Parents indicated their satisfaction with: (1) The overall diagnostic process; (2) The information given at diagnosis; (3) The manner of the diagnosing professional; and (4) The post-diagnostic support offered in relation to their child's movement difficulties. Each were rated on a 5-point Likert scale, ranging from 'very dissatisfied' to 'very satisfied'

2.2.6 Knowledge of the professional at the first consultation: Parents were asked to rate how knowledgeable they felt the professional they saw at the first consultation was. Perceived knowledge was rated on a 5-point Likert scale (from 'very knowledgeable' to 'not at all knowledgeable').

2.2.7 Stress: Parents were asked to rate how stressful they found the diagnostic process as a whole on a 5-point Likert scale (from 'not at all stressful' to 'very stressful').

2.3 Procedure

The survey (available from March to June 2014) was accessed via a website designed specifically for the project. Details of relevant support services were offered at the end of the survey, together with the opportunity to receive a brief summary of the results. Ethical approval was obtained from the Department of Psychology Research Ethics Committee at Goldsmiths, University of London.

2. Results

3.1 Initial Awareness of Difficulties

Twenty-one percent of parents stated that their first concerns regarding their child's development were exclusively related to movement; 49% had concerns regarding both movement and other areas of difficulty; and, for 30%, concerns were not related to movement at all. Concerns tended to be raised when the children were around 3.5 years (SD = 2.4; range = 2 months to 14 years; Mdn= 3). Problems were commonly identified before the child's third birthday (52%), and only rarely were parents alerted to difficulties in later childhood. In cases where initial concerns were not related to movement (30%), the average age of the children when movement difficulties were identified was 4.1 years (SD = 2.5; Mdn= 4). Although ages ranged from 5 months to 14 years, movement difficulties were usually identified between three and six years (45%). Respondents were provided with a list of both movement-related (e.g., poor balance, trouble picking up and holding objects) and non-movement-related (e.g., delays in starting to talk, behavioural problems) developmental concerns and were asked to select areas in which they first identified their children as experiencing difficulties. Here, 70% noted poor performance in daily activities that require motor coordination and concerns were reported frequently regarding poor balance and impaired motor coordination (Table 1). Only 4% of parents indicated that it was a professional who first raised concerns regarding their child's development; 96% of parents initially noted their child's motor problems.

[Place Table 1 about here]

When parents reported other concerns in relation to their children's development (aside from movement), these were commonly in relation to sensory sensitivities, difficulties with socialization and delays in starting to talk (see Table 2).

[Place Table 2 about here]

Some parents (22%) stated they were seeking a referral for a different diagnosis when they found out that their children had DCD/Dyspraxia, but many of these were, nonetheless, aware of their child's motor difficulties.

3.2. First consultation

Parents tended to seek professional help in relation to their children's movement difficulties when they were around 5 years (SD= 2.71; Mdn= 5). Although this ranged from 8 months to 14 years, 43% of parents sought help when their child was between three and six years. On average, parents sought help 1.4 years after they first had concerns in relation to their children's movement difficulties (SD= 1.95; range = 0 to 9 years; Mdn= 1). A wide range of professionals were seen at this first visit, primarily a General Practitioner (GP), Health Visitor or Teacher (see Table 3 for further details).

[Place Table 3 about here]

Fifty-two percent of parents believed that the professional seen had superficial (34%) or no knowledge about the condition (18%), with just 22% indicating that the professional had good (10%) or very good (12%) knowledge about DCD. Most children (93%) did not receive a DCD/Dyspraxia diagnosis at this initial visit; of these, 5% were given a different diagnosis (e.g., learning disability, ADHD, developmental delay) and 73% were referred to another professional. Other parents (14%) were simply told that there was no problem with their child's motor function (see Table 4).

[Place Table 4 about here]

3.3 Subsequent referrals

Following the first visit, the remaining 213 parents (93%) went on to see another professional (either following a direct referral, by seeking a private referral, or at a later stage). This was usually a pediatrician or occupational therapist. Of these 213 parents, 36% were given the DCD/Dyspraxia diagnosis for their children at the second visit, while 32% received the diagnosis at the third visit. The remaining 26% saw four or more professionals before getting a DCD diagnosis.

3.4 Final diagnosis

For the sample as a whole (n = 228), parents completed the survey around 3.4 years after their children received a diagnosis (SD = 4.7, range = 0-20, Mdn= 2). The average age of the children at the time of receiving their diagnosis was 7.8 years (SD = 2.8, range = 2-17, Mdn=7). This was around 3.6 years after concerns first emerged regarding the children's movement difficulties (SD = 2.7, range = 0-13, Mdn=3) and 2.5 years since parents first sought professional help (SD = 2.6, range = 0-13, Mdn=2). The diagnosis was commonly given by a paediatrician (44%) or an occupational therapist (32%). Other diagnosing professionals included educational/clinical psychologists (6%), neurologists (3%), physiotherapists (3%), child psychiatrists (1%), or multidisciplinary teams (4%). A written report on their child's diagnosis was given to 84% of parents, with 50% receiving a follow-up appointment post-diagnosis with the same professional. For 43% of respondents, no practical help or support (either during the process of

seeking a diagnosis, or in follow up appointments) was given. For 34%, support or assistance was offered directly (e.g., providing access to support by, for example, arranging appointments), while 20% were signposted to support or help (e.g., given relevant leaflets). Only 16% reported having their child's problems explained during the diagnostic process, or in follow up appointments.

Table 5 illustrates the forms of help that participants were given post-diagnosis (note that categories were not mutually exclusive and many parents were offered help and assistance in more than one area). Occupational therapy was the most frequent type of assistance (40%), while 18% were offered physiotherapy and just 9% had been given assistance with school provision.

[Place Table 5 about here]

3.5 Alternative routes

In 37% of cases, private help (i.e., outside the UK's National Health Service) was sought at some point during the diagnostic process. Also, 35% of the parents had a reassessment for their child's movement difficulties (e.g., at school, work). For 35% of this subgroup, the reassessment changed the diagnostic label for their child's movement difficulties and, in 25% of these cases, the new label was DCD (for 43%, the label was dyspraxia; 32% were given other labels, e.g., Irlen syndrome, Disorder of Attention and Motor Perception). Among the 61% of parents who had a child with additional diagnoses, 61% reported that none of the diagnoses was given priority over the others. In the cases where priority was given to one of the diagnoses, 47% stated that the movement diagnosis was prioritized.

3.6 Satisfaction

Table 6 illustrates parents' satisfaction ratings in relation to various aspects of the diagnostic process. A bimodal distribution was found regarding ratings of satisfaction with the overall diagnostic process: 45% of parents were 'very' (26%) or 'quite' (19%) dissatisfied and 39% were 'very' (16%) or 'quite' (23%) satisfied.

[Place Table 6 about here]

Satisfaction scores for aspects of the consultation at which the diagnosis was given were higher than the scores for the overall diagnostic process: 51% were satisfied with the information they received (34% were 'quite' satisfied and 18% 'very' satisfied), and 66% were satisfied with the manner of the diagnosing professional (36% were 'quite' satisfied and 31% 'very' satisfied). For the support offered post-diagnosis, only 27% of respondents reported satisfaction (21% were 'quite' satisfied and 6% 'very' satisfied).

A series of bivariate correlations were used to explore the relationships between variables. These demonstrated that parents who received the DCD diagnosis for their children more recently indicated higher levels of satisfaction with the support offered ($r(194) = .20$, $p < .005$). However, none of the other variables were significantly

related to the number of years since the child received the DCD/Dyspraxia diagnosis (*ps* > .10).

The age of the children at the time they received the diagnosis was not associated with parental satisfaction for any of the aspects of the diagnostic process or the process as a whole (*ps* > .10). Nevertheless, satisfaction with the overall diagnostic process increased in line with the age of the child at the time help was first sought in relation to the child's movement difficulties ($r(184) = .23$, $p < .005$).

3.7 Stress

The majority of the parents described the diagnostic process as 'very stressful' (44%) or 'quite stressful' (32%); 18% found it to be 'not very stressful', and only 6% of the parents felt that the process was 'not at all stressful'. Bivariate correlations demonstrated that as the child's age increased, parents reported the process to be less stressful ($r(185) = -.19$, $p > .01$); also, parents who experienced increased delays (from the time they first sought help for their child to the point at which a diagnosis was received) reported higher stress ($r(170) = .22$, $p > .005$).

3.7.1 Factors affecting satisfaction: Multiple regression analyses were used to explore the factors affecting parental satisfaction with the overall diagnostic process. Level of overall satisfaction was used as the dependent variable, with the following seven variables entered as predictor variables: (1) The age of the child when help was first sought; (2) Perceived knowledge level of the first professional seen; (3) The time taken to receive a diagnosis; (4) Satisfaction with the information given at diagnosis; (5) Satisfaction with the manner of the diagnosing professional; (6) Satisfaction with post-diagnostic support; (7) Stress of the diagnostic process as a whole.

The assumptions of linearity, homoscedasticity, independence of errors, and normality of residuals, were met. Five cases were identified as multivariate outliers and excluded from the analysis to prevent them biasing the output. Using a forced entry method of multiple regression, a significant model emerged that predicted overall satisfaction ($F(7,143) = 37.68$, $p < .001$). The model had an adjusted R square of .63, meaning it explained 63% of the variance in satisfaction, indicative of a large effect (Cohen, 1988).

Four of the seven factors that were expected to affect satisfaction with the overall diagnostic process were found to be significant (see Table 7). Stress of the diagnostic process was the most influential predictor of overall satisfaction, followed by satisfaction with the help offered, satisfaction with the manner of the diagnosing professional, and the time taken to receive a diagnosis. Conversely, satisfaction with the information given at diagnosis was not found to significantly predict overall satisfaction. However, this variable was highly correlated with satisfaction with the manner of the diagnosing professional ($r(216) = .79$, $p < .001$). This may be the reason why satisfaction with the information given did not make a significant *independent* contribution to the model, even though it was correlated with overall satisfaction. Neither the child's age at the time help was first sought, nor the perceived knowledge of the first professional seen, were significant predictors of overall satisfaction.

[Place Table 7 about here]

3. Discussion

By surveying 228 parents with a child who was diagnosed with DCD, the current study aimed to investigate the journey that parents in the UK go through in order to obtain a DCD diagnosis for their child. We also explored which factors affected parental satisfaction with the overall diagnostic process, including their support needs post-diagnosis.

Consistent with previous research (Maciver et al., 2011; Missiuna et al., 2007; Rodger & Mandich, 2005), the majority of surveyed parents were astute to their child's difficulties (related and unrelated to motor function) from an early age; usually when their child was around 3 years old. As children's difficulties usually become more obvious when they enter school (Rodger & Mandich, 2005), it was not surprising that most parents sought help when their child was aged between three and six. This was, on average, one and a half years after concerns first emerged.

Over half of the parents believed that the first professional they visited (often a GP, health visitor or teacher) had superficial or no knowledge about the condition. Further, some parents expressed concern that their child's problems were trivialized (e.g., being told their child would outgrow the difficulties). While this was not a significant predictor in the regression, this suggests the need for increased awareness and education among frontline professionals about signs of DCD and its impact on children's lives. Thus, our study is consistent with recommendations in the EACD guidelines (Blank et al., 2012), and is also in agreement with results from previous parent studies (Forsyth, Howden, Maciver, Owen, Shepherd, & Rush, 2007, Maciver et al., 2011; Novak et al., 2012; Rodger & Mandich, 2005).

Following the first consultation, many parents described frustration with the lack of consistency of the diagnostic process, as they often had to visit a wide range of professionals, resulting in long delays. Over a third of the parents sought private help at some stage, reportedly due to the lack of referral structure encountered within the UK's National Health Service and the long waiting times between referrals. Recent guidelines (Blank et al., 2012) emphasize the need to clarify responsibilities and enhance cooperation among professionals. Implementing clearer defined referral routes to better structure the diagnostic process may enable an effective collaboration between professionals and could reduce the delays in reaching a resolution. This is particularly important given that our results demonstrated that the time taken to receive a diagnosis was one of the key variables affecting parental satisfaction with the diagnostic process. One important step towards this has been the development of DCD pathways in some areas of the UK, which focus on identification and referral cooperation between education and health services (Forsyth et al., 2007).

Perhaps unsurprisingly, the majority of the parents (76%) described the diagnostic process as stressful and this was a key predictor of parental satisfaction with the overall diagnostic process. Stress was associated with the age of the child when help was first sought, as parents whose children were younger presented with higher levels of stress during the diagnostic process. In the same manner, satisfaction scores for the overall diagnostic process also increased in line with the age of the child at the first professional consultation. This may be related to the fact that DCD guidelines do not recommend the diagnosis of the condition before the age of 5. This is because motor

development in young children is rather variable; children with early motor delay may catch-up with their peers later in development, or children without motor delays may exhibit motor problems when confronted with more demanding motor tasks later in development (e.g., at school) (Hadders-Algra, 2010). Further, current instruments for assessment do not enable a valid and reliable diagnosis in younger children (Blank et al., 2012). In those cases where the child shows a significant motor impairment, the diagnosis of DCD may be made earlier (between the age of 3 and 5) but it should be based on at least two different assessments performed at long intervals. Consequently, parents who seek help for their child at an earlier age may experience longer delays and greater difficulties in obtaining the diagnosis. Professionals may find it helpful to alert parents to this issue, as parents may not appreciate the rationale behind the delays they are experiencing; increased knowledge of the process involved when identifying and reliably diagnosing DCD may help to reduce the stress and dissatisfaction experienced by parents.

Although 58% of parents were satisfied with the information they received following their child's diagnosis, there is much scope for improvement in this area. Only 17% of respondents declared having their child's problems explained and nearly half were not given a follow-up appointment. Follow-up appointments post-diagnosis are recommended for parents of children with other neurodevelopmental disorders (e.g., autism). This appointment allows parents to address, ideally with the diagnosing clinician, any questions or thoughts arising in the post-diagnostic period (NICE, 2011). Such an appointment may be especially helpful for children with DCD, given that the condition is less widely known and understood (Wilson, Neil, Kamps & Babcock, 2013). Although parents who reported high levels of satisfaction with the information given commented on how useful this was in helping them to understand their children's difficulties, many others had to revert to other sources (e.g., online support groups) for information and advice. Previous qualitative studies have highlighted the lack of available post-diagnostic support for children with DCD and their families in the UK (Maciver et al., 2011; Novak et al., 2012), and this finding was mirrored in the current research: 43% of parents were not offered any practical help after the diagnosis was made and only 27% were satisfied with the post-diagnostic support they received. Given that guidelines recommend that all children with DCD should receive intervention (Blank et al., 2012), this finding represents high levels of unmet need in this area. It is acknowledged that, for some children, the diagnosis may have been too recent for an intervention to have been put into place. In addition, these guidelines may have been published too recently to have affected the diagnostic process for the majority of children reported on in this study. However, it is not surprising that satisfaction with post-diagnostic support was the area in which parents declared most discontent and was a key predictor of parental satisfaction with the overall diagnostic process (as also reported in the field of autism; see Crane et al., 2015; Jones, Goddard, Henry, Hill, & Crane, 2014).

Satisfaction scores for the overall diagnostic process showed a bimodal distribution: 45% of parents were dissatisfied and 39% satisfied. Overall satisfaction scores were not found to correlate with the number of years since the diagnosis was made, suggesting that parents of children diagnosed recently expressed the same level of satisfaction, on average, as those diagnosed longer ago. Further, no significant differences were found between the satisfaction levels of parents whose children had another diagnosis besides DCD (61% of the sample) and those with only a DCD diagnosis (39% of the sample). It is unclear whether parents who have children with

particular co-occurring disorders (e.g., autism) experience specific additional difficulties (or even a degree of ease) in getting a diagnosis for their child's motor difficulties, relative to those with other conditions (e.g., ADHD) who also have co-occurring motor problems. This was outside the scope of this research, but is an important avenue for future work.

When generalizing the findings to a broader population of parents with children diagnosed with DCD, some limitations must be acknowledged. First, the sample was self-selecting, and it is not possible to establish if the opinions of respondents reflect those of non-respondents. Parents in the study may represent those who are more concerned, or more informed, about their child's condition. Second, the survey was largely promoted through online support services and organizations, meaning that parents who do not usually engage with these types of services were not reached. Third, the study was only open for parents of children who had been officially diagnosed; the experiences of parents who had been through the diagnostic process, but were not able to get a diagnosis, were not analyzed.

Further, there was a lack of ethnic diversity in the sample. Although future studies should aim to sample the opinions of parents from black and minority ethnic groups, as they may have qualitatively different experiences, these groups can be difficult to access, and are often underrepresented in such research (e.g., Crane et al., 2015). Finally, the current study was based on retrospectives reports (which often include errors) and it was not possible to verify the children's clinical history. Nevertheless, the sample was of a reasonable size (substantially larger than any other DCD study of this type) and geographically diverse. Moreover, 70% of parents had received their child's diagnosis within the past 3 years; therefore it is likely that the findings provide a good insight into current parental experiences of the process of receiving a DCD diagnosis in the UK.

The implications derived from the research are threefold. First, it is essential to promote awareness and knowledge about the condition among professionals (e.g., GPs, teachers) to facilitate early recognition and appropriate referrals. Second, clear referral pathways and reduced waiting times for both assessment and intervention would improve parents' satisfaction. Third, there is a need for improved information and support (within the health and educational system) post-diagnosis. Effective collaborative work and communication is needed between the two systems to help support children with DCD and their families appropriately.

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Table 1. Nature of initial concerns in relation to movement difficulties (n=228)

Area in which difficulties experienced	%
Poor performance in daily activities that require motor coordination (e.g., using knife and fork, fastening buttons, handwriting)	70
Poor balance (e.g., tripping over one's own feet)	64
Signs of impaired motor coordination (e.g., clumsiness, difficulty combining movements into a controlled sequence)	61
Problems with spatial awareness	45
Delays in achieving developmental motor milestones (e.g., walking, sitting)	37
Lack of speech fluency	31
Trouble picking up and holding objects	26
Trouble learning basic movement patterns	23
Problems with sucking, chewing and/or swallowing foods	21
No worries until other professional raised concerns	4

Table 2. Nature of initial concerns in relation to other areas of development (n=228)

Area in which difficulties experienced	%
Sensory sensitivity	35
Delay in starting to talk	31
Social development (e.g., relating to people in the normal way)	31
Schooling	28
Sleep problems	25
Behavior problems (e.g., hyperactivity, tantrums)	22
Rituals/obsessions/dislike of change/object attachments	22
Failure to develop normal pretend play	16
Medical problems (e.g., epilepsy)	4
No problems until other professional raised concerns	2

Table 3. Percentage of professionals seen at first consultation and subsequent referrals (N=228)

Professional seen	First consultation (n=228)	First referral (n=213)	Second referral (n=132)	Third referral (n=58)
GP	43	_	_	_
Health visitor	11	3	2	2
Paediatrician	8	55	36	53
Nurse	3	_	_	_
Teacher	17	1	1	2
Occupational therapist	6	18	39	29
Physiotherapist	.4	4	5	3
Educational Psychologist	5	6	7	2
Clinical psychologist	_	1	_	2
Speech/language therapist	–	5	3	2
Social worker	.4	_	_	_
Child psychiatrist	_	.5	1	_
Neurologist	_	.9	2	5
Other [a]	6	5	5	_

[a] Parents commonly mentioned orthopedic specialists, dyslexia tutors, audiologists, optometrists

Table 4. Outcomes at first consultation and subsequent referrals (%)

What happened	First consultation (n=228)	First referral (n=213)	Second referral (n=132)	Third referral (n=58)
Diagnosis made	7	38	55	55
Referred to another professional	73	40	25	17
Sent for tests	2	8	6	21
Told no problem or not to worry	15	6	5	–
Told to return if problems did not improve	3	5	3	–
Other[a]	3	3	6	7

[a]Other includes being given a different diagnosis, offered therapy, given general advice (e.g. exercises to practice at home)

Table 5. Type of post-diagnostic help/support offered (N=228)

Type of service	% of parents that were offered the service (categories not mutually exclusive)
Occupational therapy	40
Physiotherapy	18
Explanation of child's problems	17
General advice on management	12
Speech and language therapy	10
Help with pre/school provision	9
Statement of Special Educational Needs (SEN)	7
Contact with a DCD/Dyspraxia Support Group/Society	6
Contact with other parents	3
Help with accessing monetary benefits from the Government	2
Perceptual motor training	2
Practical management (portage)	2
Personal support/counselling	1
Other[a]	10

[a] Other includes sensory therapy, information about physical play programmes, handwriting exercises

Table 6. Satisfaction scores in relation to different aspects of the diagnostic process (n=228)

	Very dissatisfied (%)	Quite dissatisfied (%)	Neither satisfied nor dissatisfied (%)	Quite satisfied (%)	Very satisfied (%)
Overall diagnostic process	26	19	16	23	16
Information given at diagnosis	15	20	14	34	18
Manner of the diagnosing professional	10	10	13.	36	31
Post-diagnostic support	30	29	14	21	6

Table 7. Results of multiple regression analysis of variables hypothesised to predict overall satisfaction with the diagnostic process

Predictor Variable	b	SE b	β	*p*	*sr*	sr^2
Child's age when help was sought	.01	.03	.03	.62	.03	.06
Perceived knowledge of first professional seen	.12	.07	.10	.06	-.09	.01
Time taken to receive a diagnosis	-.07	.03	-.13	.03	-.11	.01
Satisfaction with information given at diagnosis	.06	.09	.06	.50	.03	.00
Satisfaction with the manner of the diagnosing professional	.28	.09	.24	.00	.16	.03
Satisfaction with post-diagnostic support	.25	.08	.22	.00	.16	.03
Stress of the diagnostic process	.42	.07	.38	.00	.32	0.10

b = unstandardised beta coefficient, SE b = standard error, β = standardised beta coefficient, *sr*= semipartial correlation coefficient, $sr^{2=}$ unique variance explained for each predictor

DV = overall satisfaction with the diagnostic process

Appendix Geographical spread of the respondents at start of the diagnostic process (N=226)

Location in the UK	**%**
East England	6
East Midlands	5
London	12
North East England	4
North West England	8
Northern Ireland	3
Scotland	8
South East England	21
South West England	11
Wales	3
West Midlands	8
Yorkshire and the Humber North	9