The perceptions and concerns of parents who have a child with Developmental Coordination Disorder

Brigid Hitchcock

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Department of Occupational Science and Therapy
School of Clinical Sciences
Faculty of Health and Environmental Science

Primary Supervisor: Clare Hocking
Secondary Supervisor: Margaret Jones

ABSTRACT

This qualitative descriptive study aimed to explore the perceptions and concerns of parents who have a child with Developmental Coordination Disorder (DCD). DCD is a neuro-developmental disorder in which a child's motor skills are delayed. This can have an adverse impact on their activities of daily living, academic achievement and mental health. DCD impacts approximately 5-6% of children attending school and affects both the individual and their family. Although there are multiple studies on the disorder and its consequences for the individual, little is known about the perceptions of parents who have a child with DCD, particularly within a New Zealand context.

The study investigated the question: "What are parents' perceptions and concerns when raising a child with DCD?" and in doing so explored how parents came to know their child had coordination difficulties, the impact this disorder had on their child and family, as well as what strategies were implemented and actions taken to support their child. The child's participation in occupations (home, school and extra-mural) and how these were influenced by DCD was central to this research.

Interpretive description methodology was used and in keeping with this approach, participants were recruited through purposive sampling via the Dyspraxia Support Group of New Zealand. The nine participants, all women, selected to participate met the inclusion criteria of being a parent of a child, aged 5-12 years who had a formal diagnosis of DCD. Some of the children had additional diagnoses of ADHD and/or dyslexia, these are common comorbidities. Data were gathered using in-depth, semi-structured, telephonic interviews. The interviews were audio-taped and full text transcripts produced for analysis. In-depth reading of transcripts and coding of meaningful units were used to identify emergent themes.

The findings of this study suggest that parents were aware from when their child was young, that they were different. These differences initially related to a delay in motor skills but later impacted significantly on the child's academic achievement as well as their social and emotional wellbeing. Due to the perceived lack of knowledge of the disorder amongst professionals, participants reported that they worked hard to advocate for their child so that their needs could be understood and addressed. Parents faced challenges in both the health care and education sectors. The findings of the study were in keeping with those of international studies, which emphasise the struggle these children have with everyday self-care and academic tasks and the fact they participate less in physical and social activities than their typically developing peers. Secondary effects of DCD such as low self-esteem, anxiety and depression were also common amongst this group of children and this gives strength to the argument that children with DCD do require support.

The implications of the study for parents are that their concerns are acknowledged and that the actions they took to support their children are shared by other mothers. For professionals dealing with these children, in healthcare and education, there is the need to be the aware that both parents and children are looking for understanding and support and thirdly, for researchers there is the call for further research into DCD, particularly looking at guidelines for identification and interventions which align with parents' concerns. It is hoped that these findings can help expand the knowledge base regarding the impact of DCD and from there create a better understanding of the needs of these children to help mitigate harm, such as restricted participation in occupations, social isolation and depression, particularly within a New Zealand context.

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ATTESTATION OF AUTHORSHIP

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed:

Brigid Hitchcock

Date: 18 October 2019

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CHAPTER 1

Introduction

Introduction to the Study

This qualitative descriptive study explores the perceptions and concerns of nine parents with a child who has a diagnosis of Developmental Coordination Disorder (DCD), aged between 5-12 years. The following research question was asked; "What are parents' perceptions and concerns when raising a child with DCD?" The study sits in the context of the literature relating to child development, developmental coordination disorder and children's participation in occupations.

The aim of the study is to generate knowledge and understanding about the perceived difficulties and needs of a child with DCD, particularly in a New Zealand (NZ) context. It is hoped that this research will build on previous knowledge gained internationally and give insights into its applicability in this country. The findings are intended to be used by parents when developing strategies to support their child, by service providers (healthcare and education) to gain a deeper understanding and therefore greater ability to address the needs of these children and by researchers studying DCD, its impact and management. The literature supports the idea that there is much to be learnt from investigating parents' perceptions and concerns when raising a child with DCD and although some work has been done in this area internationally (Maciver et al., 2011; Missiuna, Moll, King, King, & Law, 2007) there appear to be no similar qualitative studies performed in New Zealand.

An interpretive description (ID) methodology was used for this study as it was well suited to gain an in-depth understanding of participants' perceptions (Thorne, 2016). Qualitative descriptive research, as described by Sally Thorne (2016), "draws on the full spectrum of factual material and social construction to build meaningful and relevant understanding of the ideas that are of central importance" (p. 11).

Participants were recruited with the assistance of the Dyspraxia Support Group of New Zealand by purposive sampling. They were interviewed in order to gain their understanding of the condition, the impact it has had on their child and family, and what they and others might do to help children with DCD participate in age appropriate occupations. The parents' perspective is important as they have the responsibility of promoting their child's development, managing their day-to-day occupations, being the interface between the child and the health and education services, as well as being their advocate. The occupations children participated in were the focus of this study and the parents' perspectives of these were obtained. Parents are well positioned to add to the knowledge of this phenomena in that they have in-depth knowledge of their child and his or her development (Jasmin, Tétreault, Larivière, & Joly, 2018). It is acknowledged that the child's perspective of these same occupations may be different. Data collected were audio-taped and transcribed. Analysis of this data was done through in-depth reading, coding into meaningful units and then themes were formed across all nine transcripts. These methods are in keeping with the ID methodology. The findings were then discussed in terms of what is known in the literature.

As an occupational therapist by profession, I am writing within that profession's theoretical framework which views occupation and occupational performance as central to human development and wellbeing. Occupation is seen to meet people's basic needs,

promote health, make life meaningful and engage people with others (Whiteford, Townsend, & Hocking, 2000).

In this chapter I will give definitions of key concepts, explain the rationale behind the study and elaborate on its context, both within New Zealand and internationally. I will also explain my position as an occupational therapy researcher of this subject and provide an overview of the methodology and structure of this thesis.

Defining Key Concepts

Developmental Coordination Disorder (DCD)

A significant review of 319 publications between 1995 and 2005, as regard to the terminology used in DCD research, was performed by Magalhães, Missiuna, and Wong (2006). They reported that more than 9 terms were used define DCD in several countries and across a number of disciplines including medicine, education and psychology (Farmer, Echenne, & Bentourkia, 2016). This has led to confusion over the years. Even though there has been international agreement that the term DCD is preferable (H. Polatajko, Fox, & Missiuna, 1995; Zwicker, Missiuna, Harris, & Boyd, 2012) the term dyspraxia is still widely used, especially within New Zealand (Eggleston, Hanger, Frampton, & Watkins, 2012). Hence, the terms DCD and dyspraxia were used interchangeably throughout this study. This is in alignment with Gibbs, Appleton, and Appleton (2007) who stated that DCD and dyspraxia should be regarded as "synonymous", however, that it would be helpful to "adopt a single term when describing these children to avoid confusion" and that preference should be given to DCD (p. 3).

A child is considered to have DCD if they lack the motor coordination required to perform tasks that are appropriate for their intellectual ability and in the absence of other

neurological disorders (Missiuna, Gaines, Soucie, & McLean, 2006). The most widely accepted definition of DCD is that described by the DSM-5 Diagnostic criteria:

A.   "The acquisition and execution of coordinated motor skills is substantially below that expected given the individual's chronological age and opportunity for skill learning and use. Difficulties are manifested as 'clumsiness' (e.g., dropping or bumping into objects) as well as slowness and inaccuracy of performance of motor skills (e.g., catching an object, using scissors or cutlery, handwriting, riding a bike, or participating in sports).

B.   The motor skills deficit in criterion A significantly and persistently interferes with activities of daily living appropriate to chronological age (e.g., self-care and self-maintenance) and impacts academic/school productivity, prevocational and vocational activities, leisure and play.

C.   Onset of symptoms is in the early developmental period.

D.   The motor skills deficits are not better explained by intellectual disability (intellectual developmental disorder) or visual impairment and are not attributable to a neurological condition affecting movement (e.g., cerebral palsy, muscular dystrophy, degenerative disorder)" (American Psychiatric Association, 2013. p.74).

The classification allows for the comorbidity of attention deficit and hyperactivity disorder and other learning difficulties but indicates that, in the event that criteria for both or more disorders are met, diagnoses for each should be given (Missiuna & Polatajko, 1995).

Magalhães, Cardoso, and Missiuna (2011) stated that "DCD is considered to be one of the major health problems among school-aged children worldwide" (p. 1309). The prevalence of DCD is considered to be around 5-6% of school aged children with effects which can be long term, projecting into adulthood (Maciver et al., 2011; Missiuna, Gaines, Soucie, et al., 2006; Stephenson & Chesson, 2008; Zwicker, Suto, Harris, Vlasakova, & Missiuna, 2018). More boys than girls (2:1) are diagnosed with DCD (Barnhart, Davenport, Epps, & Nordquist, 2003). There would appear to be no New Zealand specific research pertaining to the prevalence of DCD in children, however, the percentage of 5-6% is widely quoted in the international literature, which includes the American Psychiatric Association, and would therefore appear to be a transferable statistic.

Children with DCD experience difficulties with motor coordination and motor planning. This affects their participation in occupations such as self-care, play, sport and school related activities (Maciver et al., 2011; Magalhães et al., 2011; Stephenson & Chesson, 2008; Summers, Larkin, & Dewey, 2008; Van der Linde et al., 2015). They can also have poor organizational skills, have difficulty with social interaction and over time experience a variety of emotional issues related to anxiety, low self-esteem and depression (Caçola & Killian, 2018; Eggleston et al., 2012; Zwicker, Harris, & Klassen, 2013; Zwicker et al., 2018).

Parents

Parent is generally defined as "a person's father or mother" ("Parent," n.d.). When recruiting participants for this study, either a biological parent or caregiver who had a child with DCD aged between 5-12 years would have met the inclusion criteria.

However, only biological mothers responded and therefore, they are the ones referred to as "parent" in this study.

Perception

The definition of perception is an "intuitive understanding and insight" ("Perception," n.d.). The perceptions of parents, their first-hand experiences, are integral in this study as they cast light on the phenomenon being studied, that of the impact of DCD on the child. Parents' perceptions provided a personal, in-depth view from the environment in which DCD was experienced by the child.

Concerns

Concern is "to be anxious or worried" ("Concern," n.d.). In this study, the concerns of parents were captured in order to gain a greater understanding of the challenges that face both children with DCD and their families. Examples of concerns these parents might have faced included; difficulties their child had with self-care tasks such as dressing and eating, their child not keeping up with their peers academically or on the sports field, their child experiencing anxiety, depression and/or social isolation, as well as the challenges they, as parents, faced in advocating for their child. My focus on these concerns included an interest in the actions parents took in response to them, the responses they looked to teachers and health professionals for and how community members reacted to the things they were concerned about. Strategies parents used to assist their child, how they facilitated their child's participation in certain occupations and what services in health and education sectors were utilized were also responses to their concerns that I was interested in.

Participation

Participation, taking part, in the everyday occupations of life is a vital part of human development and lived experience. Law (2002) stated that "through participation, we acquire skills…, connect with others and our communities, and find purpose and meaning in life" (p. 640). It is an important outcome for all children as it is closely associated with enhanced quality of life, social competence and educational success (Khetani, Cousins, Coster, & Law, 2011). Participation, in typical occupations of childhood, plays a crucial role in development of a child's self-concept, with motor competence (or lack thereof) influencing self-esteem and social adjustment (Eggleston et al., 2012; Mandich et al., 2016; S. Taylor, Fayed, & Mandich, 2007). Children with disabilities are often restricted in their participation in social and recreational activities at school and in the community which can be to their detriment (Khetani et al., 2011).

An Occupational Perspective of Childhood

An occupational perspective was taken when performing this qualitative descriptive study. Increased understanding of the occupations of children, what they can do and what they can't, provides information regarding the "meaning, demands and context of their occupations" (p. 140) which will inform occupational therapists, making them better able to support children regarding their engagement and participation in occupations (Hocking, 2009). The focus of this study was to construct a clearer understanding regarding the child with DCD and their occupations.

Within this study people are viewed as occupational beings with "the capacity to make choices, participate in occupations, and change" (Whiteford et al., 2000, p. 64). Occupation is an important part of human experience and plays a role in helping us grow and interact with others. It also provides us with a sense of satisfaction and a means of control (Whiteford et al., 2000). For children, there needs to be a focus on occupations

that facilitate "experiences of fun and happiness, feeling supported, experiencing distraction, and being able to let go of negative thoughts and feelings" (Bowden, Reed, & Nicholson, 2018, p. 274).

Human occupation refers to what we "do" and can be divided into three main areas, "productivity, play and activities of daily living" (R. R. Taylor, 2017, p. 6). Activities of daily living include self-care and self-maintenance; play involves activities that are freely undertaken such as games, sport and exploring; and productivity refers to activities that involve work; this can be paid or unpaid and may provide services for others or involve the acquisition of knowledge (R. R. Taylor, 2017). Participation in occupation appears to be a strategy that can help build resilience (Bowden et al., 2018).

People differ in how they are "motivated toward and choose to do things" (R. R. Taylor, 2017, p. 11). Kielhofner introduced the model of human occupation (MOHO) which focuses on the "motivation for occupation; the patterning of occupational behaviour into routines and lifestyles; the nature of skilled performance; and the influence of the environment on occupational behaviour" (Kielhofner & Forsyth, 1997, p. 103). Within this model there are three components of occupation; volition, habituation and performance capacity. Volition refers to motivation for occupation, habituation refers to the process of organizing occupation into patterns and routines and performance capacity refers to the physical and mental abilities that underlie performance (R. R. Taylor, 2017). It is the complex interplay between these three factors that allow us to take part and achieve in our selected occupation. The environment is also a constant influence on occupation (Humphry, 2002). Throughout childhood, transformation of volition, habituation and performance capacity takes place, which allows the child to emerge as an occupational being with personal ways of doing, thinking and feeling. Childhood

occupation is both unique and serves as a foundation for later competence (R. R. Taylor, 2017).

Children's occupational choices are initially facilitated and justified by their parents, however, as they experience doing things, their interests and values emerge. They gain awareness of their abilities by engaging with the environment through play, interacting socially and through other occupational activities (R. R. Taylor, 2017). Access to opportunities, within the home, school and the community, and resources, such as having the time, money and parental support also impact on their selection and engagement in occupations (Wiseman, Davis, & Polatajko, 2005).

As children's abilities increase, their world expands, leading to further experiences. Occupational identity emerges in childhood, when "each child begins to discover and pursue unique interests and aptitudes that individualise identity and competence" (R. R. Taylor, 2017, p. 150). This emergence of occupational identity is supported by Phelan and Kinsella (2014) who described how an awareness of social approval/disapproval of actions and the corresponding social value of participation influences children's occupational choices at a very early age, thus having implications for occupational identity. Children generally enjoy activities that utilise their strengths and provide new experiences. Changes in social structures and families as well as the use of communication technologies will also impact children's everyday occupations, the extent to which is still being realized (Vilaysack, Cordier, Doma, & Chen, 2016). Over the span of a lifetime, humans engage in a large number of different occupations. Throughout time, these occupations serve to develop individual identities, communities and societies (Wiseman et al., 2005).

All people come to realise the limits of their ability, however, having an impairment can challenge the view one has of being capable. These challenges are particularly evident when the impairment results in them participating less in the things they want to do (Law, Anaby, Teplicky, Khetani, & Coster, 2016). Children with DCD can have significant functional deficits in their level of participation in relevant occupation (Mandich et al., 2016).

Occupational Therapists

Occupational therapists seek to improve health and wellbeing through occupation. "Occupational therapy focuses on enabling individuals and groups to participate in everyday occupations that are meaningful to them, provide fulfillment, and engage them in everyday life with others" (Law, 2002, p. 640). This is achieved by improving an individual's skills, competence and satisfaction in occupations (Yerxa, 1990). When working with children "the profession places emphasis on family-centered approaches; expertise in how to promote children's play and functional performance; and focus on the interactions among children, their occupations, and their environment" (Case-Smith, 2013, p. 379). Eggleston et al. (2012) described the role of the occupational therapist as important in assisting children with DCD by developing therapy plans which take into account the individuals' interests, strengths and difficulties to increase occupational engagement and social participation. This supports the intent to adopt an occupational perspective in this study.

Global Context of Service Provision for Children with DCD

DCD is a condition that is widely reported in international literature (Caçola & Killian, 2018; Chung, 2018; Eggleston et al., 2012; Missiuna et al., 2007; Van der Linde et al., 2015; Zwicker et al., 2018). Despite this recognition, DCD remains poorly understood

by health and education professionals with little in the way of diagnostic criteria and guidelines for assessment and treatment (Barnett, Hill, Kirby, & Sugden, 2015; Soriano, Hill, & Crane, 2015). In 2010 The European Academy of Childhood Disability (EACD) brought together expert opinion and produced a document which "represents the most detailed and robust guidelines to date, which are likely to be influential in informing research and clinical practice around the world" (Barnett et al., 2015, p. 105). This document was produced mainly by German-speaking countries and it is the view of Barnett et al. (2015) that it is important that these "EACD recommendations are appropriate for the medical and educational settings in other countries" (p. 105).

Many intervention strategies have been used for children with DCD, stemming from various countries and disciplines, these include therapeutic approaches drawn from occupational therapy, physiotherapy, medicine, dietetics and education (Smits-Engelsman et al., 2013). Hillier (2007) performed a systematic review of 31 studies related to intervention with DCD and concluded that there was sufficient evidence to support the fact that therapeutic "intervention per se is better than nothing for children with DCD" (p. 8). The benefit of intervention is supported by a meta-analysis of studies by Smits-Engelsman et al. (2013) who stated that "intervention is shown to produce benefit for the motor performance of children with DCD" and that "approaches from a task-orientated perspective yield stronger effects" (p. 229). Occupational therapists have a significant role in providing client-centered treatment plans which consider the child's individual strengths, difficulties and interests (Case-Smith, 2013; Eggleston et al., 2012). This client-centered approach is important as the type of input required may be complex, as the presentation of DCD can differ due to its heterogeneous nature (Kirby, Edwards, & Sugden, 2011). This approach can also assist the child to gain increased competence, occupational engagement and enhanced social participation (Eggleston et al., 2012).

In comparable developmental disorders, best practice is seen to be provided from a multidisciplinary approach and where information related to the child's skills and difficulties is obtained from various sources including, the child, parent and teacher (Kirby et al., 2011). The importance of hearing from parents as key stakeholders and the need to be alert to potential gaps in service provision for children with DCD, points to the value of recruiting parents living in different locations in my study. In seeking information about the impact of location on parents' experiences, I acknowledge that the extent to which that was achievable was limited within the parameters of a small scale qualitative study.

Implementing guidelines into clinical practice can be challenging, as described by Pentland et al. (2016), especially when there are multiple stakeholders involved, e.g. child, family, health and education professionals. The study performed by Pentland et al. (2016) surveyed 37 participants in order to understand how services complied with the DCD best practice framework in the United Kingdom. The study concluded that there were inconsistencies in the care of children with DCD (Pentland et al., 2016). A further issue was raised by Missuana, C., Moll, S., et.al. (2006) who stated that in Canada a "maze of health care services" were offered with varied and complex pathways (p.14). This complexity of services in Canada may make it difficult for families to navigate and access the support they require. It is unclear whether services in New Zealand adhere to best practice guidelines or whether similar levels of complexity occur, as found in Canada.

New Zealand Context of Service Provision for Children with DCD

DCD is a disorder that has been identified in New Zealand for many years (Miyahara & Möbs, 1995). Services for children with DCD are administered by three providers within New Zealand that is; the Ministry of Health, Ministry of Education and the private sector.

The Ministry of Education (n.d.) has provided material on their website to inform education professionals about dyspraxia and to provide strategies on how to best meet the needs of the child within the classroom setting. The Ministry of Health (2018) website does not provide any formal pathway specifically for DCD diagnosis or intervention. There is only a general pathway for a child with developmental delay which recommends referral to a Child Development Team (CDT) by a GP, "well child" nurse or child health specialist. A CDT is a non-medical, multidisciplinary allied health service and is community based. The aim of this service is to promote and facilitate each child's development so that maximum potential is reached. Once the child enters school the CDT will only provide support within the home environment as therapists within the Ministry of Education are then tasked with the responsibility of providing intervention within the school environment.

In order for a child with DCD to gain access to publically funded health and education intervention services in New Zealand a formal diagnosis is usually required. Frequently, this alone is not sufficient, with an additional comorbidity being required (Vardhaan, 2016). A diagnosis can be obtained from either a paediatrician, child psychiatrist or psychologist, often with a supporting report by an occupational therapist. The waiting list for these services can be lengthy. Once a diagnosis is received the child can then be referred to the public system for therapy services, usually occupational therapy. In some

instances, a referral for a Needs Assessment can be made to determine whether the child is eligible for disability funding or not.

An early intervention service under the Ministry of Education (MOE) is available to pre-school children but this does not usually benefit children with DCD as identification of the disorder is most often only made once the child enters school, aged 5-6 years (Missiuna, Gaines, & Soucie, 2006). MOE does provide some support in the school environment but this is limited due to resourcing. There is a need for national guidelines for the management of children with DCD, with emphasis on early identification and intervention (Noritz & Murphy, 2013; Tokolahi, 2014).

There has been an ongoing concern regarding the lack of public health and education resources available to address this disorder. The need for services for children with DCD within New Zealand has been debated at a political level (Vardhaan, 2016). The Ministry of Education (2015) published support material in the inclusive stock take and needs analysis of child development services in New Zealand, which confirmed the belief that this group of children do not get sufficient support from the public system (Vardhaan, 2016). In November 2016, a parliamentary select committee inquiry was held into the identification and support for students with the significant challenges of dyslexia, dyspraxia and autism spectrum disorders in primary and secondary schools (Education and Science Committee, 2016). Recommendations regarding the management of DCD were limited in this report. They did include the suggestion that government encourage the Ministry of Education (MOE) to explore options for earlier identification and assessment, with a call for free screening in primary schools. Specific adaptations at school such as; special assessment conditions, extra time for processing and responding, and reader/writer assistance were among the most popular recommendations. Submitters to the inquiry suggested that programmes such as Specific Learning Difficulties (SPELD)

tutoring and the Perceptual Motor Programme (PMP) were beneficial. Some submitters said that the diagnostic pathways for children with dyspraxia were less developed than those for children with dyslexia or ASD. These submitters suggested that the Ministries of Health and Education work together to develop guidelines to facilitate the diagnosis of dyspraxia (Education and Science Committee, 2016). At the time of writing this thesis no reported information had been located that corresponded with any action being taken or implemented following this inquiry.

DCD guidelines, for both health care and education, are an issue being discussed within New Zealand but no firm action has, as yet, been taken. Despite such concerns, there has been little research in New Zealand that relates directly to the impact of DCD on the child and their family, particularly from parents' perspective. This evidence is required if services are to be improved (Jasmin et al., 2018).

New Zealand has a national Dyspraxia Support Group which provides support, advice and resources for children and families with DCD. This is an active group with 767 registered members on their database (41 of whom are international). The organization was initially a parent led, voluntary support group. This has grown to now employ staff with the aim of empowering all people experiencing the impact of DCD by;

- Providing support, sharing concerns and solutions with other parents, caregivers and professionals experiencing similar situations
- Sharing up to date information to provide education regarding the disorder.
- Building and using a store of resources and information.
- Publishing a newsletter, 'Connections', four times a year.
- Increasing general awareness and understanding of Developmental Dyspraxia/DCD (n.d.).

The national office is in Christchurch with regional contacts throughout the country. Their national fieldworker holds meetings in Christchurch four times a year and meetings are held in other centers. There is an active Facebook page and the Canterbury area run programmes for children, teenagers and young adults with DCD (n.d.). There are no other organisations within New Zealand that offer support specifically for those with DCD, however, groups such a Parent-to-Parent do offer generalized support to families who have a family member with a disability.

Significance of this Research

DCD can have long-term detrimental effects on social confidence and vocational outcomes. These effects can extend into adulthood (Mandich, Polatajko, & Rodger, 2003; Stephenson & Chesson, 2008; Zwicker et al., 2012). A study performed by Eggleston et al. (2012), in which 75 New Zealand children with DCD completed a self-rating scale, substantiated the long-term impact with the children scoring themselves significantly lower than the norm with regard to physical appearance, intellectual and school status and popularity, indicating a lower global self-esteem. Similarly, Caçola and Killian (2018) in the United States looked at the quality of life in children with DCD, and their results reinforced that the impact of DCD extends beyond motor skills to include secondary physical and mental health issues. This view was supported by the Canadian study of Missiuna et al. (2007), who stated that over time "coordination problems developed into secondary difficulties in the classroom, with peers, and with family members" (p. 99). These concerns can become exacerbated as children move from school to higher education and on to work, where there is less structure and support, plus more demands are made of them (Kirby et al., 2011).

Health and education professionals need to view children and their parents as stakeholders and therefore value parents' point of view when planning services for children with DCD

(Jasmin et al., 2018). Thus, it is relevant to conduct a qualitative study to document the perspectives of parents raising children with DCD. The perspectives these parents have on the occupational limitations and participation restrictions experienced by their children can highlight the far-reaching consequences of DCD, as well as revealing the implications of DCD that the parents prioritise as most important (Mandich et al., 2003). It is, therefore, proposed that gaining an understanding of the perceptions and concerns of parents who have a child with DCD will assist healthcare providers in the management and remediation of this disorder. This is supported by Rodger and Mandich (2005), who stated that in "sharing these parents' experiences, our aim is to alert child health professionals to the importance of heeding parents' concerns and the richness of parents' understanding of their own children" (p. 450).

I believe that gaining insight into parents' first-hand experiences could provide more evidence-based awareness of the impact of this disorder and its warning signs, assisting earlier identification. This is important as the literature supports the fact that early intervention is vital for positive outcomes for these children, for example; improved motor and coordination skills, increased self-esteem and socialization, as well as more regular participation in community occupations (Gibbs et al., 2007; Hillier, 2007; Smits-Engelsman et al., 2013; Withers, Tsang, & Zwicker, 2017). It is also hoped that the deeper understanding of the day-to-day difficulties experienced by a child with DCD, gained through this study, could potentially support improved clinical pathways for assessment and intervention, leading to more positive outcomes for these children and their families (Maciver et al., 2011). Most importantly, this study is focused on DCD within NZ. International research is available and although some findings are transferable it is important to gain insight into how NZ children and their families are affected by this disorder. There is currently a significant gap in the literature regarding the presentation of DCD, its impact and management within NZ. A better understanding

of DCD from a NZ perspective is essential if these children are to be well supported within this country.

The findings of this study could potentially provide useful information for parents of children with DCD. It would be useful for them to know that other parents have similar concerns, make similar observations, use strategies and guide their children's occupations in similar ways, thereby gaining reassurance that they are not alone in their thoughts and actions, and that it is not their child nor their parenting that is at fault. It would also provide information on how to address issues and where to seek advice.

My Interest in this Area of Research

An awareness of the difficulties children with DCD and their families face arose from my clinical experience, particularly in my private paediatric occupational therapy practice. These difficulties occurred on two levels, firstly the impact of the disorder on the child which included poor motor coordination and planning, difficulty with organizational skills and secondary psychosocial effects. Secondly, the difficulties parents encountered when trying to obtain support for their child which included limited understanding of DCD amongst health and education professionals, the lack of clear pathways for early identification and diagnosis, as well as limited guidelines for intervention. In New Zealand, the needs of children with DCD are not well met in the public system as a result they are frequently seen in private practice (Vardhaan, 2016). Consultation with colleagues and parents, as well as literature reviewed provided me with added information to support the need for further exploration into this topic.

As an occupational therapist, I have an interest in children with DCD as I believe early intervention can make a significant difference to their outcome. Their occupational performance can be impaired and addressing this issue is a strength of our profession,

despite the fact that management of this disorder is still a "great source of debate" (Mandich et al., 2016, p. 51). However, as stated by Eggleston et al. (2012), occupational therapists have an important role in assisting these children by promoting "increased competence, occupational engagement and enhanced social participation" (p. 461).

The problem with DCD now is not so much what it is, but what can be done and what approaches are best to help these children (Gibbs et al., 2007). Therefore, by obtaining in-depth information from those stakeholders affected most by the disorder, especially the parents, it is hoped that better strategies and support systems can be established to assist these children and their families.

Overview of this Thesis

This chapter has introduced the topic of study, provided definitions of pertinent concepts, explored the international and NZ context of DCD, discussed the significance of the study and finally outlined my interest in this area of research. Chapter two critically reviews the current literature related to DCD, its presentation, its impact on childhood occupation and performance, the secondary effects of the disorder, including its impact on the family, and the interface between families, school and the healthcare sector, as well as the long-term implications of the disorder. The focus of the literature review was my research question, which related to the perceptions and concerns of parents raising a child with DCD. A strong occupational focus was given to this review. Chapter three discusses my selection of interpretive description as my methodology for the study, including its theoretical underpinnings. The research methods of participant recruitment and selection as well as data collection and analysis are outlined. Ethical considerations and strategies to ensure rigour are also addressed. Relevant appendices and tables are attached. Chapters four and five are where the findings of this study are presented. Chapter four

describes what parents first noticed as being different about their child, as well as how they came to understand more about the condition. The strategies parents implemented and actions they took to support their child are detailed and the occupations they guided their child to participate in or steer away from. The emotional and social challenges resulting from DCD, for both parent and their child, are also explored. Chapter five examines the interface between the families and the healthcare and education sectors. The challenges and benefits, as well as recommendations are reviewed. Finally, chapter six discusses the findings in light of the literature, looks at implications for families, healthcare and education, OT practice and further research.   At the end of this chapter the strengths and limitations of the study are identified, closing with a conclusion.

Summary

This qualitative interpretive description study aims to increase the understanding of parents' perceptions and concerns related to the impact of DCD on their child. Its purpose is to contribute to filling the gap in the current literature, particularly pertaining to the NZ context.   Parents are stakeholders and have a deep understanding of their child's performance; they therefore hold valuable information pertaining to their child and their development. The focus of the study is on childhood occupations and how these are influenced by DCD. By gaining this first hand understanding of the condition and its impact, it is hoped that a contribution can be made to the evidence based knowledge of DCD and hence support the call for improved services for this group of children. Implications for further research and practice are also addressed.

CHAPTER 2

Literature Review

Introduction

The purpose of the literature review for this study was to gain an understanding from both the international and New Zealand literature, of what parents' perspectives and concerns are when raising a child with DCD. A strong focus was placed on the impact DCD has on childhood occupation. The premise guiding the study, and thus the literature review, was that there is much to be learnt from parents raising a child with DCD (Galvão, Veloso, Carvalho, & Magalhães, 2014; Jasmin et al., 2018; Maciver et al., 2011; Soriano et al., 2015). There have been a number of international studies in which parents of children with DCD were interviewed (Ahern, 2000; Jasmin et al., 2018; Maciver et al., 2011; Mandich et al., 2003; Missiuna et al., 2007; Pless, Persson, Sundelin, & Carlsson, 2001; Rodger & Mandich, 2005; Segal, Mandich, Polatajko, & Cook, 2002; Stephenson & Chesson, 2008; Summers et al., 2008). These were performed in a variety of countries, including; Australia, United Kingdom, Canada and Sweden, however, Canadian researchers are very dominant in this field. Mostly, relatively small samples of approximately 10-13 participants were involved, with the exception of Summers (2008) who had a much larger sample. Only three of these studies specifically aimed to gain parents' general perceptions, impressions and/or descriptions of their child with DCD. The others were focused on specific aspects such as; obtaining a diagnosis, accessing services or the long-term implications of the disorder. The majority of the interviews, although aiming to interview both parents, were held with mothers. Little emphasis was placed on ethnicity and ethnic diversity. There are relatively few qualitative studies looking at parents' perceptions of DCD. This was substantiated by Galvão et al. (2014)

who in their literature search in 2012, found 594 articles pertaining to parents' perceptions, however, only eight used a qualitative methodology. There have only been a few more studies such as these since that time, most importantly Jasmin et al. (2018). Thus, there is a paucity of research which addresses parents' first-hand accounts of the impact of DCD on their child and family. Soriano et al. (2015) supported this by saying "little is known about the parental experiences of having a child with DCD" (p. 11). The need to access parents' opinions regarding their child with DCD was also confirmed by a thorough study of 52 parents performed by Maciver et al. (2011). Their findings showed that the perceptions of parents were important in terms of understanding DCD and its ramifications, especially in light of the fact that this condition is not well understood by educational or health professionals (Maciver et al., 2011).

Aligning with the design of my study in seeking to understand what parents are concerned about and what their perceptions of their children are, the literature selected for the review focussed on studies which gathered information directly from the parents. Through this review, I aimed to gain a deeper understanding of the impact of DCD, by exploring the day-to-day struggles of the child and their family, what occupations the child was able to participate in and what they were excluded from due to their disorder. Due to the focus of the study, the management of the disorder was only briefly addressed. There would appear to be no similar qualitative studies performed in New Zealand (NZ), hence there is a significant gap in the literature pertaining to the first-hand accounts of the occupations of children with DCD, particularly from a NZ perspective.

In this chapter, the strategy for locating and selecting literature to include is described, and a summary of the literature reviewed provided. A conclusion is then drawn as to why this research is relevant, particularly within a NZ context.

Conducting the Literature Search

When carrying out this literature search, the following search terms where used; children, occupation, participation, developmental coordination disorder, dyspraxia, developmental delay, impact of DCD, parental perception/concern and occupational therapy. A variety of databases and search engines were utilized. These included CINAHL, Medline, Scopus, and SPORTDiscus, as well as Google Scholar and Cochrane Database of Systematic Reviews. ProQuest Dissertations and Theses Global, Tuwhera (Auckland University of Technology) and nzresearch.org, were used to access theses and dissertations. Reference lists from relevant articles were also checked to identify other useful literature.

The search was limited to the period from 1995-2019 and only English, peer reviewed journal articles were included. The rationale for the limited time period, despite earlier literature on clumsy children, was due to this being a Masters study which is limited in its scope and, therefore, preference was given to more current information. Articles which had their emphasis solely on intervention were excluded from the search, as were those that appeared to be of poor quality as defined by inadequate methodology and sample size, or not in a professional publication. International and NZ literature was included with a preference for qualitative studies. Focus was placed on the presentation of DCD, its impact on the child and family, the child's occupations and importantly, parental perceptions and concerns related to the condition. This gave a good insight into the current understanding of DCD.

Historical Perspective

Descriptions of children with developmental movement difficulties appeared in the literature as early as 1911 (Missiuna & Polatajko, 1995). It was not until the mid 1960s

that case studies and systematic empirical work began to appear in the literature with clumsy child syndrome being described, despite normal intelligence and no neurological findings (Missiuna & Polatajko, 1995). Since then, many terms have been used to describe children with motor delay, for example; clumsy child syndrome, sensory integrative dysfunction, developmental dyspraxia, physical awkwardness and perceptual motor dysfunction (Zwicker et al., 2012). A consensus was reached in 1994 that the term developmental coordination disorder be used and the diagnostic criteria was then added to the third edition of the DSM (Zwicker et al., 2012).

Research of clumsiness in children has evolved considerably in the last few decades, particularly with regard to the cross-disciplinary approaches to understanding DCD. Developmental disorders are now of interest to psychologists, paediatricians, neurologists, physical therapists and occupational therapists (P. Wilson & Larkin, 2008). Until the early 1990s little consideration had been given to the impact of motor delay on the family. It was then felt that this was a significant factor given the lack of support available for those with motor difficulties. The subtle nature of the disorder has meant that those impacted by it have received little support and understanding (Chesson, McKay, & Stephenson, 1990). With consensus being reached regarding the definition and terminology of DCD, as well as a multidisciplinary approach being taken, it is hoped that increased awareness and understanding of the disorder will continue to develop.

Childhood Occupation and DCD

Participation in occupation is an important part of human experience and plays a role in helping us grow and interact with others (Whiteford et al., 2000). Occupation is a complex, individual phenomenon which is influenced by the environment in which it occurs. It provides opportunities for individuals to have experiences, make a

contribution, and discover sociocultural and spiritual meaning through their own actions (Yerxa, 1990).

Humphry (2005), quoted in Ziviani, Macdonald, Ward, Jenkins, and Rodger (2006), described the occupations of childhood as "activities children find interesting or pleasurable and want to do or do because others manifest value in their doing" (p. 38). The development of childhood occupations is influenced by factors specific to each child, and by their environment (Wiseman et al., 2005). Through interactions with caregivers, exploration and play, children enhance their own development (Humphry, 2002).

Kielhofner's model of human occupation (MOHO) refers to different areas of occupation, these include; productivity, play and activities of daily living (R. R. Taylor, 2017). For children, this would include activities such as; school work, learning, playing, sport, singing, dancing, dressing, eating, toileting and showering to name a few. As children develop they experience internal changes and the environments in which they do things, e.g. home, school and the community, also change. For participation in occupation to be of meaning, there must be a supportive environment, some choice and a feeling of challenge from the activity, leading to a sense of achievement (Law, 2002) for the child.

A child needs to be motivated to engage in occupations; the more motivated they are, the more likely they are to participate (Wiseman et al., 2005). R. R. Taylor (2017) described three components of occupation; volition, habituation and performance capacity. Volition refers to motivation for occupation, habituation refers to the process of organizing occupation into patterns and routines, and performance capacity refers to the physical and mental abilities that underlie performance (Kielhofner & Forsyth, 1997). It is the complex interplay between these three factors that allow us to take part and achieve

in our selected occupation. Opportunities, parental participation, resources (time and money), parental views and values, all influence a child's occupational development and participation (Wiseman et al., 2005). Participating in occupation also "requires the physical and mental capacity to carry out the actions, and monitor and modify the process as necessary" (Hocking, 2009, p. 142).

The motor impairments associated with DCD challenge children's engagement and participation in various occupational roles. It has been demonstrated that DCD limits a child's engagement in typical childhood occupations such as bike riding, playing on the school playground, writing, craft activities, and self-care (Kennedy-Behr, Rodger, & Mickan, 2013; Missiuna et al., 2007). This can have a very deleterious effect on children themselves. It is therefore, important that occupational therapists identify occupations and conditions that support engagement in physically active pursuits for children with DCD. Targeting this population at an early stage, before inactive lifestyles are entrenched, is essential if preventive health goals are to be fully realized (Poulsen & Ziviani, 2004).

What is Development Coordination Disorder?

DCD is a neuro-developmental disorder, described as a heterogeneous condition in which children have difficulty with fine motor and/or gross motor skills (American Psychiatric Association, 2013; Blank et al., 2019; Smits-Engelsman et al., 2018). Motor performance is usually slower and less accurate than their peers, with motor planning and motor learning also impacted (Zwicker et al., 2012). DCD is a common, chronic disorder affecting most activities of daily living, that interferes with academic achievement and engagement with play (Blank, Smits-Engelsman, Polatajko, & Wilson, 2012; Jasmin et al., 2018; Zwicker et al., 2018).

Zwicker et al. (2012) have argued that although the aetiology of DCD is largely unknown, it may be due to central nervous system pathology with cerebellum involvement. There is, however, no conclusive evidence regarding aetiology in the literature; it remains poorly understood (Blank et al., 2019; Kirby, Sugden, & Purcell, 2014). The prevalence of this disorder is approximately 5% to 6% of children (Blank et al., 2019; Kirby et al., 2014; Magalhães et al., 2011; Missiuna et al., 2007) and it has been described as "one of the major health problems amongst school-aged children worldwide" (Magalhães et al., 2011, p. 1309). A higher prevalence in boys is reported, up to 2:1 (Barnhart et al., 2003; Zwicker et al., 2012).

There are a number of manifestations of DCD in children. These can include clumsiness, motor planning difficulties and fine motor delay (Barnhart et al., 2003; Blank et al., 2019; Caçola & Killian, 2018; Chesson et al., 1990; Farmer et al., 2016; Jasmin et al., 2018; Missiuna et al., 2007; Soriano et al., 2015; Zwicker et al., 2012). Functional evidence of these difficulties can include; poor postural control, slow and imprecise coordination and delay in learning new tasks, especially those which require anticipation and adaptation (Farmer et al., 2016). Due to their clumsiness these children can be excluded from activities by their peers and sometimes be teased, leading to social isolation, lack of motivation, low self-esteem, anxiety and depression (Caçola & Killian, 2018; Eggleston et al., 2012; Kirby et al., 2011; Zwicker et al., 2013). There has been reference to difficulties with visual-spatial perception and sensory motor deficits in children with DCD (Blank et al., 2019). Missiuna, Gaines, and Soucie (2006) described a progression of concerns, where parents were aware of their child's difficulties from when they were a toddler but were able to accommodate their difficulties. Then, once at school, there were difficulties in the classroom and with their peers. Later, the challenges faced by the

child or adolescent impacted on their academic performance, self-esteem and emotional health. The consequences of DCD can, therefore, be long term and persist into adulthood (Caçola & Killian, 2018; Eggleston et al., 2012; Kirby et al., 2011; Zwicker et al., 2018). There would appear to be a high level of consistency across the literature with regard to the presentation and implications of DCD (Barnhart et al., 2003; Blank et al., 2012; Mandich et al., 2003; H. J. Polatajko & Cantin, 2005; Zwicker et al., 2018).

Coexisting disorders are commonly associated with DCD, particularly attention deficit hyperactivity disorder (ADHD) and learning difficulties such as dyslexia (Dewey, Kaplan, Crawford, & Wilson, 2002; Eggleston et al., 2012; Sergeant, Piek, & Oosterlaan, 2006; P. Wilson & Larkin, 2008). This is supported by Visser (2003) who stated that "approximately half of the 7-year-olds diagnosed with DCD also had moderate to severe symptoms of ADHD" (p. 484).   It is important to regard these as coexisting disorders rather than being part of DCD (Gibbs et al., 2007; Gillberg & Kadesjö, 2003). DCD is a complex disorder which children do not grow out of (Blank et al., 2019).

What Parents Noticed

 As discussed by Jasmin et al. (2018), parents of children with DCD are stakeholders.   It is therefore important to understand their point of view regarding real life situations, in order to meet their needs as well as those of their child. Internationally, there have been a number of studies which have attempted to ascertain the perspective of the parents with regard to DCD, its presentation and impact on the child and family, as well as access to services (Ahern, 2000; Jasmin et al., 2018; Kadesjo & Gillberg, 1999; Maciver et al., 2011; Mandich et al., 2003; Missiuna et al., 2007; Pless et al., 2001; Rodger & Mandich, 2005; Segal et al., 2002; Stephenson & Chesson, 2008; Summers et al., 2008). Missiuna et al. (2007) concluded that concerns expressed by parents seemed to evolve over time.

Each family was different but there were common threads and as the child grew older, problems became more complicated and diverse. These difficulties were linked to their social and emotional development, with decreased participation in occupation being a major concern for parents (Maciver et al., 2011; Mandich et al., 2003; Rodger & Mandich, 2005).

Early Indicators of DCD

In an extensive survey of 228 parents, Soriano et al. (2015) ascertained that 96% of the time, parents were the ones who initially noticed their child's motor problems. They became aware of these differences when they compared their child's abilities with those of other children and this usually occurred by the time the child was four years of age (Jasmin et al., 2018; Missiuna et al., 2007; Soriano et al., 2015). The differences parents were alerted to related to motor skills and play, with motor differences being evident in the quality of the child's movement rather than in delays in their milestones (Missiuna et al., 2007). This was supported by Gibbs et al. (2007), who reported that some parents described delay in their child reaching their milestones, while others merely expressed that "something was not quite right" without being able to be more specific (p. 3). Some parents indicated that their child was "clumsy and not aware of their body in space" (Missiuna et al., 2007, p. 87). They found it difficult to distinguish between what was normal individual development versus what was a problem.

With regard to play, again parents reported differences as opposed to concerns. Some stated that they had to make sure their child did not get hurt but most reported that their child was sedentary in play, preferring to read books and watch TV (Missiuna et al., 2007). Children with DCD experience significant difficulties in the performance of self-maintenance activities relative to their typically developing peers and motor difficulties

had a considerable influence on their ability to be independent in activities of daily living (Summers et al., 2008). Missiuna et al. (2007) also reported that nearly all parents noticed that their child's self-care skills, e.g. feeding and dressing, were somewhat or very delayed. This impacted on morning routines, making them stressful due to avoidance or lack of proficiency in these tasks. In one of the few studies to interview both parents and children, Jasmin et al. (2018) also found that issues raised regarding the young child related to difficulties they experienced in getting dressed and organized in the morning.

In summary, parents of children with DCD are usually the first ones to identify a delay in their child's development; initially these delays were subtle and affected self-care and play skills. Over time, they became exacerbated and resulted in secondary symptoms affecting academic performance and psychosocial functioning. This is discussed more fully below.

Impact of DCD on the Child

Evidence shows that DCD does have a significant impact on children from a physical, academic and psychological perspective (Caçola & Killian, 2018; Eggleston et al., 2012; P. Wilson, Ruddock, Smits-Engelsman, Polatajko, & Blank, 2013; Zwicker et al., 2018). The child's difficulties frequently became more evident once they started school and expectations were increased (Jasmin et al., 2018). Parents noticed a progression of differences over time; in the early years there were concerns related to play and self-care; in middle childhood issues related to academic achievement and socialization; and later significant challenges occurred with emotional wellbeing and self-esteem (Missiuna et al., 2007).

a) Impact on the child's motor performance

Many of the actions we perform in everyday life have been learned informally and can be performed without close attention. We often only become aware of the intricacy of our movement when we are deprived of the skill (Henderson & Henderson, 2002). A child with DCD can often not acquire even the simplest motor skill without help. Being unable to fasten buttons, use a knife and fork or ride a bike to school may seem trivial but such failures can have far reaching effects on the educational progress of children, their social relationships and self-esteem (Barnhart et al., 2003; Chang & Yu, 2016; Henderson & Henderson, 2002; Missiuna, Gaines, & Soucie, 2006; Zwicker et al., 2012). Within medical and scientific communities, DCD is generally considered to mean an impairment of the planning and execution of physical movement, with a developmental rather than acquired origin (Blank et al., 2019; Chang & Yu, 2016; Farmer et al., 2016; Gibbs et al., 2007; Zwicker et al., 2012). Gibbs et al. (2007) also discuss the fact that there is a spectrum to DCD, and where the child lies on this spectrum will be determined by their functional ability and how this intrudes on their academic and leisure occupations. This, however, can also be influenced by environmental factors, such as culture, family background and expectations (Gibbs et al., 2007; Missiuna et al., 2007).

Children with DCD, according to Barnhart et al. (2003), can have neurological soft signs such a hypotonia, persistence of primitive reflexes and immature balance, which interfere with gross motor development. This can lead to awkward running patterns, frequent falls, dropping items and difficulty following motor commands. These children can also have difficulty planning and executing fine motor activities such as writing, feeding, gripping and dressing (Barnhart et al., 2003; Summers et al., 2008; Zwicker et al., 2018). The two overriding motor factors that were identified by parents as significant issues in their children's participation in self-maintenance activities were postural control and motor

coordination (Summers et al., 2008). Ahern (2000) stated that the most common concerns voiced by the participants in her study were that their child had difficulty learning to ride a tricycle and that eating with a knife and fork was challenging. Compared to other children, parents reported their child also had difficulty running, accessing playground equipment, dressing and using scissors (Ahern, 2000). Most children with DCD were reported to have difficulty in maintaining their posture in sitting; they were inclined to fidget, rock or lean forward on their chair, constantly change position and stand up while eating (Summers et al., 2008). Farmer et al. (2016), in their study of 33 characteristics of DCD in 129 children, found slowness in task performance in 100% of their sample. These children were slow in planning and executing tasks, slow in organizing their body to do a particular task, and slow to adjust to a particular situation. It was also found that if a child attempted to go fast then there was a reduction in the quality of the task performed and this could be accompanied by an increase in their level of anxiety (Farmer et al., 2016).

Skills, such as using cutlery and teeth cleaning, can improve over time. These activities occur in a set environment and are practiced daily from a young age, so may be more easily automated. In contrast, tasks such as note-taking occur in different environmental contexts, and so may remain an area of difficulty for a more extended period of time (Kirby et al., 2011).

It is well documented in the literature that children with DCD are frequently excluded from team sports due to their poor motor coordination (Chung, 2018; Eggleston et al., 2012; Kirby et al., 2011; Zwicker et al., 2013). This was supported by Barnhart et al. (2003) who stated that children with DCD often performed badly in sport due to slow reaction and movement. Physically competent children can often assume positions of authority and power in team selections which enhance their social and physical self-

perceptions, reaping benefits in all spheres; physically, emotionally and socially. The less competent children on the other hand became excluded and at times employed other behaviours, involving aggression or clowning around, to gain group membership (Poulsen & Ziviani, 2004). Children with DCD often choose to engage in physical skills in isolation rather than in the presence of their peers in the playground (Poulsen & Ziviani, 2004) to avoid comparison. The majority can be inactive in the playground and during physical education classes; spending more time as onlookers than their peers (Missiuna et al., 2007). Hence, this disorder is associated with low levels of physical activity and decreased fitness (Farmer et al., 2016). Obesity has been recognised in the literature as health risk for children with DCD due to their limited involvement in and frequent avoidance of physical activity (Blank et al., 2019; Zwicker et al., 2013).

Motor performance difficulties in children with DCD are often viewed as mild and not warranting attention compared with, for example, cerebral palsy. Therefore, it may be argued that the net benefits of intervention in DCD may not be justified as an investment for society. However, Blank et al. (2019) in their recommendations derived from the European Academy of Childhood Disability (EACD), report that the findings on the outcome of DCD clearly suggest that it is a considerable burden and it is, therefore, important to intervene. The burden is due to the marked influence this condition has on everyday activities and with its high prevalence rate, impacts are felt both socially and economically (Blank et al., 2019).

b) Impact on the child's academic performance

For children with DCD, starting school means demands on a daily basis to perform fine motor tasks such as; the use of scissors, drawing and writing. Such activities are often difficult for these children. They can become frustrated or try to avoid these tasks (Ahern,

2000; Jasmin et al., 2018; Missiuna et al., 2007; P. Wilson et al., 2013). Parents reported difficulty in rating their child's academic ability as they stated there was such a discrepancy between their child's cognitive ability and their performance, that their child was unable to demonstrate their knowledge through written work (Missiuna et al., 2007). Challenges with printing/handwriting were also reported by Zwicker et al. (2018) who stated that it was an obstacle to the child enjoying and succeeding in school. Problems were far-reaching and included difficulty with forming letters, with an outcome that was both slow to produce and messy in its presentation (Zwicker et al., 2018). This often resulted in a negative response from teachers, as they experienced frustration knowing the child was intellectually able to cope but did not produce the work, or could produce it verbally but not in writing (Missiuna et al., 2007). Some benefits can be obtained from using computers, tablets, and typing programs to address handwriting issues, however, what interfered with children's printing, that is their fine motor control, also interfered with effective keyboarding (Zwicker et al., 2018).

Organizational difficulties were found by Sylvestre, Nadeau, Charron, Larose, and Lepage (2013) in their cross-sectional study of 27 youngsters to be the factor that challenged children with DCD the most and led to delays in achieving set tasks, only partial completion of tasks or a tendency for the child to stop trying. It can be difficult for these children to keep up with their peers in group activities, particularly because of the speed of the tasks and verbal interchanges (Sylvestre et al., 2013). With repeated academic failure, children with DCD experienced feelings of frustration, sadness, and/or isolation (Zwicker et al., 2018). Zwicker et al. (2018) concluded that children with DCD try hard to master the fine motor skills needed for academic success but that their efforts often came at an emotional cost.

Ahern (2000) reported that children performed better in one to one teaching situations. When placed in a group learning environment, they tended to withdraw and not pay attention. Comparison with other children in a group also provoked anxiety. Farmer et al. (2016) found concentration to be an issue, reporting that 80% of the cohort in their study experienced problems with concentration.

P. Wilson et al. (2013) discussed in their review that in addition to motor difficulties, children with DCD can have difficulty with executive functioning skills, which include working memory and the ability to plan goal directed tasks, and that this may in turn have an impact on children's ability to organise and complete academic tasks, especially at speed. The literature is consistent with regard to the significant impact DCD has on the child's ability to keep up and function to their full potential within the normal school environment. Consideration does need to be given to their specific learning needs and parents should be consulted (Farmer et al., 2016; Sylvestre et al., 2013; Zwicker et al., 2018) . As Ahern (2000) reported, parents are very aware of the need to tailor their child's learning activities and environments. Lingam, Novak, Emond, and Coad (2014) interviewed 11 young people with DCD and 10 of the participants identified finding school lessons difficult to understand. The literature strongly illustrates that DCD does have a significant impact on the child's academic performance (Ahern, 2000; Blank, 2012; Farmer et al., 2016; Lingam et al., 2014).

c) Impact on the child's social interaction

DCD can have a significant impact on the social inclusion and acceptance of these children by their peers (Poulsen & Ziviani, 2004; Segal et al., 2002). Children with low motor skills have been found to choose to play with other children of similar abilities if possible or engage in more sedentary pursuits such as reading or fantasy play involving

low physical demands (Farmer et al., 2016). Poorly coordinated children perceive classmates to be less supportive and are less likely to have a special friend (Poulsen & Ziviani, 2004). This is supported by Missiuna et al. (2007), who reported that children with DCD found it hard to keep up with their peers on playground and therefore often played alone or with children younger themselves. It is well documented that physical play is important in the development of children's social life in terms of acquiring and maintaining friends and belonging to peer groups, and that children with DCD are significantly compromised in this area (Poulsen & Ziviani, 2004; Segal et al., 2002). Jasmin et al. (2018) supported this by stating that children's peers frequently did not play with them at school. Segal et al. (2002) discussed this exclusion by others in terms of "stigmatization" (p. 424). That is when the child with a disability strives for acceptance but that this is withheld. Under these circumstances, the individual then faces two possibilities: "situations where he or she must manage stigmatization or that certain situations are avoided in order to prevent stigmatization" (p. 427).

As the children got older and social comparisons started to occur, they become more aware of their limitations and parents perceived that their child got teased or bullied by others (Missiuna et al., 2007; Zwicker et al., 2018). Blank et al. (2019) in presenting the international clinical practice recommendations, also reported on the fact that lower levels of perceived competence by children with DCD have been associated with reduced social participation and that there was evidence of bullying and victimization. In summary, children with DCD have been found to be less popular and more solitary in their occupations than their peers who have no coordination difficulties (Segal et al., 2002).

d) Impact on the child's psychological wellbeing

The literature clearly describes a strong link between DCD and the long term, secondary impact of the disorder on the child's mental health (Ahern, 2000; Eggleston et al., 2012; Missiuna et al., 2007; Rodger & Mandich, 2005; Stephenson & Chesson, 2008). Stephenson and Chesson (2008) interviewed 12 mothers of children with DCD, all of whom described their child as having emotional problems. They stated that these problems manifested through anger, frustration, unhappiness, distress, depression, low self-esteem, embarrassment and shyness. These difficulties were said to have caused friction within families and considerable stress and concern to mothers (Stephenson & Chesson, 2008). Rodger and Mandich (2005) reported that parents described their child's increasing frustration and awareness of their own difficulties. Parents noticed their child experienced a sense of failure and that they were overwhelmed by extra homework because they were slow at completing their work at school (Rodger & Mandich, 2005, p. 454). The impact of these issues on their children's self-worth was of concern to parents.

Children with DCD did compare themselves to their peers and through this became increasingly aware of their own limitations, leading to low self-efficacy (Chen & Cohn, 2003; Missiuna, Gaines, & Soucie, 2006; Missiuna et al., 2007). If tasks were perceived to be too difficult the child would often not attempt them; these 'opting out' behaviours were described by most mothers (Jasmin et al., 2018; Stephenson & Chesson, 2008). Missiuna et al. (2007) commented that parents worried about their child developing a negative self-image and that when their child's self-esteem deteriorated, this was often the trigger for parents to seek help. Findings by Eggleston et al. (2012) strengthen evidence that there is an association between children and adolescents with DCD and lowered global self-esteem, as well as poor perception of their physical appearance and attributes, their popularity and intellectual ability. This is also supported by Chen and

Cohn (2003) who, from their review of the literature, stated that children with DCD frequently "perceive themselves to be less competent than their coordinated peers for the domains of athletic competence, scholastic competence, physical appearance and social acceptance" (p. 68).

Anxiety about school was described by many parents (Missiuna et al., 2007). This related to the child struggling to complete the set tasks or being overwhelmed by the work required of them. Many children were reported to experience frustration, "their hands would not do what their mind directed" (Missiuna et al., 2007, p. 94). Further concerns have been raised that children with DCD may act out in class more than their peers and exhibit poor behavior in order to gain recognition and friends (Barnhart et al., 2003). Ahern (2000) reported that the majority (10/11) parents she interviewed described their child as feeling frightened and insecure when participating in normal playground activities such as catching a ball or skipping. Children at times, also had to contend with being labelled "clumsy", "awkward" and "lazy" (Missiuna, Gaines, & Soucie, 2006, p. 471). Ahern (2000) stated that parents found that "failure was a common experience" for their children (Ahern, 2000, p. 194).

Frustration for some led to angry and/or tearful outbursts. Two children in Missiuna et al. (2007) study of 13 felt destressed enough to express suicidal ideation. There would also appear to be an increased presentation of children with DCD at Child, Adolescent Mental Health units (Tokolahi, 2014) and that children with DCD and ADHD are at risk of a number of psychiatric and personality disorders (Dewey et al., 2002). This points to the fact that, in the long term, children with DCD are at risk unless they receive the support they require.

e) Impact on childhood occupations

Participation in everyday, childhood occupations is integral to normal development and has an influence on health, self-esteem and social adjustment (Humphry, 2002; Mandich et al., 2003; Poulsen & Ziviani, 2004). Children with motor delays are restricted in their participation in childhood occupations (Chung, 2018; Jasmin et al., 2018; Kennedy-Behr et al., 2013; Summers et al., 2008). Of concern, is the fact that children with DCD appear to withdraw from childhood occupations earlier than originally thought. Kennedy-Behr et al. (2013) reported that a study of preschoolers indicated that they were already less involved in active play compared to their peers. Findings from a study by Mandich et al. (2003) revealed that incompetence in everyday activities can have serious negative effects on children.

At home, childhood occupations are mainly centered around play and self-care (Barnhart et al., 2003; Blank et al., 2019). Summers et al. (2008) performed an extensive study in both Australia and Canada, interviewing 87 parents. They reviewed activities of daily living in children with DCD compared to children with typical development. Their findings confirmed that in all areas of self-care, dressing (buttons, fastenings, shoe laces), feeding (difficulty manipulating a knife and fork), bathing/showering and toileting, children with DCD required support and frequent prompting, physical and verbal, in order to complete tasks. With toileting, most children were dry during the day, with maybe the occasional accident, however bowel control was delayed and wiping difficult, especially for the younger child (Jasmin et al., 2018; Summers et al., 2008). Parents described their younger children with DCD as poorly coordinated, very awkward and very messy (Summers et al., 2008). Jasmin et al. (2018) supported these findings which showed that parents were involved in assisting their child with self-care skills till a much later age than the norm, with parents stating that every task involving organization was

difficult (Jasmin et al., 2018). Similarly, Henderson, Peters, Barnett, and Henderson (2001) found that problems with dressing, undressing, eating were high on the list of parents' concerns.

Jasmin et al. (2018) in their study, in which they interviewed 10 children and 11 parents (one couple), found that play and sports were the main significant activities for the children at home and in the community. Some children, in this study, had concerns related to taking part in leisure activities, whereas most parents wanted to increase their child's independence in self-care and homework as well as increase their participation in physical activities. Parents and children did not always share the same expectations with regard to occupation (Jasmin et al., 2018). These findings indicate that aspects of participation were specific to each child, revealing the unique and complex relationships between the child with DCD, the environment, and their participation in occupations (Jasmin et al., 2018).

Outside of school, many parents initiated their child's enrolment in some type of team sport. The children frequently struggled as their deficits became evident, with the result that many did not want to continue (Missiuna et al., 2007). Poulsen and Ziviani (2004) supported this finding by reporting that a small number of younger children with DCD do participate in formal team games in the early school years but withdraw from these activities by seven to eight years. Team sports seem to be particularly problematic for these children who seem to do better in individual skill-based activities, for example; swimming, archery and gymnastics, as these do not involve as much eye-hand coordination (Chen & Cohn, 2003; Hessell, Hocking, & Davies, 2010; Poulsen & Ziviani, 2004). Children who participated in individual sports needed extra time to develop skills, but were more successful in these activities as the physical demands were not as fast

paced (Missiuna et al., 2007). Therefore, as summed up by Chen and Cohn (2003), children with poor self-perception related to physical activities participate in fewer community sports teams, do less physical exercise and spend less time in free play than their peers do.

Participation in occupations may be influenced by environmental factors such as parents' and teachers' reactions or peer criticism (Chen & Cohn, 2003). Another important environmental factor that affects participation is the significance placed on physical skillfulness in the society for example, western society places a lot of value on boys being good sportsmen (Chen & Cohn, 2003). New Zealand is one such culture that does place emphasis on physical occupations and sport as discussed by Eggleston et al. (2012). This cultural context is an important influence on how the child's physical ability is viewed. Participation in occupations may, therefore, be influenced by the values, attitudes and perceptions of the child and their significant others, with gender factors also being a factor (Chen & Cohn, 2003).

In order to address their difficulties, the children themselves often developed strategies. These included; simplifying their dressing by pulling trousers on and off without undoing the zip, leaving fastenings on coats undone and slipping their shoes on and off without undoing the laces (Summers et al., 2008). In the Lingam et al. (2014) study, young people (11-16yrs) reported that "being positive" was an important way to help themselves (p. 313). They worked hard practicing skills in order to improve them, some used computer programmes to assist with reading and spelling and others reported that having a choice over subjects and activities meant they were more likely to succeed. Intervention that was focused on enablement, at an activity and participation level, had a significant positive impact on the children's quality of life (Law, 2002). Parents also reported that

successful participation built confidence in their children and allowed them to try other new activities (Mandich et al., 2003). A good example of this was given by Segal et al. (2002), who described how a boy could not master riding his bicycle and lost interest in it, until the opportunity to practise that activity in the safe environment of the occupational therapy clinic occurred. His interest in riding his bicycle subsequently increased and he then rode to visit friends, which he had not done before (Segal et al., 2002).

The systematic review performed by Magalhães et al. (2011) detailed that in the literature information regarding children's occupation and participation issues is limited. A call was made for more research in this field particularly from the view of the child with DCD, as they are mostly cognitively competent and therefore able to provide useful information (Magalhães et al., 2011). This is important as altered occupational engagement in sport and physical activities in childhood and adolescence has social, emotional and physical health implications (Poulsen & Ziviani, 2004).

f) Impact on the parents and the family

Stephenson and Chesson (2008) interviewed 12 mothers and they all reportedly believed that not only were individual family members affected by DCD, but the family as a whole. Missiuna, Gaines, Soucie and McLean (2006) also reported that having a child with DCD can negatively influence the quality of family life. With family life often revolving around the child with DCD and activities being geared to their special needs, it is understandable that siblings get upset. They frequently receive less parental attention as parents try to meet the needs of the child with DCD, by giving them more time and direction to carry out tasks and spending more time teaching them than their siblings (Ahern, 2000). Family friction can also result from the frustration in dealing with the slower pace of a child with DCD. Frustration and anxiety experienced by the child often

affects parents as they struggle over homework, deal with emotional outbursts or empathize with the child's concerns (Missiuna et al., 2007).

Some parents experienced worry and uncertainty, however those feelings could frequently convert into irritation or anger, for example, when the child did not want to participate in a physical activity proposed by the parent (Pless et al., 2001). Some parents questioned whether their child was being lazy, while others tried coercion, and some were frustrated by their child's low level of motivation and their avoidance tactics (Rodger & Mandich, 2005). Missiuna et al. (2007) also discussed parents' frustration in relation to them not knowing what to do to help their child.

Parents were especially supportive of their children in physical activity, but at the same time they were also uncertain as to whether they were doing the right thing, and when their children were unwilling to participate or unsuccessful, the parents frequently thought they were to blame (Pless et al., 2001). Emotions in parenthood can influence the parent-child interaction and attempts to support the children (Pless et al., 2001). Stephenson and Chesson (2008) stated that mothers of children with DCD spoke at length about their experiences and reported feeling both "stressed and distressed" (p. 335). The mothers felt unsupported and expressed feelings of isolation. They said that their time investment in their child with DCD had pronounced effects on themselves and other family members. Specifically, they highlighted time spent fighting the system, primarily for educational support. They described being worried most of the time and several mothers felt fatigued and emotionally drained (Stephenson & Chesson, 2008). Mothers felt that they carried the burden of being the advocate for their child (Ahern, 2000; Rodger & Mandich, 2005).

Searching for a diagnosis was described by Maciver et al. (2011) as a phase that was particularly upsetting for parents, who reported an array of negative emotions and feelings including anxiety, fear, frustration, isolation and anger. A primary cause of this distress was observing significant difficulties in their child, being unable to access help and feeling that they were "subtly pushed to the side" (Maciver et al., 2011, p. 425). This was supported Mandich et al. (2003) who also reported parents feeling that their concerns for their child were trivialized. In the search for diagnosis and intervention, one mother stated, "I basically am the agitator...the driving force, or the one who sets things" (Ahern, 2000, p. 196). Parents expressed the need to constantly push in order to receive help for their child (Maciver et al., 2011) .

Parents felt anxious and unsupported due to the frequent lack of professional knowledge regarding DCD (Maciver et al., 2011), feeling that they were not being believed or helped. This led to them to be very protective of their child. Ahern (2000) used the term "defensive protectionism" (p. 198) and went on to explain that this protective instinct also arose when their child was rejected by their peers. This hurt parents and engendered fear that their child would be further ostracised, leading to guilt that they were not protecting their child sufficiently and a strong determination to further protect the child (Ahern, 2000).

In order to support their child, many parents became quite adept at finding solutions to their child's problems; they developed strategies. Jasmin et al. (2018) discussed parents developing fixed routines and their perceived need for constant reminders in order for their children to complete tasks. Strategies were also identified by Missiuna et al. (2007), who stated that parents will go to great lengths to make adaptations for their child's differences; they purchased velcro shoes, provided clothes without buttons, electric

toothbrushes and spent a lot of time assisting their child with self-care tasks. Physical activities that incorporate repetition and a constant environment, such as swimming, were encouraged by parents, rather than team sports (Missiuna, Gaines, & Soucie, 2006).

In summary, having a child with DCD can negatively impact the quality of life of the whole family (Missiuna, Gaines, & Soucie, 2006). It was stressful for families as they attempted to manage the mystery of DCD, deal with multiple health and educational professionals, address their child's limitations, meet the needs of the rest of their family and often work outside of the home (Missiuna, Gaines, Soucie, et al., 2006).

Management of DCD

Interface with the Healthcare Sector

The advice parents frequently received not to "worry" and to simply "wait and see" often resulted in a delay in receiving specialist input (Gibbs et al., 2007, p. 3). Parents have been known to spend long periods of time seeking medical advice and intervention (A. R. Miller et al., 2008; B. Wilson, Neil, Kamps, & Babcock, 2013). Ahern (2000) reported that even though parents in Australia were first concerned about their child from a very young age, around 3-4 years, it could still take over a year for a diagnosis to be made. Similarly, in an extensive survey of 228 parents in the United Kingdom, Soriano et al. (2015) found that diagnosis was confirmed approximately two and half years after parents started seeking help for their child. Many professionals, from a parents' perspective, appeared to assume that the child would out grow their clumsiness, or that the motor problems did not really matter (Ahern, 2000; Maciver et al., 2011). This indicated a lack of knowledge about movement difficulties in young children amongst the professionals consulted (Ahern, 2000; Maciver et al., 2011).

From their literature review Gibbs et al. (2007) ascertained that 25% of children with DCD will be referred to healthcare services before starting school and that parents of a higher socio-economic status who had significant concerns were more likely to secure assessment. The other 75% of children were likely to be referred within their first few years of primary school (Gibbs et al., 2007). According to Missiuna, Gaines, Soucie, et al. (2006) the most common issues raised by parents who are seeking professional advice were; concern regarding their child's movement difficulties, wanting to know the cause of the poor coordination and whether DCD is the correct diagnosis, whether other developmental disorders are involved and what they might do to help with their child's daily frustrations.

While waiting for a diagnosis parents worried that their concerns were not shared by their general practitioner (GP) nor the teachers from whom they sought help (Ahern, 2000). This led to a period of concern; that their child had difficulties, was suffering and that they were the only ones who noticed this. Professionals' minimisation of the problem led parents to question the validity of their perceptions (Ahern, 2000; Rodger & Mandich, 2005). Eventually, parents became more direct at stating what the problem appeared to be and what needed to be done. Maciver et al. (2011) interviewed 52 parents of children with DCD, placing an emphasis on accessing services. In general, they reported that parents felt that "it was because of their efforts of continuously 'pushing' that their children eventually received help" (p. 425). Parents felt that they received inconsistent information from professionals and felt able to judge this as they had spent a lot of time educating themselves regarding DCD. They felt strongly that it was up to them to make sure their child received intervention (Maciver et al., 2011; Rodger & Mandich, 2005). These findings were shared by Soriano et al. (2015), who found that 52% of parents surveyed believed that the professional they had seen had only superficial or no

knowledge of DCD and up to 26% saw four or more professionals before getting a diagnosis. A study conducted by Wilson et al. (2013) identified that less than 50% of paediatricians and around a quarter of physicians were familiar with diagnosing DCD. This further emphasizes why it is important that occupational therapists have a thorough understanding of the assessment and diagnostic guidelines for DCD so that they are able to advocate for a diagnosis, if warranted, when collaborating with GP's and paediatricians (Karkling, Paul, & Zwicker, 2017). Kirby et al. (2014) reiterated that diagnosing DCD can be challenging due the presentation varying over time, and in different contexts but that clinicians working in paediatrics, as well as child and adult psychiatry, do need to remain alert to the potential diagnosis.

Henderson et al. (2001) discussed the pros and cons of a child receiving a diagnosis of DCD. The advantages they suggested were that it could allow access to certain benefits and services. While the disadvantages were that a label may be difficult to shed, even when symptoms had improved. However, Ahern (2000) reported that parents in her study, on receiving a diagnosis, experienced a sense of validation and a reduction in feelings of anger and frustration. According to Gibbs et al. (2007), a diagnosis can be helpful in summarizing problems, communicating these to families or professionals and in planning services. The relief parents frequently felt at receiving a diagnosis also relates to being able to understand their child's difficulties better (Soriano et al., 2015). Missiuna, Gaines, Soucie, et al. (2006) were also in support of a diagnosis being given, stating that "the most important aspect of receiving the label 'DCD' is that, in understanding the nature of this disorder, the secondary consequences may be prevented" (p. 506).

Parents play a large role in the decision-making regarding their child's health needs. A key factor in making these decisions is whether they believe the services and interventions

to be effective (Miyahara & Baxter, 2011). All parents expressed relief at gaining access to help, in particular occupational therapy, with reassurance of their parenting skills and increased knowledge seen as beneficial (Maciver et al., 2011). Some parents did report frustration with the lack of continuity of service as they felt that better coordinated therapy would have benefited their child more (Maciver et al., 2011). They perceived that therapy at an early age was vital for children's development, and indicated that a clearer path for accessing these services was necessary in addition to improved service quality (Maciver et al., 2011; Pentland et al., 2016; Soriano et al., 2015) . They also called for an increase in awareness of DCD (Maciver et al., 2011; Soriano et al., 2015).

Interface with the Education Sector

Parents were often alerted to concerns regarding their child's performance by school teachers (Missiuna et al., 2008; Rodger & Mandich, 2005). According to Dunford, Missiuna, Street, and Sibert (2005), the concerns ranked most highly amongst teachers were; the child's difficulty with handwriting which included poor letter formation, untidy presentation and an inability to record work, limited gross motor skills as well as difficulties with speech and language, concentration and social interaction. Issues with confidence, use of scissors and a need for adult support were also raised (Dunford et al., 2005).

Responding to a questionnaire that asked parents to "identify their main concerns about the impact of their child's motor difficulties" (p. 210) the majority of parents (67%) stated that their biggest concern was the effect of DCD on their child's academic performance and general school related activities (Dunford et al., 2005). These concerns included the following issues; that their child may fall behind their peers, poor handwriting and the limitations this posed with regard to their child's work reflecting their knowledge, limited

concentration, child not being able to join in with play activities due to coordination difficulties and child's poor self-esteem (Dunford et al., 2005). Concerns voiced by both teachers and parents for children with DCD within the school systems are significant.

Once concerns were identified, parents sought help, either at school or with their family doctor, however, most experienced frustration with both of these routes (Rodger & Mandich, 2005). Stephenson and Chesson (2008) reported that all but one mother (11/12) in their study described having to 'fight the system' for their children's rights, especially in respect to educational services (p. 340). Within the educational system parents often experienced the following issues; their child's difficulties being viewed as relatively minor, the lack of services for children with what were perceived as low priority disorders, and limited understanding of DCD amongst teachers (Rodger & Mandich, 2005). Henderson et al. (2001) supported the fact that knowledge of DCD can vary amongst professionals, with teachers often not making the connection between movement difficulties and the child's failure to make progress at school or viewing poor coordination as a medical problem requiring medical intervention. A review of the literature highlighted that in Brazil parents were also most likely to have concerns related to the lack of infrastructure within the educational system to deal with the motor difficulties related to DCD (Galvão et al., 2014). Even when their child's difficulties were acknowledged at school, parents described that they were often overlooked, especially if the child was quiet and did not disrupt the class (Rodger & Mandich, 2005). There is, reportedly, a need for additional services in schools as well as for information and training regarding DCD for parents and teachers (Jasmin, Tétreault, & Joly, 2014).

In summary, one of the major factors leading parents to seek professional advice was their child's increased frustration and the impact on their daily occupations (Dunford et al.,

2005; Summers et al., 2008; Van der Linde et al., 2015; P. Wilson et al., 2013; Zwicker et al., 2018). In their search for services parents experienced frustrations with the health and education systems and at times with the child themselves (Mandich et al., 2003; Rodger & Mandich, 2005). When they tried to access help, several themes emerged; a sense of "maternal knowing" that something was not right, the child's difficulties were minimalised, they felt that they were "going it alone" trying to gain support services, and they were "given the run around" by service providers (Rodger & Mandich, 2005, p. 456). Parental advocacy appeared to be a vital factor in enabling these families to find appropriate intervention (Rodger & Mandich, 2005). Accessing services for children with DCD is frequently difficult for parents who have to navigate both health and education systems to find a diagnosis and appropriate interventions for their child (Ahern, 2000; Karkling et al., 2017; Maciver et al., 2011; Missiuna, Gaines, & Soucie, 2006; Rodger & Mandich, 2005).

What is Currently Viewed as 'Best Practice'

Intervention that focuses on occupation and participation is important in the management of children with DCD. This enables them to be accepted by their peers and to be a "normal kid" (Mandich et al., 2003, p. 594). Hillier (2007), following a very thorough systematic review of the literature regarding intervention with DCD, stated the following; "intervention for children with DCD is strongly supported by a rapidly growing body of literature" (p. 9). However, Hillier (2007) did conclude with a call for further research which "needs to be well designed and multidisciplinary, using a mixture of precise outcome measures as well as general indicators of participation levels in meaningful context for these children" (p. 9). Although the review was performed over 12 years ago and there has been substantial research since then, the essence of this conclusion remains true.

Early diagnosis, educational support and intervention are important as a failure to diagnose and address motor and associated features in children with DCD may have major impacts on their adult life including unemployment, mental health issues, drug abuse and poor personal skills (Gibbs et al., 2007). Early intervention can assist a child to address some of their difficulties. Improvements in the organisation and execution of motor activities can have secondary beneficial effects on body image, self- esteem and increased participation in the community (Eggleston et al., 2012; Gibbs et al., 2007). Parents also identified how early intervention professionals, using a family centered approach, shared strategies and information to support them in gaining a deeper understanding of their children's individual developmental characteristics (Pighini, Goelman, Buchanan, Schonert-Reichl, & Brynelsen, 2014). They expressed how empowering this level of understanding was for them as they learned to articulate their children's needs when liaising with health and educational services (Pighini et al., 2014).

Novak (2013) reviewed evidence based articles with regard to the best practice for children with DCD. She concluded that intervention should be led by individualised, client-centered practice with goals related to occupation and participation, and that intervention should be task-based and related to the child's interests (Novak, 2013). According to Novak (2013), task-oriented approaches and contemporary motor training offered superior motor performance gains to all other approaches, and should be considered best practice. Evidence included children receiving cognitive orientation to daily occupational performance (CO-OP) treatment, who worked on skills they had selected, succeeded in acquiring those skills and became competent in their performance (Mandich et al., 2003). Parents viewed this competence as a very positive outcome as it led their child to believe that they could perform activities of their choice and this often

resulted in increased self-esteem (Mandich et al., 2003). Activity focused therapy can also help to promote social interaction and participation.

For occupational therapists, the findings from Missiuna, Moll, Law, King, and King (2006) illustrated the importance of focusing on occupational performance issues for children with DCD and the need to facilitate parents' understanding of the condition. Identifying factors that influence physical activity habits is important when planning interventions to promote physical activity in at-risk groups, such as children with DCD (Poulsen & Ziviani, 2004). An interesting observation made by Jasmin et al. (2018) was that play should be considered in a client-centered approach to elicit children's motivation. Since children with DCD present with high anxiety and depression, playfulness should be at the heart of interventions to foster positive emotions like humour and creativity (Jasmin et al., 2018). Children should also be encouraged to identify their unique strengths and participate in activities that help develop a positive sense of self (Jasmin et al., 2018). This approach is very aligned to the principles of occupational therapy.

Conclusion

A number of studies have been performed internationally looking at parents' perspectives on DCD (Ahern, 2000; Jasmin et al., 2018; Kadesjo & Gillberg, 1999; Maciver et al., 2011; Mandich et al., 2003; Missiuna et al., 2007; Pighini et al., 2014; Pless et al., 2001; Rodger & Mandich, 2005; Segal et al., 2002; Stephenson & Chesson, 2008; Summers et al., 2008). There was consistency across the literature, with themes related to DCD having a detrimental impact on children's occupational performance, children not growing out of DCD, that obtaining professional support can be difficult, the need for increased awareness of DCD in both healthcare and educational sectors and that clear

pathways as well as ongoing support are required for these children and their families. Without this there is a recognised risk of a child with DCD developing secondary mental health issues. No similar qualitative studies have been performed in New Zealand. There is therefore, a significant gap in the literature particularly pertaining to the first-hand perspective of parents, as key stakeholders, regarding the impact of DCD on the child and the family as a whole.

Client-centered, task orientated services are recommended for children with DCD in the EACD guidelines (Blank et al., 2019). Occupational therapists play an important role in the identification of DCD and with regard to facilitating intervention, particularly participation in occupation (Eggleston et al., 2012). This role includes consulting with the child and their family in order to understand their needs, setting meaningful occupational goals and assisting them to access relevant services (Ahern, 2000; Jasmin et al., 2018; Missiuna et al., 2007). Clinicians and researchers need to pay close attention as to what parents' perceptions and concerns are regarding their child's occupational performance in order to provide effective services (Ahern, 2000; Jasmin et al., 2018), hence the significance of this study.

CHAPTER 3

Methodology

Introduction

There has been little research into this disorder with regard to its impact on children's occupational performance and development within New Zealand. In order to gain a better understanding of this phenomenon, within a local context, a decision was made to interview parents who have a child diagnosed with DCD. As parents have first-hand, in-depth knowledge of the impact of DCD has on their child's capacity to perform and benefit from occupations, and are at the forefront of advocating for their child's needs, the question asked in this study is "What are parents' perceptions and concerns when raising a child with DCD?". Qualitative research with an Interpretive Description (ID) methodology was selected for this study due to the insights that can be gained and the ability to translate them into practice (Thorne, 2016). This approach enables the exploration of the meaning of experiences (Crotty, 1998).

In this chapter, the design of my research will be explained in terms of ontology, epistemology, methodology and methods. I will expand on my position as a researcher and hence my use of practice-based questions. Thereafter, how the research was conducted will be discussed, in terms of data collection and analysis. Ethical considerations and strategies to ensure rigor will also be explored.

Interpretive Description Methodology

A constructivist naturalist paradigm was the worldview that informed my study. As outlined in Chapter One, emphasis was placed on the child's occupations and this was viewed from the perspective of the parent. In this section I explain what a constructivist

naturalistic paradigm means in relation to the ontological and epistemological underpinnings of qualitative, interpretive description methodology, and how that aligns with my professional background as an occupational therapist, including my intent to generate understandings to inform practice.

Consistent with interpretive description methodology, this study explicitly addresses children's occupations in naturally occurring environments. Through knowledge based on an understanding children's developing occupations, therapists will be ready to determine which childhood activities, in what settings promote optimal development (Humphry, 2002) hence, the significance of this study which explores the day-to-day occupations of children within the natural environments of home and school. -

Philosophical underpinnings of Interpretive Description

According to Creswell, Hanson, Clark Plano, and Morales (2007), researchers need to examine the "philosophical assumptions about the nature of reality (ontology), how they know what is known (epistemology), the inclusion of their values (axiology), and the nature in which their research emerges (methodology)" (p.238). Interpretive description (ID) is a qualitative research methodology which is aligned with a naturalistic and constructivist orientation to inquiry (Hunt, 2009). This is a relatively new methodology which arose from the need for a more comprehensive understanding of human subjective experiences and behaviour (Thorne, 2016). That is, for qualitative approaches to extend beyond mere description and to take some form of interpretive analysis (Thorne, 2016).

Ontology

The philosophical framework of ID assumes that absolute and objective knowledge is unattainable (Thorne, 2016). Rather the ontological stance is that there are multiple realities, set in experiences and social context, which are dependent on the person who

holds them (Hunt, 2009). These experiences are subjective and complex. The ontology of ID is based on the perspective that reality is constructed through social interaction and a variety of experiences (Thorne, 2016). Those experiences occur in the natural environment, which is the essence of naturalistic inquiry. It is therefore, important that phenomena be studied within the context of the environment within which they naturally occur.

In occupational therapy, the central ontology is that humans engage in occupations within ever-changing environments and are thereby transformed (Hooper & Wood, 2019). Accordingly, in this study there was a focus on participants' children, their experiences of participating in occupations, and an appreciation of those experiences as complex and subjective. The starting point of this study was the view that DCD has an impact on the child's occupation, as well as on their family, through their everyday experiences of doing things together, and as parents, doing things to support their child with DCD to participate in occupation. These experiences shape the context, the reality, of family life. The study aimed to generate knowledge about the parents' perspective of how this disorder affects them, their child and their family, as well as to detail their concerns. It was anticipated they would give personal, subjective accounts of their experiences and that those accounts would differ from one participant to another and, because multiple realities were acknowledged, there were no right or wrong answers.

Epistemology

The epistemology of ID is that knowledge is co-constructed between the participants and the researcher, taking account of the differing views participants have of the same phenomenon (Carpenter & Suto, 2008), thus "the inquirer and the object of that inquiry influence one another in the production of the research outcomes" (Thorne, 2016, p. 82) The assumption is that researchers can come to understand (interpret) the participants'

view point, which reflects their subjective state; their emotions, perceptions and intentions that are only know to the individual (Carpenter & Suto, 2008). ID studies draw on the "value of subjective and experiential knowledge as one of the fundamental sources of applied practice insight" (Thorne, 2016, p. 82).

ID also acknowledges the information the researcher brings to the study. Occupational therapists' central epistemological premise is that knowledge about occupation is primary and that this integrates biological, psychological and social knowledge. Knowledge in occupational therapy is "bound by its subject, occupation, and its desired consequence, health-promoting occupational engagement of individuals and populations" (Hooper & Wood, 2019, p. 50). In order to construct knowledge in this study, there was a need to be open to parents' perceptions and concerns regarding DCD and the impact it has. Hence, the use of open-ended questions and the ability for these questions to evolve during the data collection process. Acknowledging that the social environment impacts families and this influence changes over time, affecting occupations, expectations and perceptions, it was important that the views of a diverse range of parents be gained in order understand the phenomenon more fully. This was achieved through purposive sampling and careful selection of participants to support diversity.

The use of interpretive description research to explore the parents' first-hand perceptions and concerns rested on the assumption that there is a structure to experience that can be communicated to others in a systematic way (Thorne, 2016) and that is appropriate for the question being asked. In the interpretive description approach the researcher must find and represent the experiences of the participants in the form they are expressed, hence the use of in-depth interviews to obtain rich descriptions. Constructing knowledge of parents' perceptions and concerns will help develop knowledge to support a deeper understanding of DCD and the impact it has on children and their families. Hence, ID was a good fit for this study as it looks beyond the obvious when generating knowledge

(Hunt, 2009).

Aim of Interpretive Description Methodology

The aim of interpretive description is to generate clinically relevant knowledge for applied health disciplines (Hunt, 2009), and thus it can be described as an approach concerned with questions "from the field" (Thorne, 2016, p. 30). This sits well with occupational therapy, which is a pragmatic discipline that draws on knowledge and clinical reasoning to provide intervention choices that can help clients resolve the practical difficulties they encounter in everyday life (Carpenter & Suto, 2008). The aim of this study, as stated previously, was to generate information that will have a practical application hence Interpretive Description, which aims to uncover themes and patterns that inform practice, was a valid approach for this study.

My Position as a Researcher

The aim of this study is consistent with my professional identity as an occupational therapist. The main reason health professionals do research is to develop knowledge within a discipline, hence the importance of acknowledging one's "disciplinary orientation" as this grounds research within the applied field (Thorne, 2016, p. 73). A profession's philosophy is the foundation which helps develop a clear identity, hone professional practice and explain the complexity of a profession. The professional affiliation of researchers using ID inevitably shapes the meanings that are constructed, and must thus be considered in relation to the ontological and epistemological foundations of ID studies. Hence, my professional orientation as an occupational therapist is declared.

With ID the researcher plays a meaningful role in shaping the nature and outcome of the inquiry (Thorne, 2016), hence the importance of acknowledging my disciplinary

orientation as an occupational therapist and my experience in the field of DCD. I have worked as a paediatric occupational therapist for many years, in a variety of settings, both in New Zealand and overseas. My main area of interest has been that of child development, the wonder of it but also the fragility of it, how relatively minor delays can compound to have a significant impact on the life of a child. Through my clinical experience, I have observed how developmental delays, such as those experienced by children with DCD, can have a detrimental influence on their participation in occupation and hence, on their social, emotional and physical wellbeing. My perception, backed up in the profession's literature, is that these delays are frequently overlooked or misunderstood as they can appear to be quite subtle (Missiuna, Moll, et al., 2006). Due to the close relationship parents have with their children, they become a rich source of information about their child's development and the difficulties they experience (Jasmin et al., 2018; Missiuna, Gaines, Soucie, et al., 2006). Parents' knowledge of their child is well-developed (Soriano et al., 2015) and acknowledged in my practice where I view parents as partners in the therapy process. Given that this study focuses on the parents' perceptions and concerns, it does not discuss the child's view. Within my practice, however, I am firmly of the belief that children's viewpoints and occupational preferences are central to the provision of interventions. Like others, I feel strongly that early intervention would play an important role in minimizing the impact of this disorder on the child (Noritz & Murphy, 2013; S. Taylor et al., 2007). However, before this can be advocated for, a deeper understanding of DCD and evidence of its impact from a New Zealand (NZ) perspective does need to be illustrated, hence the aim of this study.

Aim of the Study

The aim of this study is to gain a broader understanding of the impact that DCD has on children and their families from the perspective of the parent. Through asking the

research question that guided this study, my goal is to try to fill a gap in the knowledge, as identified in my literature review, where there is little known about the day-to-day experiences of living with DCD and the impact this has on occupation, particularly from a NZ perspective. I also hope to capture information pertaining to what supports have been accessed by these children, what has been beneficial and what has not. Ultimately, I aim to generate New Zealand based information to inform local health care and education providers as to the needs of these children, and that the evidence obtained will be useful to parents of children with DCD and go some way towards advocating for a more comprehensive and targeted service for this cohort of children. Information gained will also be directly useful to parents and therapists when supporting these children. The study findings will be made available to Dyspraxia Support Group of New Zealand to aid their call for effective services for children with DCD and to provide information to their members.

To quote one participant, *"You are going to take this information and you're going to try and do a good thing out of it"* (Linda). If I can make this happen, I would have achieved my aim.

Research Design

This was a qualitative research study using interpretive description methodology. In keeping with this, purposive sampling was used to recruit potential participants. They included, English speaking parents/caregivers of a child who had a formal diagnosis of DCD and was aged between 5-12 years. Semi-structured interviews were conducted to collect data and analysis of data occurred through deep reading of transcripts, coding and the creation of themes.

Recruitment and Selection

The recruitment of participants for this study was purposive, that is selecting those who meet the criteria set and who have experience of the phenomenon being studied (Thorne, 2016). A number of inclusion and exclusion criteria were identified and are specified below.

Inclusion Criteria:

- Parent/caregiver of a child who has a formal diagnosis of DCD and is aged between 5-12 years.
- That the participant be fluent in English and residing in New Zealand.

The reason for this age limit was that this is the age-range at which a diagnosis is likely to be made and when children are most frequently engaged in therapy (Soriano et al., 2015). Between 6-12 participants were to be included in the study.

Exclusion Criteria:

- Anyone known to me was excluded from the study to eliminate conflicts of interest and power relationships.
- Parents of children who had a significant additional diagnosis such as, an intellectual disability, visual impairment or any neurological condition.

The second exclusion criterion is in keeping with DSM V definition of DCD which specifies that "the motor skills deficits are not better explained by intellectual disability (intellectual developmental disorder) or visual impairment and are not attributable to a neurological condition affecting movement" (American Psychiatric Association, 2013).

Children with an additional diagnosis of ADHD and/or a learning disability such as

dyslexia were not excluded under this criterion, as these coexisting difficulties are commonly associated with DCD (Blank et al., 2019; Eggleston et al., 2012).

In addition to meeting the inclusion and exclusion criteria, I sought to recruit a diversity of participants in order that the findings would represent a range of parents' perceptions and concerns. The demographic form (Appendix 1) collected information related to the child's age, sex, ethnicity, number of siblings in the family, position in the family, diagnosis, who the diagnosis was made by, what services had been accessed, distance to nearest hospital and socio-economic status of the family. Location within New Zealand was also obtained when potential participants provided their address on the demographic form. This information was then used when selecting participants in order to gain as diverse a participant group as possible. The kinds of diversity selected for included; child's sex and age as this gave a range of experiences and occupations, as well as variance in length of time the disorder had impacted the child. Number of children and position in family was included as this gave information pertaining to interactions within the home. It also related to parents' experience of parenting and child development, as well as time they had available to support the child with DCD. Socio-economic status of parent gave an indication of parents' potential to fund services for their child and provide other extramural occupations or not. Distance from hospital/services, and geographical region within NZ were considered in order to gauge how accessible health care and educational services were for the families in question. Ethnicity gave insight into the child's culture and the influence this may have on choice of occupations, expectations, family interactions and values.

Contact was made with the secretary of Dyspraxia Support Group (DSG) of New Zealand. The study was explained and a request made to circulate a recruitment letter (Appendix 2) to all their members. A research proposal and a copy of the recruitment letter (flyer) was then forwarded, as requested, to the organization. This information was reviewed by

the DSG Board and approval granted in May 2017. The flyer was emailed to all DSG members on 24th October 2017 and a notice placed on the DSG face book page (this was the initiative of the DSG secretary). The flyer gave an outline of the study, what was hoped to be achieved and laid out what the expectations on participants would be. Members were asked, in the flyer, to contact me directly (phone or email) if they were interested in participating in the study or if they had any further questions. A further flyer (Appendix 3) was circulated via the DSG approximately 3 weeks later, thanking those who had responded and requesting that those who had not to please do so.

Prior to recruitment, I attended the Dyspraxia Support Group Conference in Christchurch (6-7th October 2017) where I had the opportunity to give a brief outline of my study and inform the audience that an eail would be circulated to all DSG members with a request for participants. I received a couple of verbal responses at the conference from parents stating that they would be interested in participating. As ethical approval for the study had not yet been received parents were requested to await the flyer. The uptake directly related to the conference presentation was not measured.

A very good response to the two flyers was received, with 52 potential participants emailing or texting me directly stating their willingness to take part in the study. I replied to each message individually requesting they send me their postal address if they were still willing to participate in the study. Ultimately, 46/52 respondents supplied their contact details, 4 did not and 2 had to be removed from the study as their child did not have a formal diagnosis of DCD; parents informed me of this in their initial email. I then posted to each of the 46 respondents an information sheet (Appendix 4), a consent form (Appendix 5) and a demographic form with a self-addressed envelope in which they could return the completed forms to me. In the information sheet provided they were encouraged to contact me if questions did arise. All potential participants were made aware in the consent form that participation in the study was voluntary, that they could

withdraw at any stage, their personal information was confidential with their and their child's identity known only to myself, that the interviews would be recorded and that all transcripts and notes would be kept secure. Participant names and those of their children would be substituted with pseudonyms in order to maintain anonymity. Careful records were kept of contact details and dates of when information sent and received, this information plus the returned forms were securely stored.

Informed consent and demographic forms were completed and returned to me by 37 of the 46 potential participants (80% success rate). The good response rate could have been due to the fact that this was a select group of parents, all being members of the DSG, and that due to this were highly motivated to support their child, as well as assist in the generation of further knowledge around DCD. The information received from the potential participants demographic forms was placed on an Excel spreadsheet. A thorough check of this information was made to ensure all potential participants met the specified criteria, particularly as related to the DCD diagnosis and age of the child. Eleven did not meet the criteria and were removed from contention. This was mainly due to conflicting diagnoses. Participants were then selected so as to provide the greatest diversity to the study, as described above.

Selected participants were then emailed to ensure they were still willing to participate in the study. If their reply was affirmative, a time and date for an interview was set. There was flexibility around this, striving to accommodate the participants' availability and other commitments. All participants contacted were willing to participate. The initial two participants were selected and interviewed prior to information being received from all participants. The subsequent eight participants were selected once all participants had responded, with diversity being key to this selection process.

An email was sent to those participants not selected, with an explanation that only 10 participants had been selected and that the selection decision was based on maximum diversity. They were also informed that once the results of the study were completed they would be available via the DSG.

Data Collection

ID allows researchers to explore more deeply the complexities of human experience and is not so much about "collecting data as…constructing an understanding of what constitutes data and how you will articulate it as such" (Thorne, 2016, p. 133). Data collection in qualitative descriptive studies is thus typically directed toward discovering the who, what and where of events or experiences (Sandelowski, 2010).

In-depth, semi-structured interviews were conducted to capture first-hand knowledge regarding each participant's perceptions and concerns of the impact of DCD on their child. Individual interviews are a well-accepted method of obtaining information in qualitative studies as one is able to access "subjective knowledge" (Thorne, 2016, p. 138). Interviews do, however, require that the researcher is an "encouraging and judgementally neutral facilitator" (Thorne, 2016, p. 140). The participants interviewed required guidance for different reasons; a parent became upset when discussing her child's difficulties, she required support and reassurance, while other participants had a lot of information to impart and would move quickly from one topic to another, hence direction was needed in order to obtain the depth of information I required.

Interviews with participants were held telephonically. This allowed me to interview participants around the country, at little cost and at a time that was convenient to them. This was an efficient method as neither the participants nor I had to incur travel time. Telephonic interviews have also been described as "less intrusive and thereby potentially

increasing participation" (Farooq & De Villiers, 2017, p. 311). A pre-prepared guideline of indicative questions (Appendix 6) was used as a flexible guide for the interviews, as opposed to formal questions, as this allowed for a comfortable discussion forum. It also gave me, as the researcher, control over the line of questioning if required and therefore the ability to explore emerging data (Boyce & Neale, 2006). The questions were open-ended.

When compiling the guidelines for my interviews I focused on the child's occupations, thus exploring their day to day activities and how these may have been impacted by DCD. My clinical experience and information gained from the international literature provided useful ideas regarding the content of my guideline questions (Jasmin et al., 2018; Stephenson & Chesson, 2008). I was also strongly guided by my research question. The interview guide allowed for flexibility and included questions related to child's daily routine, their likes and dislikes, what led the parent to believe their child had difficulties, what activities/occupations had the child enjoyed and what had they been prevented from participating in due to DCD, what help had been sought for the child, the process of obtaining a diagnosis, what impact the condition has had on the family, the parents' greatest concerns for their child, and their view as to what would make the biggest difference as well as how they viewed their child's future. With this semi-structured method it was possible to pursue a topic of interest by modifying questions in light of the participant's responses (Creswell, 2003). As data were collected and information reviewed, it was then also possible to adapt the interview guideline in order to pursue areas of interest that I had not anticipated. The guidelines for the interviews were frequently reviewed and discussed with my supervisors. Changes were made in order to increase focus on the day to day occupations of the child. Deeper questioning as to what behaviour "looked like" was also stressed by my supervisors, as well as gaining an

understanding as to how parents became so astute about which occupations would be beneficial or not to their child.

The semi-structured format was well suited to this study in that if an interview is too structured it could lead to participants being less forthcoming in their responses (Wright-St Clair, 2015). It thus ensured relevant information was captured without inhibiting the flow of conversation. The interviews were approximately 60-90 minutes in length. Participants appeared very willing to share information about their child and family. I made notes during the interviews documenting areas of interest, emotional responses of the participant, any emerging ideas and questions that arose. These notes were informal but were a useful tool when reflecting back on the interview and were used to modify the interview guideline for further participants, as required.

The interviews were audio-recorded and transcribed by an independent transcriber who had signed a confidentiality agreement (Appendix 7). Data from these transcriptions formed the basis for this study. Ten interviews were conducted, however, one interview had to be omitted from the analysis as it was only during the interview that it became evident that the child had multiple diagnoses, including that of intellectual disability, which excluded that parent from the study. The final number of participants was therefore, nine.

All the participants were mothers of children with DCD. It would have been preferable to have interviewed both mothers and fathers, however, only mothers responded to the request for participants, with the exception of one father. This father was not interviewed as his child's demographic details did not fit the selection criteria. The children were aged between 6-11yrs, 3 females and 6 males, ethnicities included Maori (2), NZ European (5) and other (2). Six families lived within 15km of a hospital, two within 10-15kms and one more than 30km's away. Geographical distribution within New Zealand

included, Christchurch (4), Mosgiel (1), Nelson (1), Upper Hutt (1), Wellington (1) and Masterton (1). Three families identified as being of high socio-economic status, five of middle and one of low. All the children had a formal diagnosis of DCD, with two having a dual diagnosis of DCD and ADHD, one having DCD, ADHD and Dyslexia and one with DCD and Dyslexia. Four of the children were an only child and four were first born but with other siblings, indicating that 88% of the participants were first time mothers. A table collating the participants demographic information is provided in Appendix 8, pseudonyms are used.

In my ethical application, I stated that I would hold a small focus group, the purpose of this was to member check the data received. Once all the interviews had been completed I elected not to hold the focus group as I had a relatively small sample and there was a high rate of consistency amongst the data obtained from the participants. Additionally, families were from diverse geographical areas and the travel involved may have posed barriers to their participation.

Data Analysis

Collection and analysis of data generally occurs simultaneously in qualitative research, whereby they shape each other (Sandelowski, 2010). Analysis of data is both reflexive and interactive as new data is added and new insights gained (Sandelowski, 2010). In interpretive description, the objective of data analysis is in the realm of thematic patterns and recurring ideas. This is an active process which allows attention to shift from individual cases to the whole data set, thus data from all participants eventually being collated into themes (Thorne, 2016). Thorne (2016) reminds us that ID requires researchers to stay open minded and see beyond the obvious.

The first step of analysis was to review each transcript for accuracy. Thereafter, repeated

reading of the individual transcripts for deep understanding of the data and critical reflection was engaged in. As the data were reviewed, conceptual or meaningful units were identified and coded, and then organized into categories (Thorne, 2016). This was done both independently and in discussion with my supervisors for the first few transcripts. Transcripts were on word documents and during the process of in-depth reading notes were made in the margins, questions posed and concepts were highlighted. This process was performed on each individual transcript. Codes were then brought together across the nine interviews. It was a dynamic process and occurred as data were received. Recurring ideas started to emerge from the data, for example, difficulty children had with breastfeeding, sleep, handwriting, bike riding and swimming. Children's high level of anxiety, social awkwardness and poor organizational skills were also noted. These recurring ideas were then developed into meaningful units or codes. This process was aided by the fact that there was a high consistency of information across the nine interviews. Raw data and my notes were frequently referred to in order to check for resonance. Data analysis resulted in the meaning units being grouped into themes (Appendix 8). An example of this is provided in Table one.

Parent Statement	Meaningful unit (code)	Theme
"Very aware he was being left behind ...come home and say 'I'm useless, I'm terrible at reading. And he would cry and cry and cry"	Talks himself down	Heartbreaks and worries
"Following that routine really tightly… trying to get everything done in a day…"	Routines	Number one support team

Table 1. Example of data coding and development of themes

Once the codes were collated into themes this gave a comprehensive and cohesive overview of the data from which the findings chapter could then be written. During the write up of these findings, constant discussion was engaged in and feedback provided by my supervisors, with encouragement to analyse the data more deeply. The findings can be found in Chapters 4 and 5 of this thesis.

Ethics

This study was approved by the Auckland University of Technology Ethics Committee (AUTEC) on 17th October 2017, reference number 17/283 (Appendix 9).

Cultural Consultation and Considerations

The legislative basis of New Zealand is bi-cultural so consultation with Māori is very important. The Occupational Therapy Board of New Zealand, Code of Ethics (2015) were reviewed to ensure cultural issues were addressed. As stated there,

> "Te Tiriti o Waitangi is the founding document of Aotearoa, New Zealand. It shapes the diverse historical and sociopolitical realities of Māori and all other settlers and their descendants. Understanding how Te Tiriti affects all our lives is essential for helping people to participate in their desired occupation." (2015, p. 3)

The Treaty of Waitangi principles of partnership, participation and protection were adhered to when identifying how to ethically respond to prospective Māori participants (Hudson, Milne, Reynolds, Russell, & Smith, 2010). The Māori ethics framework outlines; "whakapapa (relationships), tika (research design), manaakitanga (cultural and social responsibility), and mana (justice and equity)" as primary ethical principles that required inclusion in my research (Hudson et al., 2010, p. 4). Consultation with Māori

was important as these children have been identified as being a priority by the Ministry of Health (Health, 2009). Respect and dignity must be shown to all cultures, with their values and behavioural protocols considered.

I liaised with the Māori cultural consultant at my workplace to ensure cultural issues were considered in the proposal for my study. This included my initial flyer, information sheet, consent form, demographic form and the guidelines for my interviews. Suggestion was made that I make allowance for other whanau members or support people to be allowed to join the interviewing process and the inclusion of a Māori verse was suggested for the beginning of the demographic form. Both these recommendations were adhered to. One participant identified as Māori. The transcript from this interview was reviewed by the Māori consultant at my workplace after a confidentiality agreement (Appendix 10) had been signed. No issues arose from this. In his feed-back the consultant stated the following; *"from a cultural perspective… there appear to be no specifically culturally charged comments or discussion"*.

Consultation also occurred with occupational therapy colleagues working in the field of paediatrics, parents of children I have previously treated and other health professionals. This information contributed to my understanding of the needs of children with DCD, the difficulties they experience when trying to engage in occupations and the obstacles families face when attempting to access services within New Zealand.

I am a South African born and educated Occupational Therapist (OT). I have lived and worked in New Zealand (NZ) for 30 years. As a NZ registered OT I am compelled to comply with the Occupational Therapy Board of New Zealand Code of Ethics. Over time I have worked and engaged with a range of cultures. I also lived in Te Kaha, New Zealand for two years which is a predominantly Māori community.

Informed Consent: All participants completed and signed a written consent form. All

participants were given the opportunity to withdraw from the study at any point. No participants withdrew.

Privacy and Confidentiality: The organization I recruited through, DSG, was not informed about which of their members responded to my flyer nor who was ultimately selected for the study. In order to maintain anonymity, pseudonyms were given to all participants and all other potentially identifying information has been omitted from the findings. Contact details for participants were securely stored, separately from the data. The transcriber and Māori consultant both signed confidentiality agreements. All transcripts, demographic and consent forms were kept in secure storage. Electronic data is password protected on my computer to which only I have access. All data will be stored for seven years, thereafter the files will be deleted.

Safety Considerations: During the research process participants are encouraged to share information which they would not usually discuss with a stranger. This can affect people. Sensitivity was shown and the offer of counselling was to be provided should a participant have felt upset by the interview. Participants were informed of this in the initial information sheet sent to them.

Participants were very willing to share their experiences of raising a child with DCD, however, during this process the stress and frustration of struggling to gain professional support, as well as dealing with the everyday demands of the disorder became very evident. One participant became tearful during the interview. In the event of a parent becoming distressed a strategy had been devised. This strategy was as follows; if a parent did become distressed during an interview a break could be given or the interview terminated. If the need for further support was required I would help them identify a counselling service in their area. During the interview I was empathetic, the participant wanted to continue and the interview was completed. I later discussed the episode with

my supervisors and it was decided that I would follow up with a phone call to the participant to find out if she was alright and to offer further support. I did this, she stated that she was fine and did not require counselling. At the end of each interview I asked the participants if they had been comfortable with the process, they were all affirmative.

Rigour

It is important in qualitative research that validity criteria are implemented. They "are essential to guard against the investigator's developing concepts and theories that do not authentically represent the phenomenon of concern" (Thorne, 2016, p. 148). In order to ensure this validity, Thorne (2016) has laid out the following four criteria for evaluating standards in ID.

Epistemological Integrity

Epistemological integrity must be addressed throughout the qualitative research process. In this study, the research question as well as the methods used in recruitment, data collection and analysis all stayed true to the epistemological stance of the constructive naturalist paradigm which is closely aligned to ID (Hunt, 2009). Consistency between the research question and the philosophical assumptions of the Interpretive Description methodology was, therefore demonstrated. This is important in that it indicates a "defensible line of reasoning" throughout the research process (Thorne, 2016, p. 233).

Representative Credibility

In order to achieve representative credibility theoretical claims need to be consistent with the methods used to sample potential participants (Thorne, 2016). In this study, I used purposive sampling, that is recruiting people with knowledge of the phenomenon being studied, to identify potential participants. Then in the selection of actual participants I

attempted to achieve maximum diversity by referring to the demographic information obtained from this group. These methods are true to the theoretical claims of ID.

Credibility of data was achieved by using interview techniques consistent with ID, adjustments to guidelines to ensure pertinent data were being collected and in-depth analysis of data. Frequent evaluation was provided by my supervisors.

Analytic Logic

For interpretations and knowledge claims to be made based on research performed there does need to be evidence of an inductive reasoning process. This logic needs to be visible throughout the study (Thorne, 2016). In this study, data analysis was through in-depth reading of transcripts, coding of data into meaningful units (individual transcripts initially, then across all nine interviews) followed by the generation of themes. Thick descriptions were presented and verbatim accounts have been used to ground interpretive claims. Analytical decisions were documented and are therefore traceable. These processes of generating findings were carefully monitored by my supervisors who ensured that methods used were robust.

Interpretive Authority

It is important that researchers' interpretations are trustworthy, indicating that they are grounded in data and that the researcher's personal bias or experience is known (Thorne, 2016). To achieve this, it was important for me to declare my background and reflect on any assumptions and preconceived ideas I may have had about the phenomenon being studied. The aim of this strategy was to be transparent regarding these thoughts and to consider their possible influence on data collection and analysis (Stanley & Nayar, 2014). I was, therefore, interviewed by an experienced researcher which allowed my

thoughts, assumptions and knowledge regarding the phenomenon to be explored and documented in a presupposition interview. I was then able to refer to this during the research process, ensuring any personal bias was kept in check. My profession as an occupational therapist and experience of the phenomenon was declared earlier in this chapter. Supervision also played a major role in maintaining trustworthiness of interpretations.

Conclusion

In this chapter the methodology used, Interpretive Description, was described and its philosophical underpinnings explored. My position as a researcher was made clear and the aim of the study stated. The methods used for this research were discussed, these included sampling, data collection and analysis. Ethical considerations and strategies used to enhance rigour in an interpretive description study were also described. In the following chapters, four and five, the findings of this research, as related to the perceptions and concerns of parents with children who have DCD, will be discussed.

Chapter Four

What Mothers Noticed and How They Provided Support

Introduction

Chapters four and five report the findings of this study. Information obtained from the nine participants interviewed is discussed under five main themes pertaining to parents' perceptions and concerns when raising a child with DCD.

In chapter four there are three themes, firstly, "something was a bit off" which looks at what parents noticed as being different about their child, as well as how they came to grips with understanding DCD. Secondly, "number one support team", this section reviews how mothers attempted to provide support for their child, the strategies they employed to assist them and the occupations they guided their child to participate in. And thirdly, "heartbreaks and worries" reviews the emotional and social challenges, for both child and mother, resulting from the impact of DCD.

Something was a Bit Off

All mothers became aware, from when their child was very young, that there was something a bit different about them. These concerns often grew as their child developed and subsequently struggled to keep up with their peers. When mothers were asked about their perception of their child's development as a baby or toddler, they reported one of two responses. They were either of the view that there was nothing significant to be worried about, that their child would catch up or they felt that their child was not keeping up with others and that this was of concern to them.

Those who ascribed to the first view described thinking that even though their child was experiencing some delays these issues were not notable enough to be alarmed about. Linda thought that her child would *"get things in his own time"* which was supported by other parents such as Rose who had stated that *"it will be fine"*. These mothers believed that the difficulties their children were experiencing were not clearly definable and so subtle in nature that given time they would catch up, they could therefore, *"wait and see"* (Lauren) what happened before considering any intervention. This stance was common amongst the mothers interviewed and could partially be due to the fact that for nearly all of them (8/9), this was their first-born child. They did not have another child with whom to draw comparison and therefore, limited knowledge of what the norm was regarding early development. Professionals they encountered frequently affirmed this stance that the child would grow out of his/her difficulties, with statements such as, *"it's nothing, don't worry about it"* (Jess). As Lauren stated *"the gap wasn't big enough"* or that *"maybe's he's just not into some of the stuff typical boys are....in terms of his physical skills"*. Trying to keep calm and *"not to stress out about things"* (Meg) was another tactic taken by this group of mothers.

Other participants felt more concerned about their child's development and were aware that they were not keeping up with their peers, they were *"a lot slower"* (Marie). This was noted despite the mothers' belief that their child was capable, as Marie commented *"he's much brighter I think than he's able to do"*. There appeared to be a gut instinct amongst these parents that something was just not right or as Jenny put it, *"something was a bit off"*.

Early Signs

Even though mothers had different responses to their child's early developmental delays, the areas in which they noted these differences were similar. For example, many of the mothers identified strongly with it being a struggle to breastfeed their child. The term *"not latching on"* was used by Linda, Meg and Helen in association with their child not been able to attach to the breast. The initial stages of breastfeeding were particularly difficult for the mothers, with them finding this to be a stressful and exhausting period. Helen and Lauren used strong adjectives such a *"terrible"* and *"horrible"* to describe their breastfeeding experience. For most mother's this was their first child so they were inexperienced and also felt pressure to *"do everything right"* (Helen). The mothers discussed having to be persistent in trying to succeed with breastfeeding over many weeks, with some giving up. Helen talked about the fact that she resorted to using a bottle but even then, her child took up to an hour to feed due to poor latching and sucking reflexes. Some parents experienced guilt at not succeeding in breastfeeding their child, as Lauren voiced, *"I just thought well this is my job and I can't even get him to feed"*. In looking back, a few parents felt that the child's DCD may have contributed to the difficulties they experienced with breastfeeding, Helen stating *"now I know why"* and Lauren commenting *"I don't think it was just me, I think it was also him"*.

Not being able to fall asleep, struggling to remain asleep or early wakening were the issues related to sleep that a number of these children encountered. They experienced these difficulties at different ages, some as babies and others at school-going age. These issues appeared to be mostly aligned to them being either overwhelmed or worried about something. Jenny described her child's sleep patterns as *"horrendous"*, that her son would *"literally bounce off the walls"*. Amy stated that her son would get so tired but would still not want to go to sleep. These behaviours naturally led to negative

consequences for the children with them struggling to concentrate, *'falling asleep in class"* (Jenny), or as described by Linda being *"really groggy in the morning…like a lump"*. Amy explained that if her child had had a difficult day then he was less likely to sleep and that they had been to both *"paediatrician and child development team… because anxiety has led to sleep deprivation"*. These sleep difficulties also impacted on the mothers, *"I ended up being so exhausted"* (Linda).

Late with Everything

There are specific areas of development, such as crawling, walking, talking, which children normally reach within given periods of time. These are known as milestones. Most of the mothers interviewed for this study described subtle delays in their child reaching these milestones. *"He's always been different…right from the get go…he never crawled, late with everything"* is how Jess described her son. Her explanation that *"if you're in an antenatal group* [where] *everybody else's child is walking and your child is not"* made it clear that the mothers interviewed were increasingly aware of their child's failure to meet the normal milestones. Marie stated that her child spent *"little time crawling"* and Meg described how her child *"wasn't like an early mover"*. When her son started school, Lauren reported that the *"other kids were just lapping things up and he wasn't"*. These mothers were aware that while their children were *"not that far behind"* (Lauren) or *"maybe a year behind"* (Marie) initially, the lag was clearly evident once they started school.

The majority of mothers commented on difficulties their child experienced with eating. Lauren's statement that her child *"got food everywhere"* was one shared by a number of participants. The children's struggle with accuracy when trying to feed themselves was noted with comments like, food *"wouldn't always go in his mouth"* (Marie) or she was a

"messy eater…food around her mouth" (Meg). The ability to use utensils was also raised as an issue for these children, with Helen saying that *"I still cut things up…he's ok with cutlery now but that has taken a very long time – it's still quite awkward"*. The organisation required in getting food prepared was another element of eating that was highlighted. Marie stated that her son, aged 6 years, was only *"starting to put his own weetbix in his bowl"*, something her other child had been able to do at a much younger age.

The process of dressing appeared to be an area of frustration for these children, both from a fine motor perspective, e.g. tying laces, doing up buttons (Linda) and from an organisational perspective, that is finding the correct items, which could *"take ages"* (Marie), as well as the order and orientation in which clothes should be put on. Lauren described her son as putting on his vest *"inside out, upside down and kind of had it back to front"*. Various strategies were used by parents to assist their children. One mother said *"I have to put everything out for him…it all has to be in the right way"* (Marie). Or as Meg stated, her child will wear *"what is easiest for her"*.

Toileting was an area of concern and social embarrassment for some children. Helen stated that her son was still in night nappies until just before his 10th birthday and Lauren reported that her son *"hasn't gone to school camps…toileting still an issue"*. This issue can impact on their inclusion in social activities such as staying with friends or school events as mentioned above.

Activities such as swimming and bike riding frequently highlighted the coordination difficulties these children can experience (Meg). Their motor skills are often significantly behind those of their peers as seen by Rose in her son, who was *"not particularly*

athletic...wasn't very good at sport". Linda noted that her son was inclined to *"shuffle when he walks".* Helen recalled that her son *"couldn't manipulate lego…difficulty getting some bits apart",* he subsequently played *"more with cars than things he had to manipulate".* Using scissors and writing, *"lines sort of mean nothing to him"* were skills which Marie found her son struggled to master.

In addition to observations related to everyday occupations, some participants pointed to avoidance or seeking specific sensory experiences. Helen describes her child as *"avoiding messy stuff"* and explained that he *"didn't like getting his hands dirty".* She stated that he did not tolerate loud noises and was very sensitive to odours. He did not like wearing wool and the labels in his clothes needed to be cut out. An ongoing frustration for Helen was that he *"chews his clothes…to the point of holes"* and that other strategies such as chewing gum and chewy sensory toys had not been successful in deterring this habit.

"I had no Idea" - Lacking Knowledge of the Condition

There would appear to have been little awareness of DCD amongst the mothers prior to receiving their child's diagnosis. They, therefore, had little understanding of presentation of the disorder nor the impact it would have on their child. This was summed up by Meg who stated, *"I had no idea that it existed and what is was and how it would affect her".* Similarly, Rose exclaimed *"Oh my gosh, you know I had no idea what he might be experiencing".* Another mother, Helen said that she looked up the condition on the internet and while reading about it was going *"oh my goodness".* Rose reported that she had only heard the word *"bandied about".* Some parents struggled to understand the complexity of DCD, *"we don't know what's going on – if he's lacking sleep, anxiety…"* (Amy). The participants put effort into seeking information that confirmed their concerns

were real and that their perceptions about the nature of their child's difficulties were accurate. DCD is a perplexing condition to understand. One mother, Meg, stated *"It's taken me maybe 3-4 years to try and kind of feel like I'm only really understanding what it's like for her and not even fully"*.

As mothers' awareness and knowledge of the condition developed, they appeared to become more aware of their own or other family members behaviours, often identifying with the symptoms their child was experiencing. One mother said, *"I suspect I have it ... my school reports were all good except for handwriting and PE…I'm always clumsy and falling over...avoid doing things that are going to show me up"* (Helen). A father reportedly stated, *"I must have had it as a child"* (Linda), while two mothers, Marie and Lauren, had nephews with the condition. Jenny, having had experience of the condition herself, was protective of her child stating, *"I do not want her to have the same struggles"*.

Participants also described their perception that there was a lack of understanding of the condition amongst others in the community. Many felt that people looked at them *"blankly"* (Rose) when they explained that their child has DCD or as Lauren experienced, *"I don't think it was taken very seriously"*. People *"do not understand the challenges that people with dyspraxia have… that there's a lot going on for him and he's not being lazy"* was Amy's view. One mother even had a Paediatrician say to her, *"Oh, I've never heard of this before"* (Jess). Some mothers worried that the lack of awareness amongst professionals could lead to delayed identification of the disorder, as Lauren pointed out *"if I hadn't had my nephew with dyspraxia we probably wouldn't have picked up on it, a lot of damage can be done in that time"*.

People were confused by the inconsistent nature of DCD, as Jenny described, *"one day someone might think you're pampering her and the next day they think oh you're being too hard on her"*. This could leave mothers feeling judged, for example, *"sometimes I get caught in the trap…I'm a bad parent, he should be doing this, he should be doing that, I've got to be more tougher on him"* (Amy). Due to a lack of understanding, family members could also be critical of how mothers manage their child with DCD which is what Lauren found with her husband's family; *"They don't really get it…they just think that maybe we're just being too soft on him"*. It is not surprising that some participants stated that friends, *"just don't get it"* (Amy). This lack of understanding of DCD makes it very difficult for parents who can ended up feeling unsupported. As was the sentiment of one mother, *"it is hard, you just end up running on a hamster wheel when you're constantly judging yourself and your bad parenting"* (Amy).

Parents biggest call was for an *"understanding"* of DCD (Helen, Marie, Amy and Linda).

> *"A realisation that his brain does work differently…he does need extra time to process things…he's not going to get things straight away and that if he gets it one day he may not get it the next…that it doesn't mean that he is stupid"*. (Helen)

This was added to, with calls for *"tolerance and acceptance"* (Helen) as well as *"compassion and empathy"*, especially *"within the school environment"* (Marie). These attitudes can significantly enhance a child's experience of school. To support increased understanding and awareness of DCD in the community, Lauren suggested *"more money for DSG…so they could go out and talk to schools…being out there in the public and letting people know"*.

In summary, all parents perceived differences their child's early development compared to that of either their peers or siblings. These differences included, difficulties with sleep and breastfeeding, poor eating and dressing skills, taking a long time to learn new skills such as bike riding and swimming as well as great difficulty with organisational skills. Despite having opposing initial responses to these observations, that is, either to wait and see or to seek advice, these mothers eventually all sought a diagnosis for their child. Knowledge of DCD was very limited amongst this group of mothers prior to diagnosis. Understanding of the condition was also reported to be lacking within the community. However, putting effort into increasing their understanding of the disorder did assist parents in managing their child's needs and helped to validate their perceptions of the difficulties their child was experiencing, as well as their parenting.

Number One Support Team

The mothers interviewed played a significant role in providing support for their children. They worked hard to gain an understanding of the condition and in order to address their concerns about their child, became strong advocates for them. They employed useful strategies to assist their child to overcome difficulties and were astute as to what occupations they perceived would be beneficial for their child and which would not. Two mothers described the lengths they would go to, to support their child. *"I was desperate to just do the best for him that I possibly could."* (Rose) *"I'm her number one support team…I'm her teacher and her psychologist as well as her cheerleader…I'm her comfort, I'm her security blanket"* (Jenny).

Other parents talked to the fact that they were the central person arranging support for their child, *"the whole way it's been me pushing for it"* (Lauren), *"coordinating a lot myself…a big job"* (Rose) and *"took it on myself to get hold of someone"* (Jenny). There

appeared to be a constant need for parents to be highly involved in order to get the best support and intervention they could for their child. They also pushed for expert advice in order to know how best to help their child. There was a strong feeling amongst these mothers that if they did not support their child, nobody else would.

Nearly every participant, when discussing useful strategies to assist their child, talked about the importance of routine. *"Following that routine really tightly…trying to get everything done in a day…it's hard sometimes"* (Rose) and *"routine, before and after school…she wants to follow the rules and be organised"* (Meg), are two examples of this. Marie, Jess, Amy and Jenny also all commented on the benefit of *"routines"*.

Parents used various techniques to achieve these routines. Meg, *"put images on the wall"* and used *"really clear instructions"*. Rose said that her son was *"constantly needing prompting"* while Lauren reported *"I'm not good at doing that* [routines]*…I do try…made a picture of the things I wanted him to do in the morning…I do feel I have to nag…don't like doing that"*. Jess felt her son required *"lot of nagging"* to dress himself and a *"lot of nagging to finish breakfast"*. Some parents talked about *"prompting"* while others used the term *"nagging"*. Nagging is generally accepted to be a more extreme form of prompting, it is defined as "constantly harassing someone to do something" ("Nagging," n.d.). It was interesting to note that the two parents who described *"nagging"* both had sons who had a dual diagnosis of DCD and ADHD. It is possible that due to the child's distractibility their parents were required to persistently intervene to keep them on track, resulting in a perception of *"nagging"*.

Some parents found it useful to *"break everything down"* (Linda) or use *"steps"* on a white board *"that he needs to do to get ready for school"* (Amy). Rose stated *"I need to*

train him….so very slow at so many things". While Amy found setting a timer and giving her son half an hour where *"he's allowed to do whatever he needs to do to be able to wake up…lying there, iPad, reading"* worked well, *"he needs that time to prepare himself for the day"*. Some children where good at developing their own strategies. Meg's daughter, for example, would *"practice hard to master a task"* and found that if she *"breaks it* [activity] *down"* so as to practice bit by bit, that worked for her. Other strategies she used were *"to be in charge", "be goofy to deflect"* or use *"a lot of guessing"* (Meg) in an attempt to cover for her difficulties.

Parents obtained ideas on how to help their children from a variety of sources. These included, *"reaching out to other parents"* (Linda), using the *"internet"* (Meg), *"my sister is an OT…I see what stuff she does…pick up on ideas"* (Meg), *"face book page was useful"* (Lauren) and being a member of the DSG, was helpful as *"I know they kind of get it"* (Lauren). A variety of other supports also mentioned as being useful included, access to the *"disability allowance"* (Helen and Lauren) which was useful for purchasing services their child required, the *"special needs library"* (Lauren) and *"socially speaking"* [social skill programme] (Helen).

Out of School Occupations

Like any other group of children of this age, children with DCD enjoyed a variety of occupations. These extra-mural occupations were generally selected for one of two reasons, either enjoyment, because the child wanted to participate or because the parent thought the activity would be beneficial to the child. There were two sports which Marie's son enjoyed, soccer as she said there was *"not so much to think about"* and tennis as he had *"lessons at kindy…got those early skills"* and therefore, *"felt good about it"*. Marie also reported that her son's *"second season of cricket was a lot more successful"* than the

first. From what Marie described, her son's enjoyment of these occupations appeared to be based on a number of factors, that either the task was not too complicated, the fact he had learnt the skill at a young age and that he had had time to develop the required skills. These finding are in keeping with what is known of DCD, that children can easily become overwhelmed if there is too much going on and that skills do take time to develop, also that exposure to new skills from a young age is more likely to lead to success.

Singing and music were identified by a number of mothers as being preferred activities for their children, with Linda stating that it was an *"emotional outlet"* for her daughter and Jenny felt the activities played to her daughter's *"own strengths"*. There were, therefore, additional benefits to these activities which the parents perceived to be advantageous for their child. There were a number of other activities the children enjoyed, including *"strategy games… reading… iPad"* and *"hip hop with a friend"* (Amy). Jess's son enjoyed weekends, *"loves going to the beach, fishing with Dad, walking the dog"*. Helen's son was *"very interested in birds and animals"*, while others favoured *"lego or computer games"* (Jess and Lauren). Jess's son reportedly *"loves working… stamping envelopes, dusting…he quite enjoys doing it because it's not school…probably takes longer to explain to him what we want …he likes the big picture…he needs to know why"*. *"Everyone not doing the same thing"* was Lauren's son's criteria when it came to activity selection, which could be related to the fact there was no comparison being made regarding the end product. The mothers' perception of why these activities were particularly successful related to the fact the tasks were either relatively simple, that the child had time to develop the skills required, that it was a good fit to their child's strengths or that it was an emotional outlet for them. For the child, some reasons for enjoyment included that the task was unrelated to school or that there were no demands being placed on them.

Bike riding was an activity that a number of children found difficult to learn. Lauren's son *"only got rid of trainer wheels when he was 9 years"* …he got *"teased, so spent whole day practising"*. Meg reported that her daughter rode a bike but that it was *"lot of hard work to learn…over at least a year"*. Marie felt that a *"balance bike at 1yr"*…. where *"steps of learning to ride a bike are broken down"* helped her son. Not being able to ride a bike, as with lack of participation in other sports, could be socially isolating for a child. Amy reported, *"Yeah, I get a wee bit sad for him – friends off on a biking camp and he can't even ride a bike so you know it's sad"*. Some activities were tried but were not successful. For example, Marie's son tried touch rugby but stated *"I don't like them touching me"*. Linda's son found *"anything with a team difficult"*. Meg's daughter danced, but *"didn't want to do it the next year"*. She also found, through experience, that with holiday programmes *"the environment makes a difference…not the help and support that she needed…so she struggled"* (Meg). The difficulties the children experienced in participating in the above-mentioned occupations stemmed from poor coordination, being overwhelmed in a team situation and the need for a structured environment. This is highly consistent with DCD.

Occupations; added Benefit or to be Avoided

There were a number of activities which parents viewed as being beneficial to their child's development. Meg wanted her daughter to *"do something that helped her express herself, helped her confidence"* so enrolled her in drama classes. Marie was *"very aware that physical skills don't come naturally to him* [her son]…*exposure to as many things as he can… build up his skills before he really realises* [his difficulties]". Amy arranged *"a personal trainer"* for her son and reported that *"his co-ordination is getting better"*. Other activities which parents believed to be of benefit to their child included

"swimming" as his *"separate movements are fine…altogether it turns to custard…slow improvement"* and *"big, fun gym"* for *"gross motor skills"* (Rose). Marie shared a similar view to Rose regarding her child's swimming, stating he *"can do his arms nicely, can do his legs really nicely but can't do them at the same time"*. Jess, Jenny, Meg, Lauren and Helen also involved their children in swimming to improve their physical skills. Meg noted that her child needed *"a lot more time"* to learn the skills required for swimming. Linda enrolled her son in swimming as well as *"Akido…to build up his muscles"*. Almost all parents, therefore, saw swimming as a beneficial occupation for their child. Parents used strategies such as exposure to physical activities and/or use of a personal trainer to address their child's coordination difficulties. Specific occupations like drama or singing were used to try provide an emotional outlet or develop confidence in their child.

In addition to the activities mothers encouraged, their concerns regarding the impact of failure led to avoidance of some activities. Jenny said she *"shied away from ballet…because of her* [child's] *coordination…she would find it really difficult with the sequencing"*. Amy's son *"wanted to do karate and judo"* however she felt *"he didn't have the ability to remember the moves or the attention…so we researched…found martial arts more based on self-defence and fun… worked well for him"*. When Meg's daughter *"wanted to play soccer…talked her out of it…I guess I have to feel like it's in the right environment with coaches that would understand and support her"*. Some parents did try and limit the amount of time their child spent on a screen, with Marie saying that they are now a *"screen free family"* due to fact her son *"wouldn't go outside"* and there were *"tantrums and performances"* but now he is that *"little boy that plays again"*. Another mother explained that she did not want to *"tire him* [her son] *with lots of activities"* (Lauren).

Parents were influential in the types of activities their children participated in. They either encouraged occupations that would help their child develop a particular skill or steered them away from activities where they thought they may fail.

Heartbreaks and Worries

Apart from the known physical issues related to DCD, mothers also had a number of concerns regarding their child not feeling good about themselves and struggling to fit in socially. A high level of anxiety was reported amongst this group of children, with nearly all participants identifying it in their child to some extent. *"Her anxiety goes off"*, was the way Jenny described her daughter's behaviour which she said she was *"unable to control…will become very active"*.

School was the source of anxiety for many of these children. One factor was, *"getting him to school, that's another story…a huge battle"* (Amy). Or the child wanting to get to school on time, *"to get what she needs to get done…to feel like she is not running behind"* (Meg). Her anxiety was evident in that she *"bites nails…fingers in mouth…chews her clothes"* (Meg). Lauren's son, worried *"at night about school… worrying about being able to do a task…worrying that he's upset someone…worrying that someone's not going to be his friend anymore"*. Thus, school related anxiety appears to stem from a variety of factors including; arriving on time in order to get ready for the day, social acceptance and getting tasks completed on time.

The unpredictable nature of the anxiety was described, *"it* [anxiety] *comes in waves…you just don't know what's going to set him off"* (Marie). Anxiety also seemed to prevent some children from taking part in what would normally be enjoyable experiences, for

example, *"not wanting to try new things…wanting to stay home…often opting out of things"*…stating, *"oh, I can't do that, or no, I'm not doing that"* (Lauren). Lauren also said that her son had missed spending *"nights at grandma's"* and Jess reported her son *"hasn't gone to school camps"*…as he *"won't go by himself"*.

One participant alluded to a family history of anxiety by stating it was *"kind of in the family"* (Lauren). A high incidence of anxiety was reported amongst this group. It significantly impeded the child's participation in activities and social interactions. Anxiety was described as an area of great concern to these mothers.

Mothers also talked about their child being easily overwhelmed, *"very sensitive…upset over very minor problems"* (Linda). One mother gave the example of her child who will *"get muddy if he chooses to but if somebody splashes him, it's melt down, it's like the end of the world"* (Marie). Meg discussed how *"if there is too much going on…noise…brain overloads"* and that her daughter will become *"panicky…talks quickly…throws* [things] *and stomps off…"* shows *"her frustration at the world"*. Some children did appear able to learn new strategies to manage their outbursts. Helen said that her son has,

> *"sort of been able to hold it together…last year probably burst into tears or yelled…now waited until he got to the car…that's when he started crying…we were really proud"*. We *"remind him to calm… definitely improved"*. (Helen)

Children with DCD do have a lot to contend with, constantly trying to keep up and process information. It is, therefore, understandable that they feel it is all too much at times. Learning new strategies for coping with stressful situations can be helpful.

"Talks Himself Down"

The children's self-esteem appeared closely aligned to their awareness of how they were

performing compared to their peers and/or siblings. Marie gave a very clear description

of her son's experience at school;

> *"He was aware that his peers were moving on…he was being kept at*
> *the same* [reading] *level because he didn't have the speed and*
> *fluency even though he knew all the words…very aware he was*
> *being left behind…would come home and say 'I'm useless, I'm*
> *terrible at reading' and he would cry and cry and cry…It's so*
> *heartbreaking…he was trying his best all the time…he can't fix that*
> *his confidence is gone, he thinks he's terrible and crap at*
> *everything…He's started wetting the bed again… it was all just*
> *miserable".*

Jess gave almost the same account of her son's struggle;

> *"Seeing everyone else in his class read and write…and he*
> *can't…he's different and he doesn't like being different…he hates*
> *failing in front of people…he tried really, he just wasn't the same as*
> *the other kids and they would tease him…bullied on the [school]*
> *bus…gets bullied as well at school".*

What parents reported as finding particularly hard was watching their child lose interest

in learning. Meg stated her daughter,

> *"noticed things…wasn't writing as much as the other kids and as*
> *quickly…finding it more difficult…she was really aware she wasn't*
> *doing as well as the other kids…used to love writing…she hates*
> *writing this year… she's super enthusiastic…then she sees other kids*
> *doing it and it's really hard for her and she loses her enthusiasm*
> *quite quickly".*

Lauren's son, whom she described as a *"confident kid at play centre…trying different*

things …excited about his learning"… now*, "after a year at school…not making*

*progress"…*is *"not really enjoying being at school"* and is saying things like *"I'm*

dumb". In the classroom, differences in level of skill become very evident to both these

children and their peers. This is where comparisons arose, leading to teasing and

ultimately bullying in some cases. Similar issues could occur in the home environment,

with Meg voicing concern that her daughter is *"watching her* [younger sister] *come*

*up…she's going to find that quite hard"…*she uses…*" 'I don't care'… 'I don't want that anyway'"* tactic to *"opt out".*

He knows he's *"a bit more challenged than everybody else"* was Rose's comment about her son, while Helen reported that her son's self-esteem had *"been low"* but had *"picked up a bit with the help he's had".* However, he still *"sometimes talks down about himself…says he's dumb or stupid or useless".* She states *"it's heartbreaking"* (Helen). The saddest remark was from Linda whose son said the *"world won't want me"* and reportedly that he *"wants to kill himself".* This boy was only 9 years old! These mothers described the anguish their children experience in trying to keep pace with their peers. It is their perception that this is a very real problem which does need to be taken seriously. Parents perceived it would be helpful for children with DCD to have *"opportunities to build self-esteem and confidence…especially if they were ones that didn't have to be funded privately"* (Lauren).

"Hope he Finds his Tribe"

Participants were aware and concerned about the difficulties their children experienced when interacting with others. Generally speaking, these children fell into two camps, those that withdrew and those that did not comprehend social boundaries. For example, Jenny described her daughter as being a *"serial kisser…wants everyone to be her friend"* whereas, Linda stated her son was *"more of a timid kind…doesn't initiate…he's a follower".* A few mothers revealed useful strategies to assist their child to overcome these issues. Amy described that,

> *"socially…we have worked on that, surrounded him with lots*
> *of friends…really open with parents* [of his friends] *about his*
> *dyspraxia…He's socially awkward …doesn't get boundaries…*
> *doesn't understand social cues or jokes so we've been working*
> *really hard with him on understanding…teaching him little cues…*
> *doesn't always work…you just have to keep going and going"* (Amy*).*

Linda felt that her son was most comfortable with *"long standing friends"* or with *"children with disabilities"*. Being too trusting was an issue perceived by this group of mothers to be a problem. Meg said *"I'm trying to teach her about trust…I feel like she's not getting it"* while Amy said her son was *"very lovely and a bit naïve…"* she was *"always worried someone might snatch him away"*. Other observations made by participants included, *"kids won't want to play with him because he is a bit different or learns differently or thinks differently"* (Marie), *"he is very shy with adults, barely looks up…not keen on big groups and crowds"* (Linda), he *"enjoys playing with younger children…they are at his level"* and that *"he does not have half as many playdates and stuff as my daughter"* (Lauren). Parents were able to appreciate the positive attributes of their child, with Helen saying *"he's got a good sense of humour…very kind…empathetic…he's a nice kid"!* Children with DCD do require guidance when learning to interact with others. Mothers perceived their children as being vulnerable, to either being taken advantage of or of being ostracized by others. The children themselves often selecting younger children or children who have difficulties to interact with, feeling safer with them.

When considering the future, social acceptance was an area raised by a number of participants, with Amy stating, *"the social aspect will be the most difficult"*. Helen succinctly described the…

> *"hope that he finds his tribe"… "that he finds other people who have the same sort of interests as him, he has friends… some sort of social group…that he can get a job that will interest him, enable him to support himself"*.

Mothers worried that if there was no intervention to assist their children to address the social and emotional issues they experienced then these problems could escalate as their child got older. These concerns included, *"worry about her* [daughter's] *anxiety…getting*

depression" as well as *"problems with relationships"* as she *"doesn't have those boundaries"* (Jenny). Meg felt that her daughter could be *"easily lead astray to try and fit in"*. That *"teenage pregnancy or drugs"* could be an issue as *"she is not showing signs of being able to make good decisions…"* also how was *"she going to be able to support herself"* (Meg)?   Looking ahead Marie worried that *"doors are closed"* to her son, while Linda voiced the desperate hope *"that he* [her son] *is alive"*. These are very real issues that are the source of significant stress for these mothers.

Impact on Others

DCD impacted not only the child with the disorder but had a significant effect on the parents raising the child and the family as a whole. Participants described the demands as *"relentless…there is so much there you know - there's stuff every day"* (Jenny). *"It's been hard work for us as parents and frustrating…lot harder for him* [husband]*…he doesn't understand…hasn't spent as much time with her… not having conversations with professionals* [as he is working full time]*"* (Meg). Other statements received included, *"life is so hard"* (Jess), *"I get angry…I get tired…very exhausting"* (Linda) and *"you trudge along and do the best you can"* (Jess). The emotional toll taken on these parents was clearly evident.

The family's circumstances played a role in the extent to which they could advocate for their children. For instance, having only one child did allow parents to have more time to provide support, as Amy explained,

> *"only one child so able to take that time with him - take our time in the mornings…coax him out the door, go to activities he needs, we have time to do that…if we had another child that would be completely different"*.

There was a financial impact for many families, often having to fund services themselves or cut back their work hours to be home for their children. Parents frequently made big sacrifices for their children. *"Thanks to him* [husband] *we're able to afford the things that we can… we do what we need to do privately because we can't wait for the public system"* (Amy). Another parent chose to *"take out a mortgage to get him the best help"* (Linda). Others reported,

> *"I don't work in the afternoons…had to cut my hours"* (Jess) and
> *"I don't work so I can support him...so I can be the one who goes*
> *to school and chase them…this isn't working, what are you going to*
> *do about it? You have to be one of those parents"*. (Amy)

Lauren explained that the new school she sent her son to was more expensive, hence her *"doing jobs* [at the school] *to help pay for it"*. The following statement summarises what it can be like for both parents and the child *"he's been working extremely hard and so have we"* (Linda). Some families were left feeling resigned, *"they are not bad enough to warrant, you know, funding I suppose…but they're on that line… it is what it is"* (Jess), or *"challenging…bad meltdowns and sensory reactions…made it difficult to do some things…certainly had to change the way we do stuff…we just have to accept it"* (Helen). Mothers struggled, often having to juggle a number of demands; supporting their child with DCD and the day-to-day requirements of this, working hard to obtain the most appropriate services for them, ensuring that all was well at school, trying to meet the financial obligations of obtaining intervention and attending to the needs of the rest of the family. With all these demands it could be easy for parents to neglect their own needs. They too need support, as was evident from the accounts given.

Mothers described that raising a child with DCD has *"been hard work…and frustrating"* (Meg) and that expectations had to change, *"you have all these dreams and aspirations…that changes, it just has to change"* (Amy). Hence, considering their child's

future can be difficult for some parents, something some struggle to face. Amy simply stated, *"I'd rather not think about it".*

Conclusion

Mothers were aware, from when their child was young, that they had difficulties. These issues covered a range areas including; breastfeeding, sleep, self-care, play, sport, social interaction and academic tasks. These mothers worked hard, often to their own detriment, to rally support for their child. They often felt that they were their child's sole advocate. Strategies were developed to assist the children with the demands of day-to-day life, the most commonly adopted one being "fixed routines".

The participants were highly influential in the occupational choices their children made, this often depended on what they perceived would, or would not, be beneficial to them. Occupations selected were frequently based on the need to try and develop physical skills in their child or to provide them with an emotional outlet. Parents became astute at identifying the difficulties their children were experiencing with occupations such as, poor motor control, difficulty with sequencing, limited memory and attention skills. There was also an identified environmental need for support and structure in order for the child to participate successfully. The fact that they tire easily was noticed by these mothers. Mothers frequently steered their children away from occupations that would expose these deficits, thus becoming quite protective. DCD was perceived by mothers to have a substantial effect on their child's social and emotional wellbeing. Issues raised included; the child feeling isolated, not developing adequate boundaries to keep themselves safe, emotions related to inadequacy and low mood as well as feelings of being overwhelmed. These mothers were clearly able to describe the wide-ranging impact that this disorder has had on their children and the lengths they are willing to go

to, to support them.   In summary, DCD is perceived by mothers to be of concern in that the child's ability to have fun with others, take part in sport and perform well at school were all areas negatively impacted by this disorder.

Chapter 5

Going into "Battle" with the Healthcare and Education Sectors

Introduction

Mothers sought assistance for their children from both healthcare and education services. This chapter explores the interface between the families and these sectors. There are two themes, firstly, "The one's who fall between the cracks", this discusses the challenges families encountered when dealing with the healthcare system. Mothers described the difficult process of trying to obtain an assessment and diagnosis, as well as the long wait to access services. Support that was beneficial is also reviewed. The second theme is, "Don't think school knows what to do with him", this explores the challenges the child had in performing academic tasks, the mother's perceptions of the teaching support received as well as their experiences when engaging with the education system.

"The Ones that Fall Through the Cracks"

Children with DCD usually entered the medical system when their parents started to look for answers to their concerns or when it was recommended by a professional that their child be assessed. Having their observations taken seriously was an issue for some mothers, as Jess explained,

> *"so right from when he was a baby and every time I had concerns and I would say something to the doctor they'd be like 'oh, it's all right, it's nothing, don't worry about it…he's fine, he'll grow out of it'… I just sat there and said I'm not leaving, there is something not right and I need to know what it is."*

Once it was established that there was a problem, the task was then to obtain a diagnosis. From a parent's perspective, this can be fraught, *"I had to fight to get him seen to get a diagnosis"* (Jess).

Amy empathised saying,

> *"We're quite fortunate that we are able to pay for these things and go privately because it's not cheap. If you had to wait for the public health system…your kid is probably screwed because you have to wait so long."*

Parents' motivation to gain a diagnosis was usually similar to Jess's who said, *"I want all the information that I can so I can learn everything about what he's got, so that I can help"*. It was also felt that a diagnosis *"will open doors for you"* (Amy) in terms of access to supports and that *"once you've got a diagnosis you've got strategies and things you can do"* (Lauren).

Nonetheless, receiving a diagnosis of DCD was upsetting for some parents. Linda stated that she had been *"devastated"*. She cried during the interview as she described that she was *"learning how to deal with it…trying to be patient…I get angry…I get frustrated"*. There were, however, different responses with some mothers being more accepting, such as Meg, *"I wasn't stressed…knew she had dyspraxia…keep an eye on it"* or feelings of hopelessness, *"what do I do now"* (Rose). A contrary view to obtaining a diagnosis was reportedly received from a teacher who *"didn't want to pigeon hole him"* (Lauren). Obtaining a diagnosis was not an easy process for these parents, often struggling to have their concerns taken seriously and then having to wait for their child to been seen and assessed by the appropriate professionals. Once, a diagnosis was received the participants responded in different ways with some feeling pleased to have the information as this would aid them in assisting their child, while others felt sadness or despair.

"Wait Lists are Ginormous"

In dealing with the health system, parents frequently perceived that *"they're* [children] *the one's that fall through the cracks"* and that they had to wait a long time to be seen, *"wait lists are ginormous"* (Amy). Accessing therapy services could be frustrating for these families, *"he really does need an occupational therapist…cannot afford to privately pay for one…on wait list"* (Jenny). Meg, became tearful saying,

> *"it took a year from first meeting to finishing their assessments…*
> *there was no therapy…discharged her…frustrated me…what do*
> *we do about it…how do we help her…no one prepared us for what*
> *school might be like".*

Jess also stated *"there's just no support…we are on wait lists",* although she did qualify this by adding, *"may be different in bigger cities but where we are like rurally…no specialist you can go to …you have to wait".* Mothers were aware of a need for therapy, however, many became disillusioned with the limited availability of supports offered by the public health service. Many did not have the means to pay for or have access to private services. This view was shared by participants from different parts of the country. Jenny stated that, *"we weren't going wait…everyone sort of went into battle".* Jess also described it as a *"constant fight"* with Marie relating, *"we're not waiting for my child to be below* [National Standards] *before we have an understanding of how he learns and or how he operates…so we went privately"* [to a Paediatrician].

The most common issue arising when discussing support within the public health system was the long waiting times. Jess stated that they had been on the *"waiting list for an OT for two years in the public system and we're still waiting".* Lauren mentioned that they had dealt with *"some really good OT's…working around their* [child's] *interests and setting goals…just takes so long to get into for these things…by the time get help you're looking probably a year into the future…quite frustrating".* Due to the long wait times, private therapy services were utilised. Meg employed a private SLT [speech language

therapist] whom she said would see her child at school, *"giving teacher ideas…doing awesome work"*. Mary recalled her son attending *"SLT when little – few key sounds he was not getting"*.

A few mothers voiced concern regarding services they had received, both within the private and public health sectors. One parent raised dissatisfaction with the OT service received, stating *"really just didn't think for the money we were paying it was making a huge difference …we don't do that anymore"* (Helen). Jess reported that they *"tried to get Child and Adolescent Mental Health Service interventions and they just don't give a shit…we had an appointment and they were useless"*. The family felt unsupported when trying to get assistance to deal with a bullying issue at school.

Therapy, particularly occupational therapy, was recommended by mothers and that these services *"should be available for people to access…we had money to pay for OT and things like that and the assessment…but a lot of people won't"* (Helen). More regular OT services were suggested by Lauren and Amy requested *"more access to the medical profession"* when the child is younger. Another suggestion was, *"a central kind of agency would be really, really good"* were parents would be able to obtain information and support regarding DCD (Rose). An important point was raised by Meg who stated *"one thing no one talked to us about is how we talk to* [our child] *about dyspraxia"*. Informing a child about their disorder, what it means, what to expect and providing strategies would be an important aspect in helping them to adjust to their difficulties.

"Don't Think School Knows What to do with Him"

School was not an easy environment for these children. It was frequently here that their difficulties became exposed, resulting in harsh comparisons and at times failure. An

understanding of DCD can often be lacking within schools, leading to incorrect assumptions being made of the child and occasionally the mother.

Once children entered the formal schooling system, they were reported to experience difficulties across a range of curriculum areas including, reading, writing and maths. Parents gave vivid descriptions of the problems their children were having, in particular with writing. For example,

> *"People don't understand the 'art of writing' – it isn't just about holding a pen and making it move, but it's also about the sitting and keeping still and concentrating on what he's trying to write, and write it and spell it and you know all that stuff that goes on."* (Amy)

Two parents, Linda and Meg, gave quite similar accounts of how their child experienced writing,

> *"I don't think he can process how to print letters and write a story at the same time…brain can only do one at a time."* (Linda)
> *"What he's able to write and get down is not reflective of what he knows or wants to say…he can't get it out…too many things to think about."* (Meg)

The difficulties described above resulted in the child's end product being *"not as much or as quick"* as his peers (Meg). Merely, *"holding a pencil"* or *"colouring between the lines"* (Linda) can be challenging for children with DCD. What was very evident from the accounts given was the struggle these children have in doing more than one task at a time, they can manage one element on its own but when required to combine them, they do struggle.

Reading was reported to be *"really hard"* for some children due to the fact that *"you read that word on that page but you do not know it on this page"* (Meg). Lauren also identified that her son was delayed in his reading. Maths was another area Meg stated her daughter found challenging, but that she *"finds everything hard…just trying to keep up with other*

kids". Maintaining their energy levels given the pressures of school could be hard in itself. Marie described her son, saying *"he's just completely run out of petrol"*. These descriptions illustrate the mothers' concerns as to how the motor and organisational difficulties these children experience impact on their occupational performance. These difficulties are highlighted at school as children can no longer avoid tasks they struggle with, which may have been the case at preschool or home.

Teachers – "Hit and Miss"

A number of families did have positive interactions with their school and teaching staff. A supportive environment, together with an understanding of DCD, were usually the two factors which made a difference, as Helen explained, *"a very good, understanding teacher, teacher aid and SENCO* [special educator needs coordinator]…*they've all been really good"*. She went on to state that they were *"not pushing him beyond the point where you know he can't cope…but still trying to extend him"* (Helen). Having a *"small, organised class"* (Meg) with *"one on one reading"* and *"play based learning"* (Marie), where the *"child knew others"* (Meg) and the teacher had prior experience of DCD all contributed to child's success at school. Support at school was greatly appreciated by those that did receive it, to quote Meg, *"this school she goes to is awesome – really keen on helping"*.

However, for the majority of families this was not the case. They had to work hard to advocate for their children and often felt unsupported. Strong views were expressed such as *"they're* [teachers] *not even remotely interested in helping him at all"* (Marie) or that at school it's just like *"would you bloody do it, sort of thing"* (Jess). Helen recounted that when her son cried in class the *"teacher shamed him in front of the class, told him*

not to be a baby". It was, as she described it, a *"really, really, yuck, rough year"* for her son.

Parents appeared to call for flexibility in how their children are taught with statements such as the following, *"not expecting him to learn in the same way as other kids…difference it makes for our children is just huge"* (Helen). Expectations that a child with DCD should *"stand at a desk for 20mins and concentrate…stay still…those things don't work for kids with dyspraxia…so much going on in his brain"* (Amy). The teacher's reported response was *"this is the way we do it"* and that he *"shot me down"* when questioned (Amy). Jess felt that *"one to one is so different than if it's, you know 1 to 30…I can take my time…explain to him why he needs to do something"*.

Helen reported that she,

> *"found it quite disheartening that every year you'd have to explain*
> *to a new teacher* [about their child's disorder]*, despite the fact that*
> *they've got all the reports and all the recommendations and*
> *everything on file …breaking the same ground with a new teacher"*.

There seemed to be little continuity in the method of teaching from one teacher to the next, leading to uncertainty for both the child and their parents. This appeared to stem from a lack of understanding of how children with DCD learn. Generally, participants had a *"mixed response"* when engaging with teaching staff, describing it as *"hit and miss"* (Helen).

Parents' overriding concern was that the school environment can be detrimental for many of these children. Mothers used terms such as *"school is not for him"* (Jess), *"she struggles a lot at school"* (Meg), and *"school life can be miserable"* (Helen) to describe their child's school experience. Marie stated that her son had *"started wetting the bed"* as he was *"not liking school"*. New initiatives at schools, such as the HUB format, have been very challenging for these children due to the open plan nature of the environment.

Jess reported that her son *"just doesn't cope"* and is now in the position where, *"he doesn't want to go to school…at school he is pretty hard work…when he gets home he's pretty grumpy"*.

In response to these concerns, parents tried hard to support their child, like *"making sure that* [her enthusiasm for school] *is maintained"* (Meg), letting the child know that *"if it got too much…could walk away"* and that *"if the teacher had a problem with it, they could talk to me"* (Amy). One parent took the significant step of moving her child to a special character school which she explained was *"more child led, more one to one, shorter lessons and a broader curriculum"* (Lauren). A few teachers implemented useful strategies such as letting the child choose *"if they want to sit at desk they can, if they want to lie on floor they can do that too"* (Amy). Other teachers have used *"incentives to motivate him…touch typing…he is allowed his own device as he can't produce written work to a standard or a speed…for his year level"* (Helen).

Parents' interactions with teaching staff were discussed mainly in terms of conflict. Marie reported, *"we've battled…it's not a fun experience"*. Helen used similar terms, *"a teacher that thinks they know better and they don't…so that again is a battle"*. These views were supported by another participant who explained having to be very forthright in trying to get her child's needs addressed;

> *"I did stamp my feet and say well you know that I'm not happy…*
> *I've made the teacher now text me every day and tell me what he*
> *did that day…I can be a bit stroppy…I am going to keep nagging."*
> (Jess)

Mothers also reported feeling despair, *"his* [teachers'] *belief that he is capable of more is not there…oh, it kills me"* (Marie) and the need to push for support, *"unless I advocate for it…it's just what we do…at the beginning of each term…meetings with teachers…see what I need to focus on at home"* (Amy).

Resource teacher, learning and behaviour (RTLB) was described as a service in the educational system that was beneficial for these children. Marie stated that *"RTLB"* had provided *"strategies for the teacher"*. There were, unfortunately, two accounts where the withdrawal of the RTLB service had resulted in the child's performance declining. He received *"reading recovery…made progress…came off programme…started stalling and going backwards"* (Meg) and we received *"RTLB funding because he got violent…when he started making progress they took away RTLB …now he's dropped two reading levels"* (Jess). Other academic services utilised have included *"SPELD* [SPEcific Learning Difficulties]*"* (Jess and Meg), Kip McGrath for *"English and maths"* as well as a specialist for *"use of scissors and a bit of writing and spatial awareness…this has been the best"* (Linda).

The schools' perceived lack of understanding of the child's needs was a common experience for these parents. This was summed up in a statement by Jess, *"I don't think they really know what to do with him"*. Similarly, from Marie, *"school feels there is no issue – whereas, as his parents we're like there's a huge issue here"* and from Lauren, *"mainstream school didn't seem to get dyspraxia…I got the impression they thought he was putting it on"*. Together with this was the worry that *"school did not bring concerns to parents' attention…only on questioning…work unfinished, very difficult to get him on task quickly"* (Linda). The education system was reported to be a difficult environment for most families, parent and child alike. Much of this disharmony was based around parents feeling unsupported and the child reportedly not receiving the understanding and structure they required in the classroom.

High school – "Getting Lost in the System"

Entering high school was identified as an area of potential concern for most of the mothers. They worried that the social and academic demands in this environment would be very challenging for a child with DCD, as would be the need for self-organisation. Helen's perception was that, she felt *"quite nervous"*. This she related to *"all the transitions in a day …have to be organised…which things you have to take for which subject…who's your teacher…increase in homework … how tired his is going to be"*. Her son had been at the same school for 8 years, *"now he was going to a group of kids that won't know him, won't know his background"*. Helen was concerned *"whether he is going to get bullied"*. This fear of bullying stemmed from the fact that he had been bullied before and was now *"going to school with 300 year 9's...he moves a little differently, looks a bit different"* (Helen) making him, in her eyes, vulnerable. With regard to going to high school other parents worried that their child might *"get lost in the system"* (Linda), *"worry she is going to crash"* (Jenny), or as Rose questioned, would her son have the *"ability to keep it all together?"*. Lauren's concerns related to *"how is he going to go with assessments and organising himself"*. To address these issues, she was considering *"keeping him back a year"*. Lauren also took her son to see his new high school as she said, *"I thought if he sees where it is, what they've got and the teachers aren't scary, he won't worry because he's got this idea and message that you get bullied in high school"*. Another Mother thought that a *"co-ed school was better"* as a *"boys school would be too sporty and macho"* (Rose). Helen felt that *"whole self-management…being able to actually organise himself and look after himself"* would be her son's greatest challenge. With regard to strategies that could be helpful within the school environment, one mother made the following suggestions;

> *"a teacher aide in the classroom to help…so many kids with extra issues that need that extra bit of time to learn something…increasing the knowledge of what dyspraxia is…letting them use*

technology…practice handwriting so they can functionally fill out a form…all they'll ever need it for in the future" (Helen).

Marie, reiterated the need for *"teacher aide support",* as well as addressing *"class sizes, increasing appreciation of how he* [child] *learns and attempting to cater to those needs".* Linda felt that if schools *"could cater for students like* [her son]*…it "would make it so much easier".* A mother who is a teacher, stated that *"learning support is underfunded"* and *"teachers are absolutely loaded",* making it *"a real challenge to accommodate dyspraxia"* (Rose). Amy felt support in the classroom should be introduced earlier, recommending *"support at kindy".* More *"school readiness"* was a suggestion from Jenny. Lauren highlighted that her son was *"probably going to need* [academic] *tuition for the next three years… that there was a financial need to meet the cost of this".* She made an interesting suggestion that *"rather than the disability allowance"* she wished *"that they had some kind of voucher system where they say you're going to get tuition for three years"* (Lauren).

For children with DCD school can be a very stressful environment. They struggle with the demands of the academic tasks asked of them and with the organisational skills required to manage their day at school. Added to this, their teachers often appeared to lack understanding of the disorder and were, therefore, not always able to provide the support required. Socially, they can face being ostracised, teased and even bullied. Mothers perceived the difficulties DCD imposes to become greater as their child enters high school, as this is where social and academic demands increase, as does the need for self-organisation. There was a call for increased awareness of the condition in schools and the provision of more "one on one" support within the classroom.

Conclusion

When support and understanding were received in the education and health care systems families reported how grateful they were as the benefits for their child were evident. Unfortunately, for the majority of participants this was not the case.

With regard to the school system parents reported a lack of understanding of DCD. Due to this they perceived teachers had limited knowledge of how their child learns and what supports they required to reach their full potential. In the health field, mothers' greatest concern arose from the long waiting times to access services, particularly those related to diagnosis and intervention. Due to the perceived failures or inconsistencies of both these service providers, it frequently fell heavily on the mothers to advocate strongly for their child. These participants, with their in-depth knowledge of their children needs, also provided some useful recommendations. But quite simply the biggest need identified was that of understanding of the disorder. To end, a quote from a mother who neatly summed up the needs of a child with DCD, *"you know our kids, they're great kids and they just need a bit of extra time and understanding really!"* (Helen)**.**

CHAPTER SIX

Discussion

Introduction

The research question asked in this qualitative, interpretive description study was "What are parents' perceptions and concerns when raising a child with developmental coordination disorder"? By asking this question I aimed to gain a deeper, first-hand understanding of the impact of DCD on the child, their occupations and the family as a whole, particularly from a New Zealand perspective. The interface with the healthcare and education sectors was also explored.

In this chapter, a summary of key findings will be given and then evaluated in relation to existing literature. Implications of the study with regard to: parents and family, health and education sectors, practice and further research will be discussed. Thereafter, the limitations and strengths of the study will be reviewed. The chapter concludes with a summary of findings in light of the literature.

Summary of Key Findings

Chapters four and five presented the findings of this study. Hearing mothers' first-hand accounts of raising a child with DCD gave a good insight into the complexities of this disorder and the day-to-day challenges faced by both the child and their family, mothers in particular. The participants, nearly all of them being first-time mothers, became aware that there was something different about the physical development of their child and their participation in everyday occupations. This was usually noticed when the child was very young, often prior to them starting school. Some parents were concerned about these differences, while others elected to *"wait and see"* if their child caught up with their

peers. The professionals that were consulted were inclined to try and placate the mothers with statements like *"it's nothing, don't worry about it"*.

There was a commonality to the concerns these mothers presented regarding their child. As a baby, many described difficulty with initiating breastfeeding, that their child did not *"latch on"*. Problems with sleep was an issue raised; this occurred across a range of ages, with children not being able to fall asleep, struggling to remain asleep or waking up very early. This took its toll on the child and mother, with them describing feeling *"exhausted"*. Delays in milestones were subtle, with differences being noticed when the mothers compared their child to their peers, for example at their antenatal groups. There was a slowness to them mastering the developmental tasks of crawling and walking. The majority of the mothers described their children as messy eaters who struggled to coordinate the use of a knife and fork. Getting dressed and being organised in the morning were areas of particular frustration for these mothers, their child needing a lot of support and prompting in order to get ready. Mothers noticed that participating in common childhood occupations such as riding a bike and swimming were particularly challenging for their child, they took a long time to acquire the skills required. Sporting activities and fine motor skills, such as writing, playing with Lego and using scissors, were identified as problem areas for these children.

Most of the mothers described having very little knowledge about DCD prior to their child's diagnosis. They also came to realise that, amongst professionals as well as family and friends, there was also a limited understanding of the condition. They worked hard to obtain information so as to be better able to support their child. Amongst the mothers, nearly all of them assumed the role of *"advocate"* for their child, feeling that if they did not support their child no one else would. Fixed routines were a widely used strategy by

mothers to assist their child in completing tasks and in order to get ready, particularly in the morning. Constant verbal prompting, some described it as *"nagging"*, was used to keep their child on task. Allowing extra time and breaking activities down into steps were other useful strategies employed by mothers.

The children participated in a range of extra-mural occupations, these were chosen as the child had registered interest or because the parent believed they would be of benefit to them. Children were more likely to be successful in structured activities where they were able to develop skills over a period of time. Reasons for parents' selection of activities included; to improve physical skills, to build confidence, to develop the child's strengths or as an emotional outlet. Mothers also steered their children away from activities which they perceived their child would not succeed in, protecting them from failure.

A high rate of anxiety amongst these children was described by nearly all the mothers interviewed. Much of this anxiety was identified as being related to school, either due to the demands of the work or with regard to keeping up with, and fitting in with their peers. Parents worried about how this impacted on the child's participation in activities and especially regarding their social integration. Feeling overwhelmed, having *"meltdowns"* and experiencing poor self-esteem were some of the secondary consequences experienced by these children when they were unable to participate in occupations to the same degree as their peers. With regard to interacting socially, mothers stated that their children were either withdrawn or did not comprehend social boundaries. Social skills did not come naturally to them and mothers felt they needed to be taught. Mothers voiced concern about the future, that *"teenage drugs and pregnancy"* could be an issue, or that *"doors would be closed"* to their child. Family members were also impacted by DCD, with mothers describing how *"relentless"* the disorder was and that they would feel *"angry"*

and *"tired"*. Accommodations were made in order for mothers to be there to support their child, for example, some gave up work or cut back their hours and one mother sent her child to a more expensive school, hoping for increased support.

Mothers approached professionals in both the healthcare and education sectors in order to gain assistance for their child. In the healthcare system mothers reported feeling that they had to work hard in order for their concerns to be taken seriously. Once their concerns were recognised, they felt they had to *"fight"* for a diagnosis and thereafter there was a long wait for intervention. One got the sense that it was an effort every step of the way for these mothers to gain support for their child in the public health sector.

School was described as a very demanding environment for children with DCD. It was where issues were often first identified, comparisons were made with peers and the child themselves, became aware of their differences. This is where they started to experience failure. Handwriting was a significant problem, with the child not being able to produce work at the speed nor quality expected. They struggled to keep up on the sports field and making friends was not easy for them. For the older child, difficulty with organisation skills and being socially ostracised, teased and even bullied were major concerns at school. When a teacher had an awareness of DCD, mothers felt their support greatly benefited their child. However, this was not the situation in the majority of cases. Mothers spoke with a lot of emotion when they described their child's struggles at school and how hard it was to gain the understanding and input they required. Again, mothers perceived that they had to be the ones *"pushing"* for their child's needs to be taken seriously. At times this did lead to conflict, with the word *"battle"* being used by a few mothers. Extra learning supports were often utilised and described as useful. Mainly,

the mothers interviewed were calling for more awareness of DCD and increased support within the classroom and in the healthcare system.

Situating the Findings within the Literature

There was a high level of consistency between the findings from this study and the literature that was reviewed. This will be discussed below, including three issues raised in the study which were not identified in the international literature.

"Something was a Bit Off"

Mothers were aware from when their child was young, that they were experiencing difficulties. This became especially evident when they compared them to other children. Several significant studies (Ahern, 2000; Maciver et al., 2011; Missiuna et al., 2007; Rodger & Mandich, 2005; Soriano et al., 2015), supported this finding by reporting that mothers noticed delays in their child's development prior to them starting school. Initially, these delays were subtle, as a result parents mostly had one of two responses; either that there was nothing to worry about, that their child would catch up or that their child was falling behind and this was of concern. The stance of waiting to see what would happen was the most common and this was described to have been the case for the following reasons; that many of the children in this study were first-born and their mothers reported not having another children with whom to compare their development, as a result they were not as concerned, that the delays were subtle in nature and were therefore not causing an issue (Missiuna et al., 2007; Soriano et al., 2015) or more commonly, that the professionals (G.P's, teachers) they consulted stated that there was *"nothing to worry about"* (Ahern, 2000; Gibbs et al., 2007).

Although there was a predominance of first or single children evident in previous studies the influence of this factor on parents' perceptions of their child's development, was not

explored. The predominance of first or single children in these studies may be an artefact of research, with mothers of multiple children conceivably being less likely to volunteer to participate in studies due to time pressure. The issues that do need to be explored include; how first-time mother's inexperience of normal development may have influenced their perceptions of their own child's development and how parents' possible limited knowledge of providing developmentally appropriate occupations and the lack of siblings with whom to be physically active may have influenced the development of normal motor skills in these children. Also, that these mothers potentially had more one on one time with an only child, allowing them to observe these perceived differences which may be missed in a larger family.

In this study, a number of mothers identified that they had difficulty with breastfeeding, that their child struggled to *"latch on"*. This was not identified in the initial DCD literature reviewed, hence a further search was undertaken looking at breastfeeding and developmental delay in general. A few articles were found which discussed coordination and breastfeeding, including that by Sacker, Quigley, and Kelly (2006), who concluded that "infants who were never breastfed were 50% more likely to have gross motor coordination delays than infants who had been breastfed exclusively for four months" (p. 682) and that increased duration of breastfeeding seemed to be associated with a reduced likelihood of delay. This article, however, did not address why these children were not breastfed.

Another issue not discussed in the DCD literature was the difficulty this cohort experienced with sleep, that is falling asleep, staying asleep and early wakening. A number of mothers in this study described their child's sleep as being of significant concern to them, for some this occurring when their child was an infant and for others

when the child was older. Sleep disturbance was unexplained in the very young child but with the older child it was felt that anxiety played a large role. A further review of the literature related to developmental delay and sleep revealed a few studies in this area. Bonuck and Grant (2012) stated that

> "sleep disorders negatively impact behavior, cognition, and growth and that conversely, developmental delays and disabilities may themselves precipitate sleep disorders. Young children with developmental delays experience sleep disorders at a higher rate than do typically developing children; the most common types are difficulties initiating or maintaining sleep and sleep disordered breathing" (p. 41).

According to Scher, Tse, Hayes, and Tardif (2008), the sleep of infants with a higher degree of risk for developmental delays differed from the sleep of infants with a low risk. In the high-risk group, sleep difficulties appeared to increase with age (Scher et al., 2008). Sleep disorders are, therefore, known to be associated with some developmental disorders, e.g. autism. Currently, however, the literature does not draw a link between DCD and sleep disorders.

The reason why these three issues; the influence of first-time mothers, breastfeeding and sleep, were not discussed in the DCD literature is unknown but could possibly be that the focus of previous studies had been on the child and not the infant. These factors do raise interesting questions related to the impact of DCD on infants' basic needs of feeding and sleeping, and the influence of first-time mothers and lack of siblings on a child's development. Further research is required in order to gain a better understanding of the relationship between these issues and DCD.

Once the child started to move, mothers reported subtle delays in their development. Similar findings were documented by Gibbs et al. (2007) and Missiuna et al. (2007). These changes were mainly to do with being *"slow"* (Farmer et al., 2016) to crawl and slow to walk. Trying to establish independence in self-care skills is where mothers started to note significant concerns. The alignment between the literature (Jasmin et al., 2018; Missiuna et al., 2007; Summers et al., 2008; Zwicker et al., 2018) and the findings of this study was very strong, with nearly all parents identifying feeding (coordinating cutlery, as well as getting food to the mouth), dressing (shoe laces, buttons, orientation of clothing), brushing of hair and teeth as well as toileting as areas of difficulty for these children. Mothers used terms such as he *"got food everywhere"* or that self-care activities *"took ages"*. In particular, the child's lack of organisation skills were what mothers found most *"frustrating"*.

"Number One Support Team"

Both internationally and in New Zealand, parents had to work hard to support their child, not only with assisting them to overcome their difficulties but also with regard to obtaining professional input and advice (Ahern, 2000; Jasmin et al., 2018; Maciver et al., 2011; Mandich et al., 2003; A. R. Miller et al., 2008; B. Wilson et al., 2013). In the literature and the findings parents spoke emotively, using very similar language, with regard to the role they had to play, describing themselves as *"advocates"* (Ahern, 2000; Rodger & Mandich, 2005) who had to *"battle"* for their child. Their experience was that if they did not *"push"* for services (Ahern, 2000; Maciver et al., 2011), they perceived that no-one else would. At home, many mothers found their role to be *"relentless",* needing to spend time helping their child to complete tasks, assisting them to learn new skills and to gain independence (Stephenson & Chesson, 2008). This was often to the detriment of the other children in the family (Ahern, 2000). Mothers became adept at

implementing strategies to assist their child, like daily routines (Jasmin et al., 2018), prompting both verbally and with visuals, assisting with self-care tasks by adapting clothing (Missiuna et al., 2007), breaking activities down into steps as well as providing a low stimulation environment so as not to overload the child. Similarly in the findings and the literature, mothers also played a role in determining the types of extra-mural activities their child participated in (Chen & Cohn, 2003). They would try and steer their child towards those that would be beneficial to them, that is to develop physical skills, build their confidence and strengths or be an emotional outlet for them (Jasmin et al., 2018). Overall, the role of a mother raising a child who has DCD was seen to be a demanding one (Stephenson & Chesson, 2008). The constant adaptation required depended on what the child was doing and how he or she was managing. But the fact this can change from day to day, situation to situation did take its toll on parents. One mother aptly described it as like *"running on a hamster wheel".*

"Things They Do"

The focus of this study was on childhood occupations and how DCD influenced the child's participation in these. Common in both the literature and the findings were two activities in which the child's physical discrepancies stood out; bicycle riding and swimming (Chen & Cohn, 2003; Poulsen & Ziviani, 2004; Zwicker et al., 2018). This cohort struggled to learn to ride a bike, it required a lot of encouragement and patience from parents to teach them and it took them a long time to develop the skills required. Swimming was an activity that many parents encouraged in order to develop their child's physical strength and coordination. Although the children often struggled to learn to coordinate the arm and leg action together, over time it was an occupation they were able to become quite competent at.   A general research finding is that individual sports and occupations, as well as those without significant eye-hand coordination, were easier for

children with DCD to master as there were fewer variables to adjust to and the demand on reaction time was less (Chen & Cohn, 2003; Hessell et al., 2010; Missiuna et al., 2007; Poulsen & Ziviani, 2004). Hence, team sports and ball skills have been identified as particularly difficult for children with DCD (Chen & Cohn, 2003). Frequently, these children were described as being able to manage only *"one thing at a time"*. Decreased participation in physical activity amongst this cohort can lead to health related concerns with decreased fitness and obesity in some (Missiuna, Gaines, & Soucie, 2006).

The things children in my study struggled with and that parents tended to steer them away from stood in contract to the what Eggleston et al. (2012) described as mainstream New Zealand culture, that is one of physically active occupations (farming, hiking) and sports (rugby). Does this culture, in which boys are required to be more physical and where it is acceptable for girls to be more sedentary, allow the physical deficiencies in boys to stand out and hence result in boys being more readily diagnosed with DCD than girls? This is an interesting debate; Poulsen and Ziviani (2004) also highlighted the pressure on boys to perform physically and this being associated with masculinity. A mother in my study stated that she was intending sending her son to a co-educational school as there would be less emphasis on sport. However, the international literature does support the fact that DCD is more prevalent in boys than girls, to a ratio of 2:1 (Barnhart et al., 2003; Zwicker et al., 2012).

Occupations were not necessarily the focus of the other qualitative studies reviewed, however participation (Mandich et al., 2003) and activities of daily living (Summers et al., 2008) were the subject of two relevant studies. Mandich et al. (2003) discussed the negative impact on the child when participation in occupations was restricted due to DCD, but that when supported to participate or given the opportunity to learn a new skill, the positive influence on the child's confidence was significant. Summers et al. (2008)

study revealed that DCD does have a detrimental impact on the child's participation in most activities of daily life. In this current study, parents were specifically asked about their child's participation in occupations. They gave descriptions of the far-reaching effects of DCD on self-care, academic, extra-mural, sporting and social occupations. However, as with other children of similar age, mothers also described their child as taking part in a variety of occupations, despite their disorder. These were mainly carefully selected activities, which allowed them time to develop the skills required, where they received one on one instructions and where the environment was more structured and supportive. Children did not function well in group situations, they would often withdraw. Singing and drama were chosen as emotional outlets or due to the fact they played to the child's strengths. Other activities reported to be enjoyed at home were fishing, walking on the beach, playing on the iPad, that is, mainly individual and more sedentary occupations.

When discussing school related activities, the most frequently reported concern in both the literature (Dunford et al., 2005; Missiuna et al., 2008; Rodger & Mandich, 2005; Zwicker et al., 2018) and in this study, was handwriting. This can be the activity which first highlights the child's difficulties to their teacher and is often the reason why children with DCD are referred to occupational therapy (Dunford et al., 2005; Missiuna et al., 2008; Rodger & Mandich, 2005). The child can struggle with both the quality and quantity of the work produced, *"not as much or as quick"*. As succinctly described by one mother, *"he's much brighter I think than he's able to do"*. These children are not always able to reflect their knowledge which can be frustrating for all involved, the child, the teacher and the parent, especially in light of the fact that these children are of normal intelligence (American Psychiatric Association, 2013; Blank et al., 2019).

"Fall Through the Cracks"

Mothers in my study described having little awareness of DCD prior to their child's diagnosis and that knowledge of DCD was lacking amongst professionals in both the healthcare and education sectors. This phenomenon is supported in the international literature, by Soriano et al. (2015) and P. Wilson et al. (2013). Family and friends of the mothers interviewed were also reported to lack this understanding, which was perceived to frequently lead to judgement of their parenting and their child's behaviour being criticised.

Mothers had to work hard to gain information in order to support their child as best they could. They obtained this information from various sources; other parents, websites, support groups and professionals. Parents often felt that their concerns were not taken seriously, that they were trivialized with doctors saying *"oh, it's all right, it's nothing, don't worry about it…he's fine, he'll grow out of it"…,* studies by Maciver et al. (2011) and Rodger and Mandich (2005) supported this view. Mothers thus struggled to get their child's difficulties recognized, they then had to *"fight"* to obtain a diagnosis. Thereafter, they had to work hard to obtain the intervention they perceived their child required, *"we weren't going to wait…everyone sort of went into battle".* Similar scenarios were described by Kirby et al. (2014), amongst others. The value of gaining a diagnosis, although debated in the literature, is that it has been shown to be useful in providing reassurance to parents (Ahern, 2000; Gibbs et al., 2007; Missiuna, Gaines, & Soucie, 2006; Soriano et al., 2015). Receiving a diagnosis was certainly seen by the mothers in my study as beneficial, allowing them to better understand the condition, *"I want all the information that I can so I can learn everything about what he's got, so that I can help…"* and that it provided access to services for their child, *"will open doors for you".* However, for some mothers receiving the diagnosis of DCD lead to upset and distress.

Following diagnosis, long wait lists were encountered for intervention and frequently, services were not consistent, resulting in dissatisfaction amongst parents, *"it took a year from first meeting to finishing their assessments…there was no therapy...discharged her…frustrated me…what do we do about it…how do we help her…"*. These issues are not unique to New Zealand as it is well documented in the international literature that delays to receiving services for children with DCD are frequently experienced (Blank et al., 2019; Maciver et al., 2011; Mandich et al., 2016).

"Don't Think School Knows What to do with Him"

Mothers in the study clearly described that once their child entered school their difficulties became more evident. As discussed in the literature and highlighted by the mothers interviewed for this study, handwriting was quickly identified as a problem and so were other fine motor activities such as, using scissors, dressing, drawing, craft-type activities (Dunford et al., 2005; Liberman, Ratzon, & Bart, 2013; Zwicker et al., 2018).

> *"I don't think he can process how to print letters and write a story at the same time…"*.

The children, themselves, became as aware of their differences, as did their peers.

As one mother put it, *"he was aware that his peers were moving on…"*. In my study, similar scenarios were described in the playground and on the sports field, where the child with DCD could not keep up. This was supported in the literature by Poulsen and Ziviani (2004). With time, mothers described their child feeling *"left out"* and a sense of failure resulted in lowered self-esteem and anxiety for the majority of these children. Eggleston et al. (2012) supported these findings. A clear theme in my study was that these children struggled to make friends, *"he's socially awkward …doesn't get boundaries, doesn't understand social cues or jokes…"* and were frequently subjected to teasing and even bullying while at school. The literature also makes strong reference to the difficulties these children have in establishing friendships (Zwicker et al., 2018). My

study showed that school quickly became a very unhappy place for these children, *"school life can be miserable…"*. A number of mothers also voiced their concern that in the future their child would not be able to keep up with the demands of high school, particularly as related to the increased work load and the need for self-management.

Mothers reported an inconsistency in the knowledge and understanding of DCD amongst teachers describing it as being *"hit and miss"*. Again, this was supported in the literature, particularly by Henderson et al. (2001) and Stephenson and Chesson (2008). Those teachers that did have awareness of the condition appeared to offer much valued support to the child. Some teachers used strategies that were helpful to the child, such as; letting the child select where they wanted work, providing incentives to motivate them or use of technology to assist with written work. However, those that did not, reportedly contributed to the child's experience at school as being a troubled and demoralizing one. Some services, for example; RTLB, SPELD and Kip McGrath were described by mothers as providing useful support for their child. Additional teacher aid time was also called for.

"Worries"

The secondary impact of DCD evident in my study with New Zealand children was having difficulty integrating with their peers and experiencing poor self-esteem and anxiety. This was described by nearly all participants in the study and is very evident in the literature (Blank et al., 2019; Eggleston et al., 2012; Farmer et al., 2016). These children felt *"left behind"* or *"left out"* of occupations due to their inability to keep up physically. In the study, mothers reported that socially their children were either *"withdrawn"* or were overly friendly, *"not knowing the boundaries"*. Like children internationally, they would also not attempt tasks or *"give up"* if they felt that they would

fail (Stephenson & Chesson, 2008). Parents experienced concern and frustration watching their child *"fall behind"* and many became very protective of their child (Ahern, 2000). In both the study and the literature, reference was made to children feeling suicidal (Missiuna et al., 2007). The study included children from the ages of 5-12 years, emotional concerns were evident across this age range and certainly the literature discusses these issues persisting into adolescence and adulthood (Caçola & Killian, 2018; Chung, 2018; Eggleston et al., 2012; Zwicker et al., 2013).

Summary

There was a high level of consistency between this study and the literature reviewed regarding the presentation and impact of DCD, despite contextual differences (Eggleston et al., 2012; Missiuna et al., 2007; Pless et al., 2001; Summers et al., 2008; Zwicker et al., 2018). This does, therefore, allow for transferability of data. There is agreement that the impact of DCD is significant for the child and their families, mothers in particular. The effects are experienced across a range of areas: physical, academic, participation in childhood occupations, social and psychological (Caçola & Killian, 2018; Dunford et al., 2005; Jasmin et al., 2018; Segal et al., 2002; Zwicker et al., 2018). The long-term consequences do need to be considered, especially as it is well recognised that this is not a disorder that children grow out of, they do not necessarily *"catch-up"* as they get older (Hillier, 2007). In fact, psychosocial issues can become exacerbated affecting the mental wellbeing, future academic and employment opportunities of these children (Eggleston et al., 2012). Internationally, some progress has been made regarding guidelines for the management of this disorder (Blank et al., 2019) and best practice (Hillier, 2007; Novak, 2013). The need for clear pathways in order to provide early identification and effective intervention has been strongly identified in New Zealand (Eggleston et al., 2012; Hessell et al., 2010; Tokolahi, 2014; Vardhaan, 2016) and this is supported by my study.

Implications of This Study

For Parents and Families

Dissemination of the findings of this study will allow mothers to share the experiences of others, to gain comfort from the fact that, although each child and their family are different, there are still a lot of similarities in the children's presentation and the difficulties they encounter. Most importantly, that it is not their parenting that is at fault. They will also be able to learn from each other as to which strategies are useful and gain knowledge as to where to obtain support. From this study, parents can develop insight as to what occupations are thought to be beneficial for their children, as well as what to expect as their child grows older.

There are resources which may be helpful for parents such as the Dyspraxia Support Group which provides education and support within New Zealand. Given the alignment of the findings with studies in other countries, there may be value in alerting parents to the Canadian, CanChild website (<www.canchild.ca), which provides free educational material with evidence-based tips and strategies. Parents are able to access and distribute these materials to significant others (e.g, extended family members, teachers, coaches) to increase awareness and understanding of DCD.

For the Healthcare and Education Sectors

Developmental coordination disorder affects 5%–6% of school-aged children (Barnhart et al., 2003; Blank et al., 2019). Primary care practitioners are, therefore, likely have such children in their practice and teachers will certainly have these children in their classrooms. It is hoped that this exploratory study will help to create awareness of the significant impact that this disorder has on children and their families and that this will lead to further research into the development of pathways for early identification and intervention, particularly at a local level within New Zealand.

For professionals at the forefront of providing support for children with DCD it is evident, from both the literature and this study, that it is necessary to view parents and the child as stakeholders (Ahern, 2000; Jasmin et al., 2018; Missiuna et al., 2007). Their perceptions and concerns do need to be heard in order to gain a thorough understanding of the issues at hand. There is a need to work together, to engage a problem-solving approach, so that the harmful, secondary effects of this disorder can be mitigated.

For Occupational Therapy Practice

Interventions which directly target occupations have been found to be of greatest value to children with DCD (Novak, 2013). In this study, mothers described the occupations they found to be beneficial to their children; such as swimming, drama and individual sports, as well as those that were to be avoided; such as ballet, ball skills and team sports. Mothers described various strategies which they found beneficial in assisting their child to carry out day-to-day tasks. The use of routines, breaking tasks down into simple steps and prompting were the most commonly reported strategies. Therapists can play a useful role in sharing these ideas and supporting parents to create an environment at home which is conducive to the needs of a child with DCD. There was a strong call from parents for increased knowledge of the condition and for professionals to be better educated regarding DCD. This is a role that occupational therapist could play.

Evidence suggests that task-based interventions, led by individualized, client-centered practice should be implemented (Barnett et al., 2015; Blank et al., 2019). Importantly for occupational therapists, goals should relate to occupation and participation, taking the child's interests in to account (Mandich et al., 2003; Novak, 2013). This study clearly identified the range of occupations in which the children with DCD experience difficulties

and the benefit, both they and their mothers perceived, when success was achieved in mastering a skill. Mandich et al. (2003) reported that the children in their study worked on self-selected skills during CO-OP treatment and through this became competent in their performance. Activity focused therapy can help to promote participation, social interaction and self-esteem, all vital elements for a child with DCD (Eggleston et al., 2012; Poulsen & Ziviani, 2004).

Tasks can be taught to this cohort if the conditions are supportive of their needs, that is; the activity is of interest to them, the child is given time to learn, there is the opportunity for repetitive practise, the environment is structured and where possible, one on one instruction is given as this is conducive to their learning. Similarly, social skills training can assist children to overcome their social awkwardness and help them develop friendships as they move through school and into adulthood.

New Zealand has provided a robust public health system in the past but due to increased demand and cost, this has become more difficult. It may be that the public will now have to utilise the private sector, this adjustment will take time and may place certain services out of reach for many. Whether services for children with DCD fall into this category or not is uncertain. DCD is reported to contribute significantly to the caseload of paediatric occupational therapists (L. T. Miller, Missiuna, Macnab, Malloy-Miller, & Polatajko, 2001; Missiuna, Gaines, & Soucie, 2006; Stephenson & Chesson, 2008), hence the important role this profession has in addressing the impact of this disorder.

Parents strategies would appear to align well with therapeutic models found to be successful in the management of this disorder. It may therefore, be that occupational therapists are ethically obligated to develop training modules for parents. This would

ensure some support and management is provided for these children in a cost-effective and timely manner, especially for those on the milder end of the spectrum as they most likely would not receive intervention in the public health system. Thus, OT's should look to develop effective methods to transfer this knowledge to families and support organisations.

For Further Research

Further investigation of parents' existing strategies would be valuable to other parents, that is; how did they get to be so adept at knowing what occupations would be beneficial to their child and which would not, what are those occupations, how do they develop routines to help their child and what form do these take, as well as what prompts and adaptations do they provide for their child. It would be useful to research how parents' strategies align with best practice recommendations for this disorder. From this it may be possible to devise intervention modules for parents.

How to discuss the condition with their child and how to prepare them for school are two topics which parents requested support in, it would be useful to explore these further and draw up some guidelines.

Following this study, a number of more general areas requiring further research also became evident. These are identified below;

Out of the 13 qualitative studies reviewed, only two provided information on the position in the family of the child with DCD. In Missiuna et al. (2007) study, 8/13 (61%) and in the Ahern (2000) study, 8/11 (73%) were first born. In my study 8/9 (88%) of the children were first born. A significant number of these were also a single child. There would, therefore, appear to be a high number of children presenting with DCD who are first-born children. The impact on a child with DCD of having

inexperienced parents and no siblings in their early years, if at all, is an area that should be further explored.

The impact of DCD on breastfeeding was not identified in the literature. There has been some work done by Jonsdottir et al. (2013) and Sacker et al. (2006) working more broadly in the area of developmental delay. They did identify that breastfeeding was conducive to good motor development but did not explain the reason why some children were not breastfed. Specific research into whether DCD impacts on breastfeeding would be worthwhile as this study identified a number of mothers who struggled to get their child to "*latch on*".

A correlation between poor sleep habits and developmental delay has been described in the literature (Bonuck & Grant, 2012; Scher et al., 2008) but no research appears to have focused specifically on the relationship between DCD and a child's sleep patterns. Yet, a number of mothers in this study identified poor sleep as an issue for their child. Further research is important as poor sleep impacts significantly on the child and their parents.

Most of the studies reviewed, as well as this study, interviewed mainly or only mothers. Stephenson and Chesson (2008) stated that they had difficulty contacting father's due to their work commitments and hence interviewed mothers. It would be worthwhile persevering to try and interview fathers as they are likely to shed a different light on the information obtained to date. This would be a valuable contribution to the DCD literature.

Relatively few studies have involved interviewing children (Jasmin et al., 2018) or young people (Lingam et al., 2014) with DCD, yet they are the main stakeholders and are

cognitively able to be interviewed. More work should be done to capture their perceptions and concerns regarding the condition so that we are better able to understand their needs. Longitudinal studies of these children would also be of value in order to gain a deeper understanding of the long term, secondary implications of this disorder.

As the knowledge base of DCD builds, its prevalence, presentation and impact, the evidence to substantiate the need for intervention is more readily available. Further research is now required to meet the needs of these children and their families by discovering ways to implement efficient and effective pathways for identification and diagnosis, as well as establishing "best practice" intervention methods within New Zealand.

Strengths of this Study

The study was only open to parents of children who had been formally diagnosed with DCD. The 9 participants and their children were carefully selected from 37 potential participants so as to represent as much diversity as possible. Diversity encompassed the child's age and sex, geographical region within New Zealand, distance from nearest hospital, socio-economic status and ethnicity. The consistency of the findings across participants in diverse circumstances supports the credibility of the findings.

Telephone interviews were conducted which enabled parents to remain in their own homes. This provided a comfortable, non-threatening environment for them to be interviewed in and it supported them to continue to be parents during the process. The context of the interview was appropriate to the questions being asked, that is within the family, about the family. All of the participants stated that the process had been a positive experience for them. As the researcher, it was rewarding as the telephone interviews

allowed for easy interaction with the participants, resulting in good descriptive data being generated. It was also an efficient, cost effective manner of reaching participants in variety geographical locations throughout the country. This was important so as to capture a range of experiences in different communities, healthcare and educational settings.

Using in-depth, semi-structured interviews I was able to capture the first-hand experiences of mothers who had a child diagnosed with DCD. This gave a good insight into the challenges this disorder poses for children and their families. Emergent data were able to be collected and the focus of the study could be kept on the child and their occupations. Coding of data was reviewed by both of the Supervisors involved in the study.

Overall, there was strong alignment between the literature and the findings of this study, which supports transferability of international research results. In addition, there were a number of issues that arose which have not previously been identified in the DCD literature and which would make for interesting research.

Limitations of this Study

The literature reviewed for this study was restricted to the period of 1995-2019. The limitation due to the time constraints of this being a Masters study.

The number of participants in the study was initially limited to 10, ultimately data from only 9 interviews was included in the study. This limitation was due to the restrictions of a Masters study. Only mothers were interviewed for this study. It would have been preferable to have interviewed both mothers and fathers. Fathers, however, did not

respond to the request for participants. Out of the 51 replies received and the eventual 37 potential participants identified there was only one father who made himself available. He was not selected as his son did not meet the demographic requirements for the study.

Because the interviews were conducted telephonically I was not able to observe the body language of the participants. It may be that subtle nuances in communication were lost through this method. As participants were in their own home at the time of being interviewed, some were interrupted by their children which was distracting for them. The small sample size of this study, only nine participants, suggest it is not possible to generalize the findings (Boyce & Neale, 2006), but this limitation is mitigated by the high levels of alignment with international literature. Coding of data was not checked by an independent clinician.

It is possible that parents in this study may represent those who are more informed and/or more concerned about their child's disorder as they were all members of the Dyspraxia Support Group of New Zealand (DSG). Recruitment was largely promoted through DSG, meaning that parents who do not engage with this service were not reached. As the DSG is based in Christchurch, a disproportional number of the sample were from that region, 44 percent.

A number of children in the study had a comorbidity of ADHD and/or dyslexia. These are very common comorbidities with DCD but whether they impacted on the accountant mothers gave of DCD does need to be considered.

Not all participants were equally articulate and they provided indirect information filtered through the views of the interviewer. Effort was required to conduct the interviews and analyse the data in a manner which allowed for minimal bias however,

this cannot be completely eradicated. It was also time consuming to conduct the interviews, transcribe them and analyse the data.

Conclusion

The findings of this study clearly illustrated the significant burden that DCD can have, not only on the child, but also on their mothers. Children's participation in occupations was severely curtailed by their poor motor coordination and motor planning skills. The impact was experienced over a wide range of self-care, play, academic and sporting activities, with children often opting out of what would usually be considered normal childhood occupations. This had a particular impact on their educational experiences, the result often being a sense of failure and social isolation for the child.

The children in this study were young, aged between 6-11 years. The concern is that given the alignment of my finding with international evidence that the long-term impacts identified for these children are likely to play out in the New Zealand context, therefore, underlining the need for intervention.

What did become evident was that given the correct support and environment, children were able to improve their occupational performance, which in turn benefited their sense of self-worth. Long waiting lists, limited services and a lack of understanding of DCD were all factors parents had to contend with when seeking support for their child. Across the geographic areas within New Zealand that were covered by the study, there was little consistency in the manner in which this condition was managed. The findings thus reveal the need for nation-wide, cost effective methods of intervention, in both the healthcare and educational settings. At the fore-front of this should be awareness and understanding of DCD amongst professionals dealing with children, as this should facilitate early identification. Guidelines and pathways for diagnosis and intervention should be

established. Parents were shown to become adept at establishing which occupations were beneficial to their children and developed useful strategies to assist their child to complete day-to-day tasks. Sharing of this information would be useful and working with mothers to teach them skills to enhance their child's occupational performance would be an area worthy of exploration. New Zealand would be well served to draw on international literature and, with further research, make adaptations which align with its culture.

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Appendix 1

Demographic Form

"He tanga kakaho koia kia kitea e te kanohi, tena ko te kokonga nga kau e kore e kitea"

The perceptions and concerns of Parents who have a child with Developmental Coordination Disorder

Project Supervisors: Professor Clare Hocking. clare.hocking@aut.ac.nz 09 921 9999 ext 9162

Dr Margaret Jones. margaret.jones@aut.ac.nz 09 921 9999

Researcher: Brigid Hitchcock, Occupational Therapist. bhitchcock@xtra.co.nz   021 1055702

Please complete the form below, either tick or fill in as appropriate. All information will remain confidential as stated on consent form. Many thanks!

Name of Parent/Caregiver: …………………………………………………………

1) Age of child: ……………………
2) Sex of child:
   o   Male
   o   Female

3) Ethnicity of child
   o   Maori
   o   European
   o   Pacific Islander
   o   Asian
   o   Other, please list ……………………………..

4) How many children in Family…………….............
5) Child's position in Family…………………………….

6) Child's diagnosis, if any…………………………….

7) Who made the diagnosis

- o GP
- o Paediatrician
- o Psychologist
- o Child Psychiatrist
- o Other, please list …………………………

8) What services have you accessed for your child, tick more than one if necessary.
- o GP
- o Occupational Therapist
- o Physiotherapist
- o Speech Language Therapist
- o Psychologist
- o Paediatrician
- o Child Psychiatrist

9) How far away from a major hospital do you live.
- o 0-15km
- o 15-30km
- o more than 30km

10) Socio-economic status:
Which income bracket do you best associate with:
- o High (over $100 000.00)
- o Middle ($30 000 – $100 000)
- o Low ($0-$30 000)

Participants Contact Details:
Phone:…………………………………………………………….
Email:………………………………………………………………
Address:…………………………………………………………..
…………………………………………………………………………..

Nga mihi ki a koutou mo to koutou tautoko. Heioi Ano.
Thank you for completing this form.

Appendix 2

Kia Ora, Hello my name is Brigid Hitchcock. I am an Occupational Therapist currently undertaking a thesis for my Masters' Degree. You have been contacted as you are a member of the Dyspraxia Support Group of New Zealand.

I have had a long-standing interest in Developmental Coordination Disorder (DCD) and having worked in both the public and private health sectors strongly believe there is a need for a better understanding of this condition.

For my thesis I would like to interview parents/caregivers of children aged between 5-12yrs who have DCD. I believe you hold valuable information as to how this disorder impacts your child and family. You are also acutely aware of what the needs of these children are. I am sure that gaining information pertaining to the concerns and perceptions of parents and caregivers will increase the knowledge base of all those involved with these children.

I would, therefore, like to invite you to be part of my study. This would involve a 60-90 minute phone interview. A small focus group will also be held for those selected and willing to participate, this would also be around 60-90 minutes.

Your input would be greatly appreciated. On completion of the study you would be provided with a summary of my findings.

Therefore, if you are a parent/caregiver of a 5-12yrs old child who has DCD and are willing to participate please could you contact me directly via phone or email:
Phone/Text: 021 1055702
Email: bhitchcock@xtra.co.nz
Further information will be provided on acceptance. You will have the option to opt out of the study if you wish to.

Nga mihi ki a koutou mo to Koutou tautoko. Heioi Ano.
Thank you for your time.

Kind regards

Brigid Hitchcock
Approved by the Auckland University of Technology Ethics Committee on *17 October 2017*, AUTEC Reference number *17/283*

Appendix 3

Kia Ora, Hello my name is Brigid Hitchcock. I am an Occupational Therapist currently undertaking a thesis for my Masters' Degree. I sent a flyer out via the Dyspraxia Support Group a few weeks ago requesting parents/caregivers of children aged between 5-12yrs who have DCD/Dyspraxia and are willing to be interviewed for my study to please contact me.

Thank you so much to those who have done so - I have really appreciated your response. Please could I make a further plea to those who have not yet done so if you are willing could you contact me and those who have received forms if you could please return those to me as soon as you can.

Thank you for your participation. I do believe you hold valuable information which I am sure will increase the knowledge base of those involved with these children and thus ultimately benefit those with DCD.

Therefore, if you are willing to participate please could you contact me directly via phone or email:
Phone/Text: 021 1055702
Email: bhitchcock@xtra.co.nz
Further information will be provided on acceptance. You will have the option to opt out of the study if you wish to.

I look forward to hearing from you.

Nga mihi ki a koutou mo to Koutou tautoko. Heioi Ano.
Thank you for your time.

Kind regards

Brigid Hitchcock

Participant Information Sheet

Date Information Sheet Produced:

08.08.2017

Project Title

The perceptions and concerns of parents who have a child with Developmental Coordination Disorder.

An Invitation

My name is Brigid Hitchcock. I am an Occupational Therapist with many years of clinical experience in working with children. A particular area of interest of mine has been Developmental Coordination Disorder. I believe that further study is required and I would really value your input as I feel your experience will help gain a deeper insight into the needs of these children and their families.

What is the purpose of this research?

The purpose of the study is to gain a greater understanding of the perceptions and concerns of parents who have children with DCD. This knowledge will then be used to inform families, health care professionals, educators and service providers of the needs of these children so that more effective supports can be provided.
This study will contribute towards my Master of Health Science degree. On completion of the study I plan to write a journal article and may present the findings at a conference.

How was I identified and why am I being invited to participate in this research?

The Dyspraxia Support Group of New Zealand were asked to send out information regarding my study to their members. Thus, as a member of this group you have received an invitation to participate in the study.
If you are a parent of a child with DCD aged 5-12yrs and can converse in English then you are a potential participant for my research. Having parented a child with this condition you have an in-depth understanding of how it has impacted his/her life and that of your family. You will also have knowledge of what supports/services you have found useful and which were not. Your perceptions and concerns are of value as this is how we can all learn more about the impact of DCD and how to better support these children.

How do I agree to participate in this research?

At the bottom of this information sheet you will find my contact details (email and phone). If you are willing to participate in the study please could you contact me directly. I will ask for some general information about you and your child and arrange how to contact you, either via phone or skype. I will ask you to sign a consent form. Your participation in this research is voluntary (it is your choice) and whether or not you choose to participate will neither advantage nor disadvantage you. You are able to withdraw from the study at any time. If you choose to withdraw, then you will be offered the choice of having any data that is identifiable as belonging to you removed or allowing

it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

We will agree on a convenient time for an interview of about an hour. I am happy to interview just you, or you and your partner together, as you both have views that are relevant. You are also very welcome to have a support person(s) with you if you wish to. The interview will be recorded so that I have an accurate understanding of your perceptions and concerns. The information obtained from the interviews will be reviewed, themes identified and findings then collated. I will also ask if you would like to participate in a focus group with other participants to give me feedback on preliminary findings. The interview and focus groups will be via phone or skype. This information will form the basis of my Master's thesis and will also be shared with participants as well as healthcare professionals and service providers with the view to improving support provided of this group of children. Your personal details will remain confidential.

What are the discomforts and risks?

When one is interviewed regarding a personal matter, particularly one that affects the well-being of our children and families, emotions can be brought to the surface. There is the possibility that you may experience this during our interview. If this should occur please inform me - we can then either have a break or end the interview if it is too difficult for you to continue.

How will these discomforts and risks be alleviated?

If you do feel distressed and require support I can help you identify a counselling service in your area.

What are the benefits?

It is hoped that this research will lead to a better understanding of the needs of children with DCD and what parents have found to be helpful. Collating and sharing this knowledge will hopefully help to improve support and outcomes for these children and their families.
This research will also contribute the completion of my Masters of Health Science Degree.

How will my privacy be protected?

I will ensure that your privacy is protected. All information you provide will be identified by a pseudonym and I will be the only one who is able to connect you with your personal details. Any identifying information from the interview will be removed or changed before the findings are reported.

What are the costs of participating in this research?

It is expected that each interview will take approx. 60 -90 minutes. If you agree to also participate in a small focus group and are then selected this will require a further 60-90 minutes of your time. As all interviews will be performed via skype or phone I do not envisage any travel costs and phone cost will be covered by myself.

What opportunity do I have to consider this invitation?

A two week period will be given from the time you receive the information pertaining to the study for you to consider whether or not to participate. If I have not heard from you before this time, the Dyspraxia Support Group will then email you again to check if you want to participate.

Will I receive feedback on the results of this research?

Yes, you will receive a summary of the findings and you will be able to view your individual transcript should you choose to do so.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Professor Clare Hocking, clare.hocking@aut.ac.nz, phone: 09 921 9162

Concerns regarding the conduct of the researcher should be notified to the Executive Secretary of AUTEC, Kate O'Connor, *ethics@aut.ac.nz* , 921 9999 ext 6038.

Researcher Contact Details:

Brigid Hitchcock, bhitchcock@xtra.co.nz,   phone: 021 1055702

Approved by the Auckland University of Technology Ethics Committee on *17 October 2017* AUTEC Reference number *17/283*

Interview Consent Form

AUT
U N I V E R S I T Y
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

The perceptions and concerns of Parents who have a child with Developmental Coordination Disorder

Project Supervisors: Professor Clare Hocking. clare.hocking@aut.ac.nz 09 921 9999 ext 9162

Dr Margaret Jones. margaret.jones@aut.ac.nz 09 921 9999

Researcher: Brigid Hitchcock, Occupational Therapist. bhitchcock@xtra.co.nz 021 1055702

○ I have read and understood the information provided about this research project in the Information Sheet dated 08.08.2017.

○ I have had time to consider whether to take part in the study.

○ I have had an opportunity to ask questions and to have them answered.

○ I have had an opportunity to discuss the study with whānau/family or a friend prior to signing this consent form.

○ I understand that taking part is entirely voluntary (my choice).

○ I understand that details about my child(ren) are confidential,

○ I understand that the identity of my fellow participants is confidential.

○ I understand that no material which could identify me will be used in any reports on this study.

○ I understand that notes will be taken during the interviews, that information may be charted, and that interviews will be audio-taped.

○ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

○ If I withdraw, I understand that the relevant information about myself and my child including tapes and transcripts, or parts thereof, will not be used.

○ I agree to be interviewed (1:1) for this research; Yes○ No○

○ If selected, I agree to take part in a small focus group Yes○ No○

○ I wish for a support person to be in attendance with me: Yes○ No○

○ I agree for my contact details to be stored and for the researcher to

  contact me in the future should further study be performed. Yes○ No○

○ I agree for data collected from me to be stored and potentially used for

  further research in the future. Yes○ No○

○ I wish to receive a summary of the findings from the research: Yes○ No○

Participant's signature:
……………………………………………………………………………………………

Participant's name:
……………………………………………………………………………………………

Date:
……………………………………………………………………………………………………
….

Appendix 6

The perceptions and concerns of Parents who have a child with Developmental Coordination Disorder.

Researcher: Brigid Hitchcock ph: 021 1055702

Interview Guidelines:

Researcher will provide a brief introduction outlining the aim of the interview as well as expressing appreciation of participation and emphasising confidentiality.

- Can you tell me a little about your child, likes/dislikes
- What led you to believe your child had difficulties
- How did these difficulties first present and how old was your child.
- What activities is your child involved in/ daily routine - school, home, extra-mural, friends (social interaction)
- What activities has your child been prevented from participating in due to DCD
- How is your family affected by your child's condition?
- Where have you sought help for your child
- What supports have been useful for your child
- Does your child have a formal diagnosis, if so what was the process involved in obtaining this
- Does your child have any other diagnosis apart from DCD (comorbidity)
- What aspects of your child's condition have had the most impact on their daily life and that of your Family
- What is your greatest concern for your child
- What do you believe would make the biggest difference for your child, what is their greatest need
- How do you see your child's future

Focus Group Guidelines:

Researcher will present a summary of what information has been gathered to date. Confidentiality will be emphasised and appreciation of participation expressed.

- Discussion as to whether findings to date are plausible or not – what stood out for participants in presentation of data.
- Explore the different themes that appear to be emerging – see if there is agreement
- Question whether some families are more affected than others – if so, why - does there seem to be a variance of the condition in different regions and in different socioeconomic groups
- Query if anything has been missed in the interviews/questioning
- Encourage participants to ask questions regarding the study and the direction it is taking.

Appendix 7

Confidentiality Agreement for Transcriber

The perceptions and concerns of Parents who have a child with Developmental Coordination Disorder

Project Supervisors: Professor Clare Hocking. clare.hocking@aut.ac.nz 09 921 9999 ext 9162

Dr Margaret Jones. margaret.jones@aut.ac.nz 09 921 9999

Researcher: Brigid Hitchcock, Occupational Therapist. bhitchcock@xtra.co.nz 021 1055702

✓   I understand that all the material I will be asked to transcribe is confidential.

✓   I understand that the contents of the tapes or recordings can only be discussed with the researchers.

✓   I will not keep any copies of the transcripts nor allow third parties access to them.

Transcriber's signature: …… ……………………………………………………………………………

Transcriber's name: ……Shoba C Nayar……………………………………………………………………………………………

Transcriber's Contact Details (if appropriate):

Email: snayar19@gmail.com………………………………………………..

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Date: …21/12/2017…………………………………………………………………….

Project Supervisor's Contact Details (if appropriate):

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Approved by the Auckland University of Technology Ethics Committee on 17 October 2017 AUTEC Reference number 17/283

Note: The Transcriber should retain a copy of this form.

Appendix 8
Demographic Information Pertaining to Participants

Participant Number and Pseudonym	Age of child	Gender of child	Ethnicity of child	Number of children in family	Child's position in family	Child's diagnosis	Km's from Hospital	Socio-economic status
5 Jenny	6yrs	Female	NZ European	3	1st	DCD and Dyslexia	0-15	Middle
12 Rose	11yrs	Male	South American/European	1	Only child	DCD	0-15	Middle
16 Linda	9yrs	Male	European	1	Only child	DCD	15-30	Middle
25 Amy	7yrs	Male	Maori	1	Only child	DCD	0-15	High
26 Marie	6yrs	Male	NZ European	3	2nd	DCD ADHD	More than 30	High
42 Jess	8yrs	Female	Maori	1	only	DCD ADHA Dyslexia	0-15	Middle
22 Lauren	10yrs	Male	NZ European	2	1st	DCD ADHD	0-15	Low
43 Meg	7yrs	Female	NZ European	3	1st	DCD	15-30	Middle
9 Helen	11yrs	Male	NZ European	2	1st	DCD ADHD	0-15	High

Appendix 9
EXAMPLE OF THEMES
1) What parents perceived/noticed - Something was a bit off
A) It will be fine (P12, p 4)

 I didn't have anything to compare it with - He will get things in his own time (P16, p3)

First child – she's cruisy – were trying not to stress out about things – P43 p10

At four check - " the gap wasn't big enough you know" - "so there's the kind of wait and see thing" (P22, p 16) Think maybe he's just not into some of the stuff typical boys are – in terms of his physical skills (P22 p4)   OR

B) Something was a bit off (P5,p2 -

He was a lot slower (P26, p1) –

He's much brighter I think than he's able to do (P26,p2) --

What they noticed - chronologically:

Breastfeeding:

Struggled with sucking – bottle and breast Also reflux (P26.p8)

Wouldn't latch on – took 5 weeks (P16,p3)

She breastfed but it was hard – she didn't latch. First baby I didn't really know what was going on. Tried different strategies, including Plunket – so exhausted. (P43 p9)

Breastfeeding – "it was horrible the first six weeks" - wasn't getting enough.

"I felt really bad about that" - I just thought well this is my job and I can't even get him to feed" (P22 p15). Looking back – "I don't think it was just me I think it was also him" (P22 p16)

Breastfeeding - terrible, he couldn't get a good latch. I expressed milk for him - bottle for 3 months but then I was exhausted - reverted to formula. Even on bottle - take like an hour for him to have a feed - very poor latch and suck - "now I know why" (P9 p4)

We were trying very, very hard on very little sleep - it was very, very stressful. First time mum you want to do everything right! (P9p4)   His sister I fed for four years. (P9p4)

Sleep:

Sleep was Horrendous (P5,p7)

Literally, bouncing off the walls

Wasn't sleeping at night, falling asleep in class, wasn't concentrating (P5,p17)

Sleep is a biggie (P12, p14)

Sleep – always been a problem – he gets so tired but he just doesn't want to go to sleep. It just depends what's going on for him – if he's had a rough day then no he won't sleep – but if it's been a good day then yeah he'll stay asleep. (P25,8)

Issues of sleep right from the beginning - I ended up being so exhausted. Not being able to get to sleep - really groggy in the morning – he just like a lump (P16,p4)

Milestones:

He's always been different (P42,p2)

He um right from the "get-go" he had all the, the signs associated with dyspraxia   - he never crawled, late with everything. If you're in an ante natal group everybody else's child is walking and your child is not. Everyone else's child is crawling, yours is not.(P42 p …)

She wasn't like an early mover – 2yrs 7mths at preschool – wasn't talking.

 (P43 p 9)

Milestones early but little time crawling (P26,p8)

compared to our older daughter - maybe a year behind what she was.(P26 p1)

milestones – not that far behind – then at school – "other kids were just lapping things up and he wasn't" (P22 p16)

Appendix 10

17 October 2017

Clare Hocking
Faculty of Health and Environmental Sciences

Dear Clare

Re Ethics Application: **17/283 The perceptions and concerns of parents who have a child with Development Coordination Disorder**

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 16 October 2020.

Standard Conditions of Approval

1. A progress report is due annually on the anniversary of the approval date, using form EA2, which is available online through http://www.aut.ac.nz/researchethics.
2. A final report is due at the expiration of the approval period, or, upon completion of project, using form EA3, which is available online through http://www.aut.ac.nz/researchethics.
3. Any amendments to the project must be approved by AUTEC prior to being implemented. Amendments can be requested using the EA2 form: http://www.aut.ac.nz/researchethics.
4. Any serious or unexpected adverse events must be reported to AUTEC Secretariat as a matter of priority.
5. Any unforeseen events that might affect continued ethical acceptability of the project should also be reported to the AUTEC Secretariat as a matter of priority.

Please quote the application number and title on all future correspondence related to this project.

AUTEC grants ethical approval only. If you require management approval for access for your research from another institution or organisation then you are responsible for obtaining it. You are reminded that it is your responsibility to ensure that the spelling and grammar of documents being provided to participants or external organisations is of a high standard.

For any enquiries, please contact ethics@aut.ac.nz

Yours sincerely,

Kate O'Connor
Executive Manager
Auckland University of Technology Ethics Committee

Cc: bhitchcock@xtra.co.nz; Margaret Jones

Appendix 11

Confidentiality Agreement for Maori Cultural Advisor

AUT UNIVERSITY
TE WĀNANGA ARONUI O TAMAKI MAKAU RAU

**The perceptions and concerns of Parents who have a child with Developmental Coordination Disorder**

Project Supervisors: Professor Clare Hocking. clare.hocking@aut.ac.nz   09 921 9999 ext 9162

                     Dr Margaret Jones. margaret.jones@aut.ac.nz   09 921 9999

Researcher: Brigid Hitchcock, Occupational Therapist. bhitchcock@xtra.co.nz   021 1055702

- I understand that all the material I will be asked to review is confidential.
- I understand that the contents of the transcripts or recordings can only be discussed with the researchers.
- I will not keep any copies of the transcripts nor allow third parties access to them.

Consultant's signature: ....

Consultant's name: ....AIDEN WHAREKAURI TAIPETI...................................

Consultant's Contact Details (if appropriate):

....

....

....

....

Date: ....02 JULY 2018...................................

Project Supervisor's Contact Details (if appropriate):

....

....

**Approved by the Auckland University of Technology Ethics Committee on 17 October 2017 AUTEC Reference number 17/283**

Note: The Consultant should retain a copy of this form.