





## RESEARCH ARTICLE

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# The diagnostic trajectory of developmental coordination disorder in the Netherlands: Experiences of mothers

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## Abstract

**Background:** Receiving a diagnosis can have a major impact on the child and its family. Parental satisfaction concerning the diagnostic trajectory is important with regard to acceptance and coping with their child's problems. Our aim was to describe the diagnostic trajectory of developmental coordination disorder (DCD) in the Netherlands and identify factors that are related to parents' satisfaction.

**Method:** Mothers of 60 children with a DCD diagnosis completed an online survey concerning their experiences during and after the diagnostic trajectory of obtaining this diagnosis.

**Results:** Forty percent of the mothers rated the diagnostic trajectory towards a DCD diagnosis as stressful and 47% rated the knowledgeability of the first professional they consulted (mostly a general practitioner, paediatric physical therapist, or youth health care physician) as having no or just superficial knowledge about DCD. Around 60% of the mothers described a lack of knowledge and support at their child's school after receiving the diagnosis. Notwithstanding this, the majority of the participating mothers was (very) satisfied with the diagnostic trajectory. Higher appreciation of both the manner of the diagnosing professional and the post-diagnostic support provided were predictive of higher satisfaction.

**Conclusions:** Our results underline the importance of improving the knowledgeability in primary schools and primary health care professionals with regard to DCD.

## KEYWORDS

diagnostic process, diagnostic trajectory, maternal satisfaction, parents, developmental coordination disorder (DCD)

## 1 | INTRODUCTION

Research among parents of children being diagnosed with developmental coordination disorder (DCD) in the United Kingdom (UK) has shown a disturbingly low level of parental satisfaction with the diagnostic trajectory (Alonso Soriano et al., 2015). In addition, small-scale

studies have reported problems that parents experience with finding their way to and through health services following the first concerns about their child's motor development. (Ahern, 2000; Missiuna et al., 2006; Rodger & Mandich, 2005). The diagnostic trajectory of DCD has been described as long, inconsistent and frustrating for families (Ahern, 2000; Maciver et al., 2011; Missiuna et al., 2006;

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Rodger & Mandich, 2005; Wilson et al., 2013), while parental satisfaction concerning the diagnostic trajectory has been shown to be important with regard to acceptance and coping with their child's problems (Ahern, 2000; Goodwin et al., 2015; Howlin & Moore, 1997; Rentinck et al., 2009). The nature and duration of the diagnostic trajectory may differ between countries. The main aim of our study was to explore the experiences of parents in the Dutch diagnostic route, from the first concerns about their child to the moment that their child received the diagnosis of DCD. Also, we aimed to identify factors during this trajectory that are critically related to parents' satisfaction with the trajectory.

Research among parents of children with a confirmed DCD diagnosis by Alonso Soriano et al. (2015) revealed four factors that were predictive of parental satisfaction with the overall diagnostic trajectory in the United Kingdom: 1. the stress of the diagnostic trajectory; 2. the manner of the professional involved in the diagnosis; 3. satisfaction with post-diagnostic support; and 4. the time taken to receive the diagnosis. In addition, research among parents of children with another developmental disorder, autism spectrum disorder (ASD) (Brogan & Knussen, 2003; Crane et al., 2016; Goin-Kochel et al., 2006; Howlin & Moore, 1997; Moh & Magiati, 2012; Siklos & Kerns, 2006a) showed that higher parental satisfaction was related to lower parental stress, higher perceived collaboration with professionals and higher perceived helpfulness of the professional while receiving information about the diagnosis. Also, the amount of perceived support was an important factor. Parental satisfaction was higher when professionals provided parents with ample opportunity to ask questions and listened to their expectations. Manner was also an important factor in the diagnostic trajectory of ASD. Specifically, if professionals showed good communicative skills and invested time to establish a collaborative relationship with the parents, and then parents were more likely to be satisfied. Finally, the duration of the diagnostic trajectory also affected the satisfaction of parents of children with ASD. That is, the longer the diagnostic trajectory, the lower the reported parental satisfaction. Moreover, parents tended to be more satisfied with the diagnostic trajectory if they consulted fewer professionals to obtain the diagnosis and if their child received the diagnosis at an early age (Brogan & Knussen, 2003; Crane et al., 2016; Goin-Kochel et al., 2006; Howlin & Moore, 1997; Moh & Magiati, 2012; Siklos & Kerns, 2006a). In sum, studies among parents of children with DCD specifically in the United Kingdom and studies among parents of children with ASD have revealed important factors in the diagnostic trajectory of DCD that may serve as avenues to increase parental satisfaction with this trajectory.

Until now, no systematic research has been performed that described the Dutch trajectory towards a diagnosis DCD from the parental point of view. Using an online survey we aimed to explore the trajectory of obtaining a DCD diagnosis in The Netherlands, from the first concerns about the child's motor development until the formal DCD diagnosis. In addition, we aimed to analyse whether factors that were identified in former studies (Ahern, 2000; Alonso Soriano et al., 2015; Brogan & Knussen, 2003; Crane et al., 2016; Goin-Kochel et al., 2006; Howlin & Moore, 1997; Maciver

### Key Messages

- In general, mothers of children with DCD are satisfied with the diagnostic trajectory in The Netherlands.
- Knowledge of DCD symptoms should be improved in primary health care professionals.
- The DCD diagnosis helped 86.7% of the parents in accepting their child's problems.
- Manner and post-diagnostic support predicted satisfaction.

et al., 2011; Missiuna et al., 2006; Rodger & Mandich, 2005; Siklos & Kerns, 2006b) were also related to the degree of parental satisfaction with the Dutch DCD trajectory. Following former studies (Ahern, 2000; Maciver et al., 2011; Missiuna et al., 2006; Rodger & Mandich, 2005), we hypothesized that parents would be generally unsatisfied with the diagnostic trajectory. Based on the study of Alonso Soriano et al. (2015) we hypothesized that experienced stress of the diagnostic trajectory, the manner of the diagnosing professional, satisfaction with post-diagnostic support, and the time taken to get a diagnosis would be important predictors for the overall satisfaction of parents with the diagnostic trajectory. In addition, the age at which the child was diagnosed was hypothesized to be an important predictor for parental satisfaction, based on studies among parents of children with ASD (Brogan & Knussen, 2003; Crane et al., 2016; Goin-Kochel et al., 2006; Howlin & Moore, 1997; Siklos & Kerns, 2006a). The results of the present study are important for health care professionals that are involved in the diagnostic trajectory of DCD and those working in primary care facilities as they may provide insights on how to improve care services for families.

## 2 | METHOD

### 2.1 | Participants

Information about the study was spread via the Dutch website for parents of children with DCD ([www.balansdigitaal.nl](http://www.balansdigitaal.nl)) and associated Twitter and Facebook groups, via the website of Dutch paediatric physical therapists (<http://nvfk.kngf.nl>), the Dutch multidisciplinary DCD taskforce ('landelijke stuurgroep DCD') and emails to rehabilitation centres. Parents that had participated in earlier studies from our group ([www.beweginginzicht.nl/en](http://www.beweginginzicht.nl/en)) also received the invitation.

The online survey was completed by 61 respondents (100% mothers, aged 28–56 years [ $M = 41.8$ ,  $SD = 5.83$ ]). Data from one respondent was excluded from the analyses as the diagnosis DCD of the child had not yet been established. The data from 60 surveys have been analysed.

The median of the time between obtaining the DCD diagnosis and completing the questionnaire was 2.8 years

(min-max .00–16.25 years). Ninety percent of the mothers had a Dutch Nationality (10% Belgian) and lived throughout The Netherlands (median of 6.7% [min–max: 1.7–21.7] of the participants from every county) when their child received the diagnosis. None of the mothers was ever diagnosed with DCD.

The children (83.3% boys) were on average 10.1 years old ( $SD = 3.78$ , min–max: 5–24 years, 96.6% was 18 years or younger) when the survey was completed. Four participants entered an invalid date of birth for their children. These were not included when calculating the average age of children in the sample.

The 53.3% of the children had more than one formal diagnosis (21.7% ASD, 26.7% Attention Deficit (Hyperactivity) Disorder (AD(H) D), 6.7% Dyslexia, 6.7% specific language or speech disorder, The 6.7% Dyscalculia, 3.4% Epilepsy). 60.0% of the children attended main stream education, 28.3% special education, the remaining 11.7% already finished school or was switching from main stream education to special education, or attended practical education of main stream education with personal support.

## 2.2 | Instruments

An online survey was developed based on the studies of Alonso Soriano et al. (2015), Brogan and Knussen (2003), Howlin and Moore (1997) and Siklos and Kerns (2006a) addressing different aspects of the diagnostic trajectory during three periods:

1. Pre-diagnostic period: from first concerns to the first consultation,
2. Diagnostic period: from first consultation to final diagnosis,
3. Post-diagnostic period: from receiving the diagnosis until present.

Questions concerning background, (experiences during) the diagnostic trajectory and the period before and after the diagnostic trajectory were included.

### 2.2.1 | Background information

Sixteen closed questions to collect descriptive information about the child and parents/care takers.

### 2.2.2 | Pre-diagnostic period

Five questions referred to the period before the first consultation and aimed to identify the (nature of) the first concerns, when these were raised and who they were raised by.

### 2.2.3 | Diagnostic trajectory

Fourteen questions concerning the diagnostic trajectory, based on Alonso Soriano et al. (2015) were included. Parents were asked about the outcome of the first two consultations and their thoughts and feelings at the time when they received the diagnosis. Parents

indicated the extent to which they experienced certain specific feelings on a five-point Likert scale ranging from 1 (*not at all*) to 5 (*to a great extent*).

#### *Knowledgeability*

Parents were asked to rate the knowledgeability of the professional(s) they consulted, for three different occasions (first consultation, second consultation, receiving the DCD diagnosis) on a five-point Likert scale, ranging from 0 (*no opinion*) to 1 (*not at all knowledgeable*) to 4 (*very knowledgeable/expert*).

#### *Manner*

Parents were asked to rate the degree to which they experienced five aspects of manner (Table 7) of the diagnosing professional. The answers with regard to the professional being evasive were recoded such that a higher score represented a better manner (less evasive). The five items referring to the manner of the professional were analysed with Principle Component Analyse (PCA) with Varimax rotation (with Kaiser Normalization) to test if the answers to these questions could be summarized by one factor. One component had an Eigenvalue larger than 1 (3.37), explaining 67.39% of the variance. Factor loadings and group averages per item are displayed in Table 7. The component score for manner was calculated as the average of the five items.

#### *Stress*

Parents rated the amount of stress that they experienced during the diagnostic trajectory on a five-point rating scale ranging from 1 (*not stressful at all*) to 5 (*very stressful*).

#### *Satisfaction diagnostic trajectory*

Parents were asked to rate their degree of satisfaction with both the whole diagnostic trajectory and with six specific aspects of the diagnostic trajectory (Table 9) of the diagnostic trajectory on a five-point scale ranging from 1 (*very dissatisfied*) to 5 (*very satisfied*). A PCA with Varimax rotation (with Kaiser Normalization) was conducted to identify any components within this variable. One highly reliable (Cronbach's Alpha = .96) component with an Eigenvalue larger than 1 (5.55) could be extracted explaining 79.29% of the variance. Factor loadings and group averages per item are displayed in Table 9. The component score for satisfaction with the diagnostic trajectory was calculated as the average of the seven items.

### 2.2.4 | Post-diagnostic period

Eight questions referring to the post-diagnostic period were included in the survey, based on Brogan and Knussen (2003) and Siklos and Kerns (2006a). Which post-diagnostic support was received, what worried them most after receiving the diagnosis (open question), what helped them most after receiving the diagnosis (open question), current motor problems and the extent to which receiving the diagnosis helped them in accepting the problems of their child.

### Satisfaction post-diagnostic support

Parents were asked to rate their degree of satisfaction with the post-diagnostic support with regard to the motor problems of their child on a five-point scale ranging from 1 (*very dissatisfied*) to 5 (*very satisfied*).

### 2.2.5 | Support

Parents were asked to indicate which forms of support they received, in the period preceding the obtainment of the DCD diagnosis (*pre-diagnostic support*, Table 10) and the period after obtaining the DCD diagnosis (*post-diagnostic support*, Table 11). Parent could choose multiple forms of support.

## 2.3 | Procedure

The online survey was designed with Perseus Survey Solutions (Perseus Development Corporation). Informed consent was obtained from the participating parent/guardian. The study was approved by the local ethics committee of the Faculty of Social Sciences at (ECSW2016-0905-398). The Central Committee on Research Involving Human Subject confirmed that the Medical Research Involving Human Subjects Act (WMO) does not apply to the present study (Case number: 2016-2787).

The survey took 20–30 min to complete and was open from June 2016 to November 2016. The full survey contained 73 items. Jumps were build-in to skip irrelevant items for individual respondents.

## 2.4 | Analyses

The pathway from the first concerns to receiving the formal diagnosis was examined using frequency tables. The answers 'no opinion' or 'do not know' were defined as missing value in the statistical analyses.

The duration of individual diagnostic trajectories was estimated by calculating the difference between the age at which the child received the diagnosis and the age of the child at which the parents first consulted a professional for the child's motor problems. One data point (the age at which consultation took place was filled in as 0 years and 0 months), was considered invalid.

Spearman's rank correlations were calculated as a measure of the strength of the relationship between the factors and overall parental satisfaction, since these variables were measured using an ordinal scale.

Multiple regression was used to analyse the predictive value of the hypothesized variables Duration, Stress, Manner (component score), Satisfaction with post-diagnostic support and Age (months) when diagnosed for the reported satisfaction (component score) with the overall diagnostic trajectory.

Analyses were performed using the Statistical Package of Social Scientists (SPSS) with  $\alpha = .05$ .

## 3 | RESULTS

### 3.1 | Pre-diagnostic period

Forty-eight percent of the participating parents indicated that their initial concerns were solely related to the motor development of their child. The most frequently mentioned concerns concerned activities of daily living (like using cutlery) and school activities (like keeping up during gym class) (Table 1). First concerns with regard to activities of daily living were most frequently raised by parents, while concerns with regard to school activities were most often raised by teachers (Table 1).

Of the participating parents 52% indicated that their first concerns were not restricted to the motor development of their child. They were asked to indicate the nature of these concerns on a list of other areas of development. Sensory sensitivity and social development were most frequently chosen (Table 2).

**TABLE 1** Initial concerns related to the child's motor development ( $N = 60$ )

Initial concerns	%	Mean age (months) (SD) <sup>a</sup>	Concern first raised by (%)		
			Parents	Teacher	Other professional
Problems with activities of daily living	85	48(15.1)	84.3	9.8	5.9
Problems with motor activities at school	85	54(12.7)	27.5	70.6	2.0
Signs of impaired motor coordination	70	45(18.6)	61.9	19.0	19.0
Poor balance	62	35(18.1)	75.7	13.5	10.8
Problems with spatial awareness	53	40(19.5)	87.5	0.0	12.5
Lack of speech fluency	33	20(15.9)	75.0	10.0	15.0
Delays in achieving developmental motor milestones	33	32(9.7)	70.0	15.0	15.0
Trouble picking up and holding objects	27	28(17.0)	87.5	6.3	6.3
Problems with sucking, chewing, and/or swallowing foods	23	8.9(14.4)	78.6	0.0	21.4
Other	8.3		80.0	20.0	0.0

<sup>a</sup>Age of the child (SD), when the specific concern was raised, in months.

## 3.2 | Diagnostic trajectory

### 3.2.1 | First consultation

The average age at which parents sought professional help for the motor problems of their child was 52 months ( $n = 59$ ,  $SD = 28.1$ ,  $min-max$ : 2 months –118 months). By the age of 3 years 25% of the

**TABLE 2** Initial concerns in relation to other (non-motor) areas of development ( $n = 31$ )

Areas of development	%
Sensory (over/under)sensitivity	67.7
Social development	51.6
Dislike of change	48.4
Behaviour problems	41.9
Other	38.7
Delay in starting to talk	29.0
Learning problems	29.0
Sleeping problems	29.0
Medical problems	22.6
Excessive fatigue	16.1
Listlessness	9.7

parents had consulted a professional. One third of the parents ( $n = 20$ ) indicated that they sought professional help when their child was 4 years of age (48–60 months). At the age of 6 years 80% of the parents had had a first professional consultation (Table 3).

Approximately half of the participating mothers rated the knowledge of the professional concerning DCD as sufficient or expert (Table 4). On the other hand, 43.3% of the parents rated this knowledge as less than sufficient.

The majority of the children (88.3%) was not diagnosed after the first consultation, 35.0% was referred to another health care professional and 20.0% was directly referred for further research and tests, 15.0% of the parents were told not to worry about the problems of their child (Table 5).

### 3.2.2 | Second consultation

The 53 (88.3%) parents whose first consultation did not result in a DCD diagnosis of their child went on to consult a second professional (Table 3). The paediatric physical therapist was mentioned most frequently (22.6%). The professional's knowledge about DCD was rated as sufficient or expert in a little more than half of the cases (Table 4). On the other hand, 33.9% of the mothers rated the professional's knowledge as insufficient. The diagnosis DCD was the outcome of 17% of the second consultations (Table 5).

**TABLE 3** Percentage (%) of respondents that reported seeing a specific professional at first consultation and subsequent referrals

Professional	First consultation ( $n = 60$ )	Second consultation ( $n = 53$ )	Diagnosed by ( $n = 60$ )
Paediatric physical therapist	43.3	22.6	–
General practitioner	20.0	9.4	–
Occupational therapist	1.7	7.5	–
Youth health care physician	13.3	1.9	–
Paediatrician	8.3	17.0	10.0
Paediatric physician	5.0	18.9	73.3 <sup>a</sup>
(child)neurologist	3.3	3.8	8.3
Speech and language therapist	1.7	–	–
(child)psychiatrist	–	1.9	5.0
Psychologist/special education generalist	–	1.9	1.7
Other	3.3 <sup>b</sup>	15.1 <sup>c</sup>	1.7 <sup>d</sup>

<sup>a</sup>Including being diagnosed by national multidisciplinary teams, as these are known to include a Paediatric physician.

<sup>b</sup>Including national multidisciplinary teams ( $n = 3$ ).

<sup>c</sup>Special Education needs assistant in the school, multidisciplinary team, ear-nose-throat specialist, sensory motor integration therapist, specialized developmental coordination disorder (DCD) team and eurhythm therapist.

<sup>d</sup>Unspecified private practice.

**TABLE 4** Rated knowledgeability (%) of the successively consulted professionals

Knowledgeability of ...	Knowledgeability (%)				
	No opinion	Not at all	Superficial	Sufficient	Expert
The professional during your first consultation ( $N = 60$ )	10.0	23.3	20.0	30.0	16.7
The professional during your second consultation ( $N = 53$ )	11.3	9.4	24.5	26.4	28.3
The diagnosing professional ( $N = 60$ )	0	0	5.0	20.0	75.0

### 3.2.3 | Final diagnosis

The average age at which the children in the present sample received the DCD diagnosis was 84.3 months ( $SD = 21.51$ ,  $min-max$ : 36.00–130.00). The period between the first consultation of a professional with regard to the motor problems of the child and receiving a DCD diagnosis lasted on average 33.5 months ( $SD = 25.61$ ). Of the 60 participating mothers 45% indicated to have seen four or more health care professionals before obtaining the DCD diagnosis. In addition, 11.7% saw one professional, 25% saw two and 18.3% saw three health care professionals.

In 73.3% of the cases the diagnosis was made by a paediatric physician (Table 3). The level of knowledge of the diagnosing professional was labelled as ‘expert’ by 75%, as ‘sufficient’ by 20% and as ‘superficial’ by 5% of the mothers. Importantly, not one mother

**TABLE 5** Outcomes of the first and second consultation (%)

Outcome	First consultation ( $n = 60$ )	Second consultation ( $n = 53$ )
Referred to other health care professional	35.0	20.8
Referred for further research and tests	20.0	24.5
Told not to worry	15.0	9.4
Diagnosis DCD	11.7	17.0
Taking further steps on own initiative	11.7	9.4
Diagnosis other than DCD	3.3	7.5
Told to return if the problems did not resolve themselves	3.3	5.7
Other	10.0 <sup>a</sup>	15.1 <sup>b</sup>

<sup>a</sup>Start of therapy ( $n = 5$ ), motor performance was described lying ahead compared to peers ( $n = 1$ ).

<sup>b</sup>Told there was a psychological cause for the motor problems ( $n = 1$ ), (suggested to) start therapy ( $n = 3$ ), further testing ( $n = 1$ ), probably developmental coordination disorder (DCD) but wait until child reaches 5 years of age ( $n = 1$ ), referred to early detection team at the age of 1 years and 11 months ( $n = 1$ ).

**TABLE 6** Percentage (%) of respondents that reported experiencing several feelings to a certain extent when their child received the DCD diagnosis ( $N = 60$ )

Feelings	Not at all (%)	Barely (%)	To some extend (%)	To a high extend (%)	To a very high extend (%)
I felt sympathy for the problems of my child	1.7	1.7	18.3	31.7	46.7
I felt relief	5.0	10.0	25.0	31.7	28.3
I felt hopeful for the future	15.0	18.3	38.3	25.0	3.3
I felt helplessness	36.7	35.0	16.7	5.0	6.7
I felt anger	61.7	18.3	10.0	8.3	1.7
I felt tension	35.0	23.3	33.3	8.3	0.0
I felt fear	43.3	15.0	33.3	8.3	0.0

rated the knowledgeability of the diagnosing professional as insufficient.

Relief (60%) and sympathy (78%) were experienced to a high degree when receiving the DCD diagnosis (Table 6). Negative feelings like fear, anger and tension were experienced less. The extent to which mothers reported the feelings relief ( $r_s = .16$ ,  $p = .245$ ), hope ( $r_s = -.10$ ,  $p = .464$ ), helplessness ( $r_s = -.04$ ,  $p = .797$ ), anger ( $r_s = .14$ ,  $p = .289$ ), tension ( $r_s = -.19$ ,  $p = .150$ ) and fear ( $r_s = .04$ ,  $p = .793$ ) was not related to the duration of the diagnosis. On the other hand, the duration of the diagnostic trajectory was negatively related to the experience of feelings of understanding towards the problems of the child,  $r_s = -.30$ ,  $p = .025$ .

### 3.2.4 | Manner

The majority of the mothers indicated that they experienced the diagnosing professional as sympathetic, understanding, communicatively skilled, not evasive and approachable for questions to a (very) high extent (Table 7).

### 3.2.5 | Stress

The diagnostic trajectory was rated as stressful (31.7%) or very stressful (8.3%) in 40% of the cases, whereas 35% of the mothers rated the trajectory as not (at all) stressful ( $M = 3.0$ ,  $SD = 1.19$ ). The parents of 37 children described what they found most stressful during the diagnostic trajectory (Table 8). The answers of the five mothers that rated the diagnostic trajectory as ‘very stressful’ were ‘uncertainty’, ‘driving back and forth to the hospital continually’, ‘the lack of an explanation and feedback of how things go’, ‘leaving you clueless about the “how’s” and “why’s”’ and ‘seeing many different therapists, without us knowing how this was necessary given the motor problems of our child’.

### 3.2.6 | Satisfaction

Seventy-five percent of the mothers was (very) satisfied, whereas 13.3% was (very) dissatisfied (Table 9). Mothers were particularly



**TABLE 7** Ratings of respondents (%) that indicated experiencing several aspects of manner to a certain extent, group means (SD) and factor loadings per item ( $N = 60$ )

Manner	Not at all %	Barely %	To some extent %	To a high extent %	To a very high extent %	Mean (SD)
Sympathetic	3.3	3.3	15.0	48.3	30.0	3.51 (.82)
Understanding	1.7	5.0	11.7	53.3	28.3	3.59 (.75)
Communicative	1.7	5.0	15.0	51.7	21.7	3.54 (.76)
Evasive	68.3	15.0	10.0	6.7	0.0	4.38 (.75)
Approachable for questions	3.3	6.7	21.7	43.3	25.0	3.36 (.87)

Note: Extraction Method: Principal Component Analysis.

**TABLE 8** Summary and percentage (%) of the answers to 'What was the most stressful to you' ( $n = 37$ )

	%
Feeling unsure, powerlessness and unheard	29.7
Practical issues (transport, combination with job)	16.2
Burdening of the child	10.8
Awaiting the results/diagnosis	10.8
Lack of understanding at school	8.1
No information on the reason for the different assessments	8.1
Long waiting period	5.4
Attitude of the professional	5.4
Social emotional problems of the child	2.7
Finding out what DCD meant	2.7

satisfied with the understandability of the provided information, the opportunity to ask questions, answering of raised questions, feedback of test results and the extent to which mothers were listened to and felt heard.

### 3.3 | Post-diagnostic period

The majority of mothers were satisfied (41.7%) or very satisfied (25.0%) with the received post-diagnostic support ( $M$  ( $SD$ ) = 3.72 (1.11)). Receiving the DCD diagnosis helped 86.7% of the parents to a (very) high extent in accepting the problems of their child. On the other hand, 13.3% of the mothers reported that receiving the diagnostic barely helped them or not helped them at all in this acceptance. There was a positive correlation between the extent to which receiving the diagnosis helped in accepting the problems of the child and the overall satisfaction about the diagnostic trajectory, ( $r_s = .30$ ,  $p = .022$ ).

Parents were asked about what they were worried about most after receiving the DCD diagnosis. Problems with regard to education and school skills were reported in 33.3% of the cases, 26.7% reported worrying about the future of their child in general, 5% reported financial worries and 10% reported other worries. On the other hand, 16.7% of the 60 participation mothers indicated not to have had any worries after receiving the diagnosis.

A slight majority of the mothers (58.3%) indicated that the motor problems of their child did not decrease since he/she received the diagnosis. The remaining mothers indicated that the motor problems were reduced during this period.

Fifty-eight mothers described their current needs. While 53.5% indicated to have no needs, 22.1% described a need for information about the disorder, the best help, the future and co-morbid problems (attention, concentration, social-emotional problems). More than half (61.5%) of these mothers described a lack of knowledge and support in school. A need to have contact with other parents that have a child with DCD was reported by 8.5% of the mothers. Two mothers were in need of support for their child during adulthood.

### 3.4 | Support

#### *Pre-diagnostic support*

The majority of parents received pre-diagnostic support by their health care professional (Table 10). A minority was put into contact with other parents of children with DCD during the pre-diagnostic period.

#### *Post-diagnostic support*

The vast majority of the parents received support aimed at giving information about the problems of the child, treatment of the child or supporting the child in daily life (Table 11). Aspects that were more directly focused on providing *parental* support (parental guidance, financial support, contact with other parents or a support group) were provided to the minority of the parents following the DCD diagnosis.

### 3.5 | Predictors of satisfaction

The assumptions of linearity, homoscedasticity, independence of errors (Durbin-Watson test = 1.98), and normality of residuals, were met. No cases were identified as multivariate outliers. The regression model including all variables that were hypothesized to be predictive for average maternal satisfaction with the diagnostic trajectory; Stress, Manner (components score [Table 7;  $M = 4.0$ ,  $SD = .73$ ]), Duration, Age when diagnosed (months) and Satisfaction with post-diagnostic support resulted in a significant model,  $F(5,56) = 35.92$ ,

**TABLE 9** Ratings of satisfaction (%) with (several parts of) the diagnostic trajectory towards obtaining the DCD diagnosis ( $N = 60$ ), group means (SD) and factor loadings per item

	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	Mean (SD)	Loading
Overall diagnostic process	5.0	8.3	11.7	45.0	30.0	3.87 (1.10)	.88
Understandability of the provided information	3.3	6.7	8.3	55.0	26.7	3.95 (.96)	.88
Amount of information provided	6.7	6.7	16.7	48.3	21.7	3.72 (1.09)	.85
Opportunity to ask questions	1.7	8.3	10.0	51.7	28.3	3.97 (.94)	.89
Answering of raised questions	1.7	6.7	15.0	46.7	30.0	3.97 (.94)	.93
Begin listened to and feeling heard	6.7	3.3	15.0	45.0	30.0	3.88 (1.10)	.94
Feedback of test results	5.0	6.7	13.3	40.0	35.0	3.93 (1.10)	.86

Note: Extraction Method: Principal Component Analysis.

**TABLE 10** Percentages (%) of respondents that received the different kinds of pre-diagnostic support ( $N = 60$ )

Pre-diagnostic support provided	%
I was provided with the opportunity to ask questions	91.7
The problems of my child were explained to me	86.7
I was provided the opportunity to have a follow-up appointment with the same professional	85.0
I was provided with a written report	80.0
I was explained were to go for help or support	75.0
I was put into contact with other parents of children with DCD	18.3

$R^2 = .78$ ,  $p < .001$  (Table 12). The more positive mothers were about the manner of the diagnosing professional and the post-diagnostic support provided, the higher the parental satisfaction with the overall diagnostic trajectory. There was a trend for a negative relation between the duration of the diagnostic trajectory and maternal satisfaction. The amount of stress mothers experienced during the trajectory and the age of the child at time of the formal diagnosis were not related to overall satisfaction.

## 4 | DISCUSSION

The aims of the present study were to provide an overview of the trajectory of obtaining a DCD diagnosis in The Netherlands, to measure parental satisfaction with this trajectory and identify predictors of this satisfaction. Mothers of 60 children diagnosed with DCD participated in an online survey concerning their experiences from the first concerns about their child's motor abilities up until their present needs. Only mothers filled in the survey. The vast majority of them was (very) satisfied with the diagnostic trajectory. Notwithstanding this, 40% rated the diagnostic trajectory as stressful. In line with the expectation, higher appreciation of both the manner of the diagnosing professional and the post-diagnostic support provided were predictive of higher satisfaction with the diagnostic trajectory towards a DCD diagnosis.

**TABLE 11** Percentages (%) of respondents that received the different kinds of post-diagnostic support ( $N = 60$ )

Kind of post-diagnostic support received by parents	%
I was provided with a written report	95.0
My child received treatment	93.3
I was provided with the opportunity to ask questions	88.3
The problems of my child were explained to me	86.7
I was provided the opportunity to have a follow-up appointment with the same professional	83.3
I was explained were to go for help or support	76.7
I got help in getting support in school	73.3
My child was referred to special education	30.0
I received parental guidance from a health care professional	28.3
I received financial support from the government	25.0
I was brought into contact with other parents of a child with DCD	23.3
I was brought into contact with a parental support group	23.3

Similar to the United Kingdom (Alonso Soriano et al., 2015), the average duration of the diagnostic trajectory was almost 3 years. Sixty-three percent consulted more than two professionals during that period and the average age at which children received the DCD diagnosis was approximately 7 years. Although the majority of the mothers (75%) retrospectively indicate to be generally satisfied with the overall diagnostic trajectory, the duration of the trajectory can be considered undesirably long. The answers to questions that map the specific experiences and feelings during the diagnostic trajectory provide avenues to improve care service for children with DCD.

The nature of the initial concerns reported by Dutch mothers is similar to those reported by parents in the United Kingdom (Alonso Soriano et al., 2015). Also comparable to other studies, these initial concerns are raised early in development (Alonso Soriano et al., 2015; Missiuna et al., 2007; Rodger & Mandich, 2005). The average age of the child at which parents seek help for these initial concerns is a little more than 4 years. This is around the time when Dutch children first attend primary school. Upon entering school, motor problems become more visible (Rodger & Mandich, 2005). By the age of 6 years, when



**TABLE 12** Multiple regression results with the hypothesized predictor variables and overall satisfaction with the overall diagnostic trajectory as the dependent variable ( $n = 56$ )

	Overall satisfaction					95% CI upper bound	95% lower bound	Zero-order correlation
	b	SE(b)	Bèta	t	p			
Duration	-.004	.002	-.119	-1.722	.091	-.009	.001	-.272
Stress	-.091	-.05	-.114	-1.550	.127	-.209	.027	-.410
Manner	.585	.096	.471	6.124	<.001	.394	.777	.736
Satisfaction with post-diagnostic support	.396	.062	.478	6.366	<.001	.271	.521	.738
Age child when diagnosed	.000	.003	-.006	-.088	.930	-.007	.006	-.104

children start to read and write, 80% of the parents has consulted a professional. However, the initial concerns with regard to the motor problems were visible to parents way before the age of five. Although the natural individual variability in motor development speaks against diagnosing DCD before the age of five (Blank et al., 2019), it seems advisable to invest in tools with which preschool motor performance can be followed. This may help in establishing the early onset of DCD symptoms (DSM criterion C) during the diagnostic trajectory. In addition to motor problems, mothers reported several other areas of initial concerns, such as social problems, behavioural problems and learning problems. This stresses the need to record difficulties in other developmental areas as part of history taking during assessment, as was also recommended in the Clinical Practice Guideline for DCD (Blank et al., 2019) and is congruent with the International Classification of Functioning (ICF) Disability and Health (World Health Organization, 2007) and other research showing the importance of focusing on activities and participation during intervention in addition to addressing the motor difficulties (Maciver et al., 2011; Segal et al., 2002).

In line with the Dutch health care system (Nederlandse Vereniging van Revalidatieartsen, 2019) parents generally first consulted their general practitioner, paediatric physical therapist, or youth health care physician following the initial concerns about the motor development of their child. Forty-seven percent of the mothers rated the knowledgeability of the first professional they consulted as having no or just superficial knowledge about DCD. Also 30% of the currently diagnosed children was not diagnosed nor referred for further assessment after their first consultation. In line with Maciver (Maciver et al., 2011), this indicates the need to develop the expertise of professionals in primary care about DCD symptoms in order to facilitate early recognition.

The knowledgeability of the diagnosing professional was rated as at least sufficient by 95%. Not one mother rated the diagnosing professionals' knowledge as being insufficient. This high rated knowledgeability could be the result of the Dutch DCD guideline that was released in 2013 ([https://richtlijnen database.nl/richtlijn/developmental\\_coordination\\_disorder\\_dcd/startpagina\\_-\\_developmental\\_coordination\\_disorder\\_dcd.html](https://richtlijnen database.nl/richtlijn/developmental_coordination_disorder_dcd/startpagina_-_developmental_coordination_disorder_dcd.html)) based on the international EACD guideline (Blank et al., 2011) stating that only trained professionals with enough knowledge and experience with DCD are allowed to

diagnose DCD. In line with the expectation, higher appreciation of both the manner of the diagnosing professional and the post-diagnostic support provided were predictive of higher maternal satisfaction with the diagnostic trajectory towards a DCD diagnosis. The reported high rates of satisfaction with the overall diagnostic trajectory may reflect the high degree of satisfaction with the diagnosing professional.

As predicted, satisfaction with the provided post-diagnostic support was predictive of satisfaction with the overall diagnostic trajectory. Eighty-seven percent of the mothers reported that receiving the diagnosis was helpful in accepting their child's problems, particularly positive feelings of relief (60%) and acceptance (78%) were being reported. This is in line with other studies that showed that parents' satisfaction with the diagnostic trajectory was important with regard to acceptance and coping with their child's problems (Goodwin et al., 2015; Howlin & Moore, 1997; Rentinck et al., 2009) and may be an epiphenomenon of the formal acknowledgement of their child's motor problems. With regard to the provision of post-diagnostic support it is somewhat striking that only a small part of the post-diagnostic support is aimed at providing parental support in the form of parental guidance, being brought into contact with other parents and/or support groups. Peer support may empower parents in supporting their child (Shilling et al., 2013). As around 60% of the mothers describe a lack of knowledge and support at their child's school, the experiences of others may empower parents in asking for the necessary support. Also, it is important to inform (primary) schools (teachers). Educated occupational therapists and paediatric physical therapists may play a role in this as they are often involved with the child's school (Maciver et al., 2011; Stephenson et al., 1991) and may play a role in supporting the child's participation, also in other areas like sports clubs (Adams et al., 2018; Barnett et al., 2013).

The present study has some important limitations. First, it is unclear if professionals from a multidisciplinary team were counted individually as the option of consulting a multidisciplinary team was not included as an answer category in the survey. Twenty percent of the mothers indicated that they were referred for further testing after which they returned to the same professional. This may be indicative of being seen by a multidisciplinary team. Second, the current percentage that was unfairly send home and told not to worry is hard to interpret. It is unclear how many were justly told not to worry about

their child's motor development since the current study focused on parental satisfaction of parents of children with a formal DCD diagnosis. Experiences from parents who started a diagnostic trajectory that did not result in a formal DCD diagnosis remain unknown. Given that the duration of the trajectory takes approximately 3 years, it may well be that parents (and thus children) dropped out. The recently published Dutch DCD clinical practice guideline (Nederlandse Vereniging van Revalidatieartsen, 2019), based on the DSM-5 criteria (American Psychiatric Association, 2013) and the renewed international EACD recommendations (Blank et al., 2019) for DCD, will contribute to further standardize terminology, diagnostics and intervention for children (suspected of) DCD among professionals in The Netherlands and can be expected to contribute to the shortening of the diagnostic trajectory. However, reasons for the length of the diagnostic trajectory were not directly examined in the current study. It might be due to factors related to the healthcare organization and practitioners but it might also be that parents did not follow through immediately after the first or second consultation. Future research may address this issue. A third limitation concerns the representativeness of the sample. Like in other studies (Alonso Soriano et al., 2015; Crane et al., 2016), the current sample lacks ethnic diversity. Parents with (for example) Dutch as a second language may have more problems in understanding the information provided by the professional and this might influence their satisfaction with the diagnostic trajectory. Future research should aim to include parents with a migration background. The current study represents the experiences as reported by mothers. Receiving a diagnosis for one's child also affects fathers. Their subjective experiences and needs during and after the diagnostic trajectory may be different from that of the mothers (Jackson & Andipatin, 2019). As such, it is advisable to stimulate parents to fill in the survey together. Nevertheless, the current sample of 60 children originates from all over The Netherlands, contains the predictable male majority, shows initial concerns that are similar to those reported by parents in the United Kingdom (Alonso Soriano et al., 2015) and is large enough to identify meaningful statistical relationships. Lastly, the current set of predictors accounted for a significant (78%) amount of, but not all variance in the satisfaction data. Future research may seek to identify additional important factors that predict the satisfaction of parents.

To conclude, this is the first study that describes the diagnostic trajectory towards a DCD diagnosis in The Netherlands. In line with studies in other countries, the Dutch trajectory is long. Nevertheless, the far majority of the mothers was (very) satisfied with the diagnostic trajectory. In line with other studies, a diagnosing professional that is perceived as sympathetic, understandable, communicative, not evasive and approachable for questions and the provision of post-diagnostic support are important factors in this regard. Our study provides important avenues to improve the trajectory of parents from first concerns to receiving the DCD diagnosis for their child and the period thereafter. First, improve the knowledgeability of teachers and support coordinators in primary schools and primary health care professionals (like general practitioners) with regard to DCD. Second, stimulate monitoring of early motor development following first

concerns. Third, record difficulties in other developmental areas (such as social development) as part of history taking during assessment and incorporate them in intervention programmes. And fourth, empower parents by informing them about the existence and merits of support groups when their child is diagnosed. Future research should examine the extent to which parents received specific health care services for their child after being diagnosed. This in order to get an objective picture of the processes of care for children with DCD and identify factors that have been most helpful in supporting the child and empowering its parents.

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#### CONFLICT OF INTEREST

The authors did not receive support from any organization for the submitted work. The authors have no conflicts of interest to declare that are relevant to the content of this article.

#### ETHICAL STATEMENT

This study was performed in line with the principles of the Declaration of Helsinki. The study was approved by the local ethics committee of the Faculty of Social Sciences at Radboud University (ECSW) (ECSW2016-0905-398). The Central Committee on Research Involving Human Subject confirmed that the Medical Research Involving Human Subjects Act (WMO) does not apply to the present study (Case number: 2016-2787).

#### CONSENT TO PARTICIPATE

Informed consent was obtained from all individual participants included in the study.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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