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The Lived Experience of Adults with Dyspraxia/DCD

A thesis

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by

Leanne Maria McAllum

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Abstract

Abstract of a thesis submitted in partial fulfilment of the requirements for the Degree of Ph.D.

The Lived Experience of Adults with Dyspraxia/DCD

by

Leanne Maria McAllum

Dyspraxia is an emergent social phenomenon that has generally been associated with childhood and motor coordination difficulties. The experience of Dyspraxia in adulthood is, conversely, not well understood with only a small number of studies examining Dyspraxia across the life course. Dyspraxia is predominantly conceptualised in both the research literature and practice using the biomedical model. Dyspraxia is one of several neurodivergent experiences and possibly the least well known, having only been recognised in the past two decades, in comparison to a longer social awareness of experiences such as Dyslexia and Autism. Known as Developmental Coordination Disorder (DCD) in the medical literature, the phenomenon has been etiologically defined as a physical functional deficit. By contrast, Dyspraxia can also be understood as having cognitive functional aspects, such as in the Aotearoa New Zealand context. The objectives of this research were firstly to examine the lived experiences of participants with Dyspraxia/ DCD in relation to predominant social biomedical conceptualisations. A second objective was to identify the repercussions of contemporary social framings of Dyspraxia/ DCD in Aotearoa New Zealand and how Dyspraxia is understood and addressed, particularly in adulthood. The approach taken to answer the research objectives was that of the thematic analysis of semi-structured interviews undertaken with both people with Dyspraxia and professional participants. In this work, a qualitative approach was employed in the form of semi-structured interviews with twenty-three people with Dyspraxia to better understand the lived experience. Further, twenty-six professionals in medical and education fields were also interviewed to investigate the role of institutions on the Dyspraxia lived experience. Participants were located through two gatekeeper organisations, cold-calling and snowball sampling techniques. This research, undertaken by an insider researcher with Dyspraxia, highlighted that an examination of Dyspraxia is unable to be considered independently of social contexts. Further, it was found that biomedical framings affected the lived experience of participants with Dyspraxia/ DCD in Aotearoa New Zealand

and the subsequent social response to the phenomenon. The lived experience of Dyspraxia in adulthood was found to have implications for how people with Dyspraxia construct their identity with Dyspraxic participants describing the need to adapt in normative social settings to achieve inclusion. This thesis adds to current conceptualisations by utilising the capabilities approach (CA) to examine the lived experience of Dyspraxia in relation to the medical and social models. Throughout are a range of accounts from Dyspraxic participants, describing their attempts to access the capabilities necessary to ensure the life outcomes they value. The CA can account for the significant changes between childhood and adulthood described by study participants within their social worlds. In contrast to the biomedical perception that DCD is a physical deficit, this thesis shows that the attainment of capabilities is complex and evolves across the lifespan in response to personal heterogeneities but also the social environments that Dyspraxic participants inhabit. The CA was found in the discussion to improve upon, and complement, current conceptualisations of Dyspraxia. Conceptualising Dyspraxia in alternate ways to better explain study findings, such as using the CA, suggests a range of areas for future research and practice.

Keywords: Dyspraxia, DCD, Lived Experience, Neurodiversity, Qualitative, Ableism, Disability, Stigma, Cognition, Capabilities Approach, Social Science

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My extended family and friends have been a constant source of motivation and support throughout this process. My gratitude to my husband knows no bounds and without him there would not be a completed thesis. Words can't express how instrumental he has been in my being able to finish this work. Similarly, I am hugely thankful for my children and their encouragement and patience with my ongoing work efforts over the past six years.

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strength and courage and a reminder that I am never alone, that my efforts are not simply mine but rather part of a much larger story. Finally, I would also like to thank myself and recognise that as much as I worked on this doctorate, this doctorate worked on me until I have been carved into a different human, and I think, a better one.

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List of Abbreviations

AD(H)D: Attention Deficit (Hyperactivity) Disorder

ADL: Activities of Daily Living

ASD: Autism Spectrum Disorder

DCD: Developmental Coordination Disorder

EACD: European Academy of Childhood Disability

ICF: International Classification Framework

IEP: Individual Education Plan

LSC: Learning Support Coordinator

MoE: Ministry of Education

MoH: Ministry of Health

NCEA: National Certificate of Educational Achievement

NGO: Non-Governmental Organisation

NZQA: New Zealand Qualifications Authority

QoL: Quality of Life

RTLB: Resource Teacher of Learning and Behaviour

SAC: Special Assessment Conditions

SENCO: Special Education Needs Coordinator

SPD: Sensory Processing Disorder

SpLD: Specific Learning Disability

Participant codes

D/ED Person with Dyspraxia diagnosed through education sector

D/MD Person with Dyspraxia diagnosed through health sector

D/SD Self-diagnosed person with Dyspraxia

DP Parent of person with Dyspraxia

PP-M Professional participant with expertise in medical specialization

PP-E Professional participant with expertise in education specialization

PP-M+E Professional participant with expertise in both a medical and education specialisation

Situated standpoint

My interest in impaired motor coordination, also known as Dyspraxia or Developmental Coordination Disorder (DCD), derives from my own experiences and those of my son. It has been fascinating to interact with societal institutions, most notably the education system, over the course of my life and to be confronted by expectations concerning what is an acceptable degree of motor dexterity to possess and what is not, and to consistently fall short of this socially constructed norm. I faced challenges with handwriting, sporting ability and the reduced self-esteem that being less capable engendered. Supporting my son on his life journey in an education environment that sometimes disadvantages him, sometimes supports him but that, either way, regards him as a minority for whom concessions must be made, rather than someone whose learning style should be accommodated, has also proven an interesting and at times challenging experience.

My own experiences with acquiring physical developmental milestones as a child would include not crawling as a baby and having trouble learning to tie my shoelaces. Learning to ride a bike took much longer than my friends and I would fall into gutters because I'd lose my balance cycling to school. I vividly remember the embarrassment and mortification I felt every year at the compulsory school swimming sports. Despite many swimming lessons, my coordination abilities were such that my primary school teachers decided that I would swim, not lengths like all my friends, but widths with the younger children. I remember the humiliation at age 9 when my teacher used me as an example, in front of the entire class, to illustrate how not to hold a pencil and showed everyone how messy my handwriting was. I still hold my pens/ pencils in a fist grip and my writing speed is slow and was assessed a few years ago as being lower than the 8th percentile. I could never catch, kick, or throw well and I ran in the classic Dyspraxia' way too, with my legs flicking out to the sides. Then there was the shame of coming last in every running race on primary school sports day, even though I tried my absolute hardest, and the confusion I felt at being different, as well as the intense longing to be like everyone else.

In high school I dreaded the 3x weekly PE lessons because I experienced stigma and felt shame when the other students laughed at me or were frustrated by my team sporting ability. The last experience of embarrassment I recall as a child was having to do a dance routine at my German high school, with friends, and the mortification I felt when other girls in the class laughed at me. My childhood and

teenage years were made harder because of my Dyspraxia, both my confidence and self-esteem were affected, as was my ability to make friends and find social acceptance amongst my peers, illustrated by the following quote from my research diary:

> I remember being 18 years old and the tangible relief of making friends, who may have been 10 years my senior, but feeling for the first time that I really belonged. I was accepted and not found lacking because I was terrible at sport and therefore not worthy of knowing. Because after a while you also begin to believe that you're not as good as all the people who can do the things you can't and you can't help but think that they're right and you're not worth knowing. Maria McAllum (D/ED 40-50)

I am including the above because I feel the need to justify my right to contribute to the narratives around movement challenges. Looking back, I see that my movement capabilities as a child were probably on the low to moderate side of the Dyspraxia/ DCD spectrum. Looking forward I see my son, who also has Dyspraxia/DCD, but who is being raised in a family that can give him the support and confidence he needs to succeed, despite the motor coordination challenges he has. Unlike me, when my son's confidence has again been shaken at school, although he has tried his hardest, he will come home and be reminded of all the abilities he does have, such as a keen intelligence and a cheerful nature.

As an adult, Dyspraxia is a mild inconvenience for me because I have managed to adapt. I have strategies and I have learnt the skills that were a challenge for me to acquire as a child. I can live with avoiding parallel parking and finding verbal instructions difficult. Granted, the challenging experiences I associate with Dyspraxia, and still experience as an adult, are thrown into sharp relief in quite specific circumstances, sometimes in response to coordinating my body in space in new and unfamiliar ways. For example, doing a hill start in my EV hybrid that has pedals and not a release brake. The complexity of the left/ right sequencing in relation to going up or down meant that I nearly went through my driveway hedge but, after two years of practicing, albeit only when the need arises, I have almost got the hang of it. Similarly, even the simplest sequencing tasks sometimes trip me up and I find myself in avoidance-mode and having what my husband calls 'a Dyspraxia moment', a description which is, for me, both validating and supportive. Further, I sometimes have trouble with information recall and theories that are not easily conceptualised in relation to real world examples. My family tell me I am utterly literal and almost never 'get jokes', but despite this we laugh together a great deal.

I have also had the opportunity to identify, not only the weaknesses, but the strengths I associate with my unique life journey with Dyspraxia a privilege that I acknowledge that not every person with Dyspraxia will have. Nevertheless, undertaking this PhD has challenged me deeply because the subject is so personal and tied up with so many other life experiences. I passionately wanted to do this research to understand Dyspraxia better myself and to help Dyspraxia be better understood. Thanks to the life stories of the people who participated in my study, this study has evolved into a thesis that hopefully does justice to their experiences.

Chapter 1: Introduction

The purpose of this study is to better understand the lived experiences of adults with Dyspraxia/ developmental coordination disorder (DCD) in Aotearoa New Zealand (NZ) and explore the effect of institutions on the life outcomes of this population. To date, there have been very few qualitative studies that prioritise the life experiences of the adult Dyspraxia/ DCD population, with exceptions including a small number of retrospective studies and more recent studies that prioritise the perspectives of people with Dyspraxia themselves (Walker et al., 2021). Quantitative DCD studies identify a continuation of DCD into adulthood for at least half of the childhood population identified as having DCD, which indicates that the mechanisms underlying DCD may be more than developmental (Blank et al., 2019). However, given the absence of longitudinal studies, DCD researchers are unable to determine whether DCD is a developmental delay or a deviance (Blank et al., 2019). DCD research into adult manifestations of DCD are somewhat inconclusive due to an identified lack of consistency between studies as well as identified inadequacies in how motor challenges are assessed, with some studies identified as exhibiting weak evidence for significant motor coordination issues (Blank et al., 2019).

This thesis will begin with a brief overview of the current literature and framings of Dyspraxia/DCD, followed by an explanation of the theoretical positions and concepts that will be used in this study. Chapter 2 will provide an explanation of the methodology used and how this inductive research was conducted. The following empirical chapters explore key themes of Dyspraxia/ DCD relevant to the Aotearoa New Zealand context. Chapter 3 looks at the role of biomedical conceptualisations on the social response to Dyspraxia/ DCD by individuals and social institutions. Chapter 4 explores the socially situated perspectives of participants with Dyspraxia/ DCD and how they construct their social identity in response to current medical framings. The significance of interpersonal social interactions and current social arrangements in Aotearoa New Zealand and the role of institutions on the life outcomes of Dyspraxic participants is investigated in Chapter 5. Chapter 6. is a discussion chapter which conveys and elaborates upon the significance of the main findings of this study. This study concludes with a conclusion chapter.

In recent decades, awareness around a range of experiences known as specific learning disabilities (SpLDs) has increased and diagnostic categories, such as that of the SpLDs of dyslexia, attention deficit (hyperactivity) disorder, dyscalculia and dysgraphia, have become better understood. SpLDs are

disorders that relate to challenges with literacy, mathematics, handwriting, reasoning, listening and speaking (McDowell, 2018). SpLDs can have adverse implications for: learning, the ability of a person to access an education curriculum, self-concept, motivation, the development of maladaptive behaviours and an increased risk of adversity in adulthood (McDowell, 2018). Negative repercussions associated with SpLDs in adulthood, include adverse implications for mental and physical health, social interactions, career prospects and a greater risk of criminal behaviour (McDowell, 2018). Another emerging diagnostic category is Dyspraxia or DCD, which is broadly defined as impaired motor coordination in children (Gibbs et al., 2007). Dyspraxia and DCD are socially emergent framings of motor coordination because they are recent conceptualisations with some individuals using the term Dyspraxia, others DCD and still others using both terms. Searches of databases such as Google Scholar, Proquest and Jstor reveal that the majority of papers written about DCD prioritise biomedical conceptualisations of childhood presentations of DCD (Blank et al., 2019; Blank et al., 2012; Cairney et al., 2013). A number of qualitative childhood studies have been undertaken which similarly prioritise medical framings of the DCD experience (Eggleston et al., 2020; O'Dea et al., 2021; Zwicker et al., 2018), and an even smaller number of studies have qualitatively engaged with the DCD experience in adolescence and adulthood (Forde & Smyth, 2021; Payne & Ward, 2020). Fewer studies still have looked at neurodiversity framings of Dyspraxia in line with a social model of disability, for example incorporating co-occurring cognitive difficulties as part of the Dyspraxia lived experience rather than framing cognitive aspects as co-occurring conditions (Walker et al., 2021). There is also a dearth of studies looking at real-life concerns affecting adults with Dyspraxia from their perspectives rather than that of researchers. Promoting the Quality of Life (QoL) of adults with Dyspraxia/ DCD requires research studying the current social barriers to their wellbeing.

DCD/ Dyspraxia is presently assumed to be a developmental disorder with a neurological basis that is frequently defined using a spectrum of difficulty from mild to severe (Leveto, 2018) and has also been framed using the terms neurodiversity and neurodivergence. The use of neurodiversity has replaced SpLDs in psychological literature in recent decades and commonly refers to AD(H)D, DCD, Dyslexia and Autism, although mental health difficulties and other conditions, for example Tourettes syndrome may also be included (Grant, 2009). Neurodivergent experiences can best be described as a spectrum of difficulties that overlap, with each affected child presenting with a unique profile (Reid, 2005). Chapman (2020) states that the neurodiversity concept challenges the social defaulting to normative perceptions of ability, arguing that diversity is the actual norm. Neurodiversity differs from traditional understandings of the social model which typically regard impairments in relation to a species-typical norm with regards to essential functional and cognitive capabilities (Chapman, 2020).

Neurodiversity generally refers to a belief that a person's cognition and processing of information is a central aspect of identity (den Houting, 2019), and, in the instance of Dyspraxia/ DCD, how people physically interact with the social world. The neurodiversity movement represents a collective resistance, rejecting the attribution of disorders to conditions like Autism, Dyslexia and Dyspraxia, advocating instead for framing these experiences as non-pathological human difference (Jaarsma & Welin, 2012). Neurodiversity, as a concept, is reliant on a biomedical framing people, with Dyspraxia, for example, understood to arise from alternative brain wiring and a neural makeup that, while not a deviation, is both "real" and biological (Runswick-Cole, 2014). Neurodiversity further encompasses the "diversity of human minds" in contrast with terms like 'special needs' which stigmatise people with perceived or actual impairments and obfuscate how diverse needs are often unmet due to "non-inclusive societal" practices and "environmental factors" (Monk, 2022, p.20). According to Robertson (2010) neurodiversity encapsulates both the neurology and identity of neurominorities in relation to human diversity and is a concept that has been influenced by other signifiers of diversity including ethnicity, gender and sexual orientation.

However, the neurodiversity movement subscribes to the social model of dis/ability which regards a person with an impairment as being dis/abled by the social context they inhabit, with proponents calling for both social acceptance of difference, in conjunction with the provision of social support, to address the needs of neurodiverse people (den Houting, 2019). According to Ashby (2010), the medical model has been found to socially construct neurodiverse social conditions, such as Autism, linguistically, and in terms of both cultural representation and the political response. Further, medical conceptualizations frame neurodiverse experiences in relation to normal/abnormal, dis-abled/able dichotomies without addressing the social environments that "render these categories meaningful, and operating from an assumption that disability is inherently inferior to non-disability" (Bottema-Beutel et al., 2021, p.21). Conversely, the neurodiversity movement adopts inclusive terminology in relation to neurodiversity:

> Neurodiversity: The range of natural ability that exists in human neurodevelopment.
> Neurotypical: A person or people whose neurodevelopment falls within the range usually considered to constitute 'typical' development
> Neurodivergent: A person or people whose neurodevelopment falls outside of) or diverges from) the range usually considered to constitute 'typical' development (e.g., a group of [Dyspraxic] people is a group of 'neurodivergent' people)

Neurodiverse: A collective term for a group including mixed neurodevelopmental (e.g. a group of [Dyspraxic] and [non-Dyspraxic] is a neurodiverse' group) (Pellicano & den Houting, 2022, p.10).

DCD is the term most often used in the literature to describe motor coordination difficulties, but whether the condition is described as DCD or Dyspraxia varies between stakeholder groups and sometimes, from country to country. Children with Dyspraxia/ DCD have been found to exhibit a high level of co-occurrence of other developmental disorders including dyslexia, autism spectrum disorder (ASD) and hyperactivity, with 50% of DCD individuals exhibiting attention deficit (hyperactivity) disorder (AD(H)D) (Landgren et al., 1996). The framing of DCD, and most research, has been dominated by various disciplines including the fields of "kinesiology, occupational therapy, paediatrics, physiotherapy and psychology" (Blank et al., 2012, p. 217). Some researchers estimate that there is a 2% incidence of severe cases of DCD in a population (Gibbs et al., 2007). However, 5%-6% is the most quoted estimate in the literature of individuals with normal intelligence who have some degree of DCD (Blank et al., 2012) Prioritising the accounts of participants with Dyspraxia/DCD aims to address the lack of inclusion typified by most studies about DCD to date. Further, the structure of this study was created in response to the dominant themes in the participant narratives of people with Dyspraxia/ DCD and not to satisfy a preconceived research model or agenda.

Any attempt to understand the subjective experiences of individuals with Dyspraxia/DCD and the interconnections that exist between them, and their social world, is situated within a particular time and cultural context and is therefore subject to change. How a society perceives dis/ability and diversity is historically and culturally situated and it is only when individuals are unable to meet the demands required of the society they inhabit that a physical or cognitive perceived inadequacy is made visible (Shakespeare, 2008). The dominant societal discourse conceptualizing dis/ability is the medical-individual discourse. Dominant societal discourses are ideological in nature, serving to uphold mainstream power arrangements (Parker, 2014). To understand the lived experience of Dyspraxia, especially in relation to social institutions this study will investigate whether people with Dyspraxia/ DCD, who inhabit the same ideological systems as the wider populace, are potentially at greater risk of marginalisation, simultaneously experiencing their societally ascribed roles or identity while being aware of their disadvantage (Parker, 2014). Medical experts agree that failing to diagnose and treat motor coordination difficulties and the co-occurring developmental disorders associated with Dyspraxia/ DCD may have significant consequences in adulthood including unemployment, psychiatric disorders (Hellgren et al., 1994), substance abuse, reading disorders, criminality, reduced educational outcomes and a low level of interpersonal skills (Rasmussen & Gillberg, 2000). Medical

professionals maintain that a proportion of DCD individuals will become capable adults (Kirby, 2004) without professional intervention. However, the current medically derived narratives about DCD, and Dyspraxia, may not encompass the lived reality of the percentage of the population who experience coordination difficulties. Current social conceptualisations may omit those with less severe symptoms and fail to address the life experiences of individuals with Dyspraxia/ DCD in relation to society.

Foucault famously said "people know what they do, they frequently know why they do what they do, but what they don't know is what they do does" (Dreyfus & Rabinow, 1982, p. 187). It is important to acknowledge that many claims have been made by health and educational professionals on behalf of the estimated 120 - 420 million Dyspraxia/ DCD individuals worldwide. In dramatic contrast however, the voices of people with Dyspraxia/ DCD are almost entirely silent, not contributing, except anecdotally, to the social narratives about them. Current societal discourses in Aotearoa New Zealand may have significant repercussions for people with Dyspraxia/ DCD. The discourses that affect those with Dyspraxia/ DCD, exist in certain local or regional institutions and in particular practices, enabling, as Rose (1998, p. 297) stated, "the distribution of power to some while limiting the power of others, granting some the power to judge while others are judged, to cure and to be cured or to speak the truth while others must acknowledge its authority and embrace it, aspire to it, or submit to it". Individuals adopt an approach to their lived reality, which accepts that reality is the way it is and that no alternative exists (Parker, 2014). The rejection by Foucault of societal assumptions that power is the repression and domination of subjectivity, enables power to be understood, not as oppressing the capacities that people possess, but rather that power creates, forms and uses people as subjects (Rose, 1998). Power, then works through subjectivity and not against it (Rose, 1998). An investigation of power in relation to 'the self', is not contingent on analyses of suppression by the state but on studying how subjectivity has been employed by powerful societal actors as a resource or target to further certain regulation practices and to implement particular social tactics and strategies (Rose, 1998).

Of relevance to this study are the investigations undertaken by Foucault into modern notions of the self in relation to the role of institutions and what he calls 'technologies of the self'. The idea of technologies of self, applied to the social experience of Dyspraxia/ DCD enables an exploration of the ability people have to "effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality" (Foucault, Martin, Gutman, & Hutton, 1988, p. 18). At the level of the modern self, Foucault identified contemporary constructions of autonomous subjectivity as being embodied in the way we improve

ourselves, and our rejection of that which we consider to be undesirable and forbidden, in pursuit of what we understand to be permitted and desirable. The wide dissemination of societal norms achieved by socially dominant groups ensures that their universal identity and cultural expressions become unremarkable (Young, 2004). The dominant groups become 'normal' with other groups being defined as different and exhibiting lack, leading to a complex form of oppression where the oppressed are simultaneously rendered invisible, in terms of personhood and voice, whilst being visible as different and remarkable people (Young, 2004). Such stereotypes are ubiquitous within society and so invisible as to be incontestable (Young, 2004). As individuals, we formulate our ideas about what 'normal' selfhood is, through cultural technologies like film and advertising, but the aspiration to be a certain type of self occurs through operations that simultaneously distinguish as well as identify (Rose, 1998). To be the self, we are, we cannot be the self we are not. We reject the self that is maligned, the not normal child, the not normal adolescent, the not normal adult; through our lifestyles, personalities and aspirations we aspire towards our desirable selves (Rose, 1998). Rose (1998) observes that:

> In political life, in work, in conjugal and domestic arrangements, in consumption, in marketing and advertising, in television and cinema, in the legal complex and the practices of the police, in the apparatuses of medicine and health, human beings are addressed, represented and acted upon as if they were selves of a particular type: suffused with individualized subjectivity, motivated by anxieties and aspirations concerning their self-fulfilment, committed to finding their true identities, and maximizing their authentic expression in their lifestyles (p. 289).

People are not actors who possess agency, nor are they the passive creation of societal forces; rather, agency is produced through what one does in relation to the cultural forces exerted upon a person (Rose, 1998). As Rose (1998) so eloquently states:

> What humans are able to do is not intrinsic to the flesh, the body, the mind or the soul – it is constantly changing from place to place, time to time, with the linking of humans into apparatuses of thought and action – from the simplest connection between one organ or body part and another in terms of an 'imaginary anatomy' to the flows of force made possible to the links of an organ with a tool, with a machine, with parts of another human being or beings, within an assembled space such as a bedroom or a schoolroom (p. 310).

What are the linkages between an individual with Dyspraxia and the forces, processes, or objects they encounter? Furthermore, what capacities are created and what possibilities are engendered; to whom

is power allocated or delimited in the society that individuals with Dyspraxia/ DCD inhabit? The intention of this study is to improve current understandings of the linkages between individuals with Dyspraxia/ DCD and current institutional contexts, particularly the Aotearoa New Zealand education and healthcare sectors, recognising that:

> In any society, there are manifold relations of power which permeate, characterise and constitute the social body, and the relations of power cannot themselves be established, consolidated nor implemented without the production, accumulation, circulation and functioning of a discourse (Foucault, 1980, p.93).

This study also intends to help address the lack of qualitative studies about Dyspraxia/ DCD and identify, explain, and interpret current narratives about Dyspraxia/ DCD in the Aotearoa New Zealand context through exploring alternate discourses that may better reflect the life experiences of adults with Dyspraxia/ DCD.

1.1 Dyspraxia/ DCD in Aotearoa New Zealand and internationally

In recent years sociologists have claimed that a person's lived experiences during childhood, adolescence and adulthood, can be described discursively in terms of culturally or institutionally constructed normative stages, transitions or statuses (Barnes & Mercer, 2010). Cultural institutions, like that of education or the healthcare sector, have the potential to define a person's cultural and social role (Barnes & Mercer, 2010). Dyspraxia/ DCD represents a fascinating anomaly in the politicisation of dis/ability issues, because individuals who are aware that they have been diagnosed with Dyspraxia/ DCD are predominantly children or young adults (Davis, 1997). Consequently, as a social minority there have been few attempts at self-determination and self-definition (Davis, 1997). Instead people with Dyspraxia/ DCD have been "observed, written about… instructed, regulated, [and] treated…and controlled" (Davis, 1997, p. 1) by well-meaning professionals and even parents.

This study will include a focus on the Aotearoa New Zealand education system in order to determine whether participation in education may be the point in the life cycle of a person with dyspraxia where their impairment becomes a dis/ability in response to social factors (Barnes & Mercer, 2010). In Aotearoa New Zealand, for example, the current education system is dominated by a reliance on assessment criteria for examinations that may disregard whether the curriculum is designed to suit the education needs of all children and adolescents (Barnes & Mercer, 2010). The focus of current

education discourses on academic outcomes and academic success, emphasizes ablest values, disregarding the learning-generated barriers potentially experienced by students with SpLDs (Barnes & Mercer, 2010). Whether current institutional practices, like those in education, promote the exclusion and/or marginalisation of young adults with one or more learning impairments within mainstream state institutions, will be a central focus of this study.

The term Developmental Coordination Disorder, commonly known as DCD, has been introduced by DCD experts. Nevertheless, Dyspraxia is still widely used by parents, support groups and foundations in Aotearoa New Zealand and abroad, and by individuals with Dyspraxia. Movement matters (2023) which represents the key national bodies that represent Dyspraxia/ DCD in the United Kingdom and provide resources for professionals and parents, defines DCD as:

> A common disorder affecting fine and/or gross motor coordination in children and adults… DCD is distinct from other motor disorders such as cerebral palsy and stroke. The range of intellectual ability is in line with the general population. Individuals may vary in how their difficulties present; these may change over time depending on environmental demands and life experience and will persist into adulthood.
>
> An individual's coordination difficulties may affect participation and functioning of everyday life skills in education, work, and employment. Children may present with difficulties with self-care, writing, typing, riding a bike, play as well as other educational and recreational activities. In adulthood many of these difficulties will continue, as well as learning new skills at home, in education and work, such as driving and DIY. There may be a range of co-occurring difficulties which can also have serious negative impacts on daily life. These include social and emotional difficulties as well as problems with time management, planning and organization and these may impact an adult's education or employment experiences.

The Dyspraxia Foundation (2023a), in response to the confusion that surrounds the terms DCD and Dyspraxia, states on its website that having diagnostic criteria can be useful to explain the condition, particularly for researchers investigating DCD. However, the Dyspraxia Foundation website goes on to say that many people with lived experience prefer to identify as 'Dyspraxic' and regard Dyspraxia as being "a fundamental part of their identity" (Dyspraxia Foundation, 2023a). Further, people who identify as having Dyspraxia object to the term DCD, comprised as it is of:

> ‘developmental’ – which suggests they should have ‘grown out of’ their difficulties by adulthood,
> ‘coordination’ – because this doesn’t convey the range of difficulties they experience day to day, both physical and non-physical; and
> ‘disorder’ – because they regard themselves as ‘different’ rather than ‘disordered’ (Dyspraxia Foundation, 2023c).

The Dyspraxia Foundation (UK) promotes a broad conceptualisation of the Dyspraxia experience, including cognitive difficulties such as executive functioning difficulties (Dyspraxia Foundation, 2023c). Biomedical experts, conversely, do not promote use of the term Dyspraxia but prefer use of the term DCD for people who fulfil the requirements of DCD criteria (Blank et al., 2019). The discrepancies that exist between expert and general stakeholder perceptions about the terminology, definitions, and descriptions of Dyspraxia/ DCD are indicative of the complexity inherent in ascribing a label to a condition with a potentially broad array of symptoms.

Individuals experiencing severe consequences in their daily lives are estimated at 2%, with a further 3% experiencing some degree of impaired motor coordination ability in their daily lives (Blank et al., 2012) Most claims that have been extrapolated to encompass the DCD adult population have been based predominantly on childhood studies (Blank et al., 2019). Further, the sample populations in these studies are typified by a symptomatology consisting of delays in the acquisition of developmental motor milestones relative to the general population which calls into question whether they accurately represent adults and children whose ‘symptoms’ may have both cognitive (Moody, 2014) and motor coordination aspects. Significantly, Moody (2014) identifies that both Dyspraxia and Dyslexia present differently in adults than in children, stating that:

> There are two main common misconceptions: the first is that Dyslexia’s chief characteristic is difficulty with reading. This is very often not the case. An adult with dyslexia may be slightly slow in reading but otherwise competent. The chief characteristics of Dyslexia in adulthood are weaknesses in phonology, auditory short-term memory (working memory), and visual processing skills. These weaknesses stand in contrast to strong verbal reasoning abilities.
>
> The second is that Dyspraxia in adulthood is characterised chiefly by poor motor coordination. This is also often not the case. Adults with Dyspraxia often have improved their motor coordination skills over the years, and their chief difficulties in education and employment are more likely to be related to the cognitive aspects of Dyspraxia, such as difficulty with sequencing

> and structuring information, organisational skills, time-keeping, and sometimes social skills (p. 252).

If DCD is represented by a spectrum of severe to less severe, only the more severe and obvious cases of DCD/ Dyspraxia may be recognised and diagnosed using current diagnostic requirements based on the DSM-5 (American Psychiatric Association, 2013). There is a high likelihood that individuals with less severe DCD symptoms may not be identified by educators or medical professionals in Aotearoa New Zealand and will not receive a Dyspraxia or DCD diagnosis.

Children, and possibly adults on the severe and obvious end of the Dyspraxia/ DCD spectrum, may benefit greatly from a Dyspraxia/ DCD diagnosis and subsequent clinical interventions, particularly if they experience other co-occurring developmental disorders such as dyslexia, AD(H)D and ASD. Given this benefit, it is of concern that great many children still fail to be identified, or, if identified then this may only be in high school or university in response to academic shortfalls which may be too late to avert poor health outcomes, reduced employment opportunities, reduced life expectations, self-esteem issues, social isolation, anxiety and depression (Kirby et al., 2013). This is significant because early identification has been proven to promote good life outcomes for DCD (Blank et al., 2019). While Dyspraxia must be diagnosed by a qualified medical professional, Dyslexia, by contrast, is typically assessed and identified by educational psychologists. However, the symptoms and signs attributed to Dyslexia significantly overlap with Dyspraxia; with 40-57% of individuals with Dyslexia, depending on the severity of motor coordination difficulties (Chaix et al., 2007), exhibiting some form of impaired movement capabilities. Dyslexia in adulthood, like Dyspraxia, describes symptoms including difficulties with handwriting and coordination skills (Dyslexia Foundation of New Zealand, n.d.-a). Despite the co-occurring nature of neurodiverse conditions, Dyspraxia appears to be perceived through medical narratives as a physical impairment while Dyslexia is defined as a learning dis/ability. Dyslexia advocates have begun to reclaim the term dyslexia as a point of pride, arguing that people with dyslexia have strengths and traits common to dyslexia:

> Dyslexia isn't simply an issue with basic reading and writing skills, it's an entire learning preference which can bring a broad spectrum of difference – from enhanced creativity and 'out-of-the-box' thinking on the plus side to issues such as auditory and information processing, planning and organising, motor skills, short-term memory and concentration (Dyslexia Foundation of New Zealand, n.d.-c).

In recognition of the preoccupation of researchers globally to study dyslexia, rather than to call for and promote changes in the education sector (MacKay, 2012), dyslexia advocates are drawing on the wealth of experimental evidence and research about dyslexia to legislate for change in Aotearoa New Zealand schools (Dyslexia Foundation of New Zealand, n.d.-b). In conjunction with the Ministry of Education (MoE) and the New Zealand Qualifications Authority (NZQA), the Dyslexia Foundation of New Zealand has been increasing the number of young people each year, who have learning differences, who are able to receive the National Certificate of Educational Achievement (NCEA) Special Assessment Conditions (SACs), such as the use of a computer, reader or writer assistance and/ or extra time in exams (Dyslexia Foundation of New Zealand, n.d.-b). The National Certificate of Educational Achievement (NCEA) is the primary qualification for secondary school students in Aotearoa New Zealand (New Zealand Qualifications Authority, 2024). While students who have been assessed for impediments that prevent them from learning normally; (by an educational psychologist), are able to benefit from SACs, no similar advocacy has been undertaken for people with Dyspraxia/ DCD. Unlike dyslexia, Dyspraxia/ DCD appears predominantly perceived as a medically defined dis/ability (Conrad, 2007). Nevertheless students with Dyspraxia/ DCD in New Zealand schools are able to take advantage of the work of dis/ability advocates, if they are able to access an assessment from an educational psychologist (New Zealand Parliament: Report of the Education and Science Committee, 2016).

DCD researchers observe that the condition is often regarded as mild in comparison to conditions like Autism and not warranting of social investment but epidemiological data indicates that DCD is the most common coordination disorder and therefore social intervention is warranted (Blank et al., 2019). Given the significant percentage of the population estimated to have DCD, the societal and economic burden is likely to be significant due to DCD adversely affecting daily activities at school and work, as well as the psychosocial implications and impact on both physical and mental health for this population (Blank et al., 2019).

While dominant cultural stereotypes may portray the dis/abled experience as one of deficit and loss, dis/ability advocates provide narratives that are more complex and nuanced and more representative of people's experiences (Linton, 1998). In the past two decades there has been an increasing momentum within the Autism community to challenge biomedical and neurotypical conceptualisations of autism and instead embrace neurodiverse narratives that frame Autism as a unique cultural identity (Bagatell, 2007, 2010; Bumiller, 2008; Jaarsma & Welin, 2012). "Activism, advocacy, research, and policy" has enabled dis/abled people individually and as part of dis/abled

person's organizations to challenge discrimination, revisioning "traditional medicalized understandings of disability as individual pathology to a system of social oppression and exclusion" (Morrison et al., 2021, p,128).

1.2 The medicalisation of DCD

Conrad's (2007) theory which highlights the trend in recent decades of medical professionals to medicalise illness or diseases that relate to people's behaviour, their mental state or physical condition, can also be applied to Dyspraxia/ DCD. The medicalisation of a problem, like Dyspraxia, is dependent first and foremost on a medical definition, "that is, a problem is defined in medical terms, described using medical language, understood through the adoption of a medical framework, or 'treated' with a medical intervention" (Conrad, 2007, p. 6). The process of medicalisation follows five stages, during which a behaviour identified as 'bad', transforms into a behaviour that is 'sick' (Conrad & Schneider, 1992, p.60). First, a behaviour is defined as being deviant (Conrad, 2007), and what we are concerned with for the purposes of this research are children who possess poor motor coordination. The second stage of medicalisation involves publishing a newly conceived medical definition, in this case DCD, in professional journals, leading to the creation of a new medical aetiology as well as methods of diagnosis (Conrad, 2007). Third, relevant stakeholders undertake claims making (Conrad, 2007). For example, medical professionals may make claims in conjunction with other interest groups, such as parents, to lobby the government for resources to assist DCD children. The fourth step in the process of medicalisation involves the legitimation of a claim, where claims making becomes enacted as opposed to merely rhetorical (Conrad, 2007). Finally, a medical concept of deviance is institutionalised (Conrad, 2007) resulting, for example, in DCD's inclusion in the DSM-5 and the provision of funding for some children with DCD to receive medical treatment. DCD has been academically legitimized internationally which is demonstrated by the European Academy of Childhood Disorders International clinical practice recommendations on the definition, diagnosis, assessment, intervention, and psychological aspects of developmental coordination disorder (EACD) (Blank et al., 2019) and is likely in the process of being institutionalized (Conrad, 2007) in many countries. In the healthcare sector, both in Aotearoa New Zealand and internationally, however, confusion likely exists in fields not specialising in Dyspraxia/ DCD with one study identifying, for example, that many general practitioners lack training in the recognition of neurodevelopmental disorders (Thapar & Thapar, 2002).

Medicalising an experience like Dyspraxia/DCD may benefit the Dyspraxia population in terms of access to medical accommodations but may also, as discussed by Busfield (2017), divert attention from socially oppressive practices that diminish the QoL for this group and limit alternatives. Medical interventions, for example addressing developmental delays in children, are likely ineffective in addressing the factors that contribute to socially attributed stigma. As Busfield (2017) states, it's easier to attribute a person's difficulties with an impairment to their individual circumstances, rather than find the political will to address any social practices, or inequalities, that may disadvantage them. The medicalising of an issue like Dyspraxia/ DCD needs to be critiqued, not in relation to important gains of medical scholars and practitioners on behalf of people with Dyspraxia/DCD, but rather to address the issue of attributing a pathology to an individual and their life experiences. Medicalisation differs from pathologisation in that the former is a classification system whereas the latter is a social construction that attributes a devalued status to certain human experiences deeming them abnormal, and an illness requiring specialist intervention (Spencer & Carel, 2021). Framing dis-abling conditions along pathological lines is defined by negative views of abnormality and positive perspectives of medical rehabilitation (Shyman, 2016).

1.3 Ableism

The medical model has been found to be grounded in ablest normativity, socially constructed through powerful discursive practices that have their basis in essentialist and ubiquitous societal perceptions of normal and abnormal (Slee and Allan, 2001). The concept of normality is the central tenet of the biomedical model and upon which the process of othering dis/abled minorities is based, in conjunction with the portrayal of dis/ability as a universal deficit (Loja et al 2013). Prior studies have noted that these discourses create hierarchical structures that are imposed on individuals and which influence who is included and accepted in normative social life and who is relegated beyond the boundaries of acceptability (Slee & Allan, 2001). The basis of an ableist social system are normative assumptions about the normalized individual, their physicality, mind and appearance and the distinction between those who possess a perceived ideal human state and those who society deems exemplify how the normal embodied human should be (Campbell, 2019). Dis/abled individuals may face oppression because they challenge the normative assumptions upheld by political, cultural and social forces about the human body and mind (Marks, 1999). According to Marks (1999), oppression is experienced by dis/abled people because dis/abled populations disturb how society culturally and politically perceives the normal body. Reeve (2002) further notes that oppression is not experienced by all

impaired people and observes that greater understanding of social and personal capabilities can help explain where the experience of oppression originates and ends for impaired individuals.
Thomas (2004b) argues that framing dis/ability as a form of oppression that occurs through social relationships creates an opportunity to redefine dis/ability in terms of disablism affording it the same significance as other social categories, including racism and sexism.

Research has shown that dis/abled people are at greater risk of being socially disadvantaged and of experiencing economic deprivation (Oliver, 1996). It is estimated that 15% of adults live with a dis/ability, experiencing higher rates of involuntary unemployment and/or poverty and often leave school early (Martin et al., 2004). Of significance for individuals with Dyspraxia/ DCD is the recognition within sociology of the extent to which poverty and social exclusion disproportionately affect dis/abled people, particularly with regards to how disadvantaged a dis/abled person may be in the labour market (Abbott et al., 2005). Thomas (2004a) argues for a social relational conceptualization of dis/ability and a recognition, in keeping with Finkelstein (2001), that dis/abled people are oppressed, stating that:

> Finkelstein propounds the view that disability is entirely socially imposed and amounts to a form of social oppression. [Disability advocates and scholars] argue that disability is caused by impairment and social exclusion, the latter being more significant and amounting to social oppression. [Medical sociologists] believe that disability is caused by both impairment and social disadvantage but see impairment as by far the more significant cause; they ignore (rather than explicitly refute) suggestions that a form of social oppression is at work (p. 578).

Recent shifts in international policy have shifted the focus from medical discourses to issues of equity and diversity, as illustrated by the creation of the United Nations Convention on the rights of persons with disabilities (UN CRPD) United nations (2006b) and ICF (Cerniauskaite et al., 2011). The former is an international agreement that seeks to protect and promote the rights of dis/abled people globally and the latter incorporates social model framings of dis/ability by situating dis/ability as the experience of an impairment in relation to environmental factors.

While there are several new dis/ability approaches, including new materialist approaches (Goodley & Lawthorn, 2019) in the field of critical dis/ability studies, this study has focused on the emergent and interdisciplinary theoretical approach of critical studies of ableism promoted by Campbell (2008; 2009, 2019) and Wolbring (2008, 2012). Campbell and Wolbring attempt to de-stabilise the socially idealised version of species typical personhood, an idea that is based on normative presumptions of

what it means to be human. As Thomas (2007) argued, where women experience sexism, non-white ethnicities endure racism and LGBTQ communities are subject to heteronormative phobias, people possessing impairments are exposed to disablism. Ableism promotes "paranoia, confusion, fear, and inadequacy. Ableism is an ideal that no one ever matches up to" (Goodley & Lawthorn, 2019, p. 235). The result of a social defaulting to an ableist ideology, comprised of individualist and isolationist social positions that engender prejudice, are social arrangements that promote contemporary manifestations of "homophobia, xenophobia, nationalism, racism, sexism alongside disablism" (Goodley & Lawthorn, 2019, p. 237). An ableist ideology leads to a world where people with disabilities feel that they don't fit in, are excluded by default of their physical or cognitive difference.

Of relevance to this study is the role of socially constructed ideas about ableism and disablism in relation to Dyspraxia/ DCD, and equally other neurodiverse experiences, with disablism defined as being:

> A form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing (Thomas, 2007, p. 632).

Campbell (2009) argues for a change of focus from disablism, and disability situated in the body, to what Campbell calls ableist normativity and argues for the shifting of focus of critical dis/ability studies away from the dis/abled body onto the able body. Campbell (2009) challenges the idea that anyone who isn't a male, white, heteronormative, financially autonomous adult inhabits the space of the Other and as such, represents the Self against which all other individuals judge themselves.

Campbell (2008) argues that while many researchers may use the terms disablism and ableism interchangeably that the two terms have different meanings in relation to normative social constructions. Campbell (2008) argues that much academic scholarship has adopted an approach to dis/ability based on disablism thereby prioritising an 'able-bodied voice/lens toward dis/ability' and thereby studying the phenomena of dis/ability from the point of view of the 'other' (Marks, 1999). Ableism can be defined as:

> System of causal relations about the order of life that produces processes and systems of entitlement and exclusion. This causality fosters conditions of microaggression, internalized ableism and, in their jostling, notions of (un)encumbrance. A system of dividing practices,

> ableism institutes the reification and classification of populations. Ablest systems involve the differentiation, ranking, negation, notification and prioritization of sentient life (Campbell, 2017, as cited in Campbell, 2019, p. 147).

Like the other major social signifiers, including race and gender, an individual's neurobiology is another potential characteristic an individual possesses (Nicolaidis, 2012). Lawthorn (2019, p.236) argued that "ableism is empty in the sense that it is stripped of the human qualities of humanness, mutuality, vulnerability and dependence". The adoption of a critical theory of ableism acknowledges that while reality is socially constructed within the inter-subjective space between individuals, the multiplicity of subjective realities that individuals inhabit are underpinned by "political, social, cultural, economic, ethnic, … gender" (Brown & Dueñas, 2020, p. 548) and dis/ability values in response to socially situated power relations.

Butler (1993) argues that sex and gender are performatively inscribed meaning that sex and gender are not something someone is but rather something someone does, an act or a number of actions that are constructed within social arrangements (Butler, 1990). Applying Butler's (1993) ideas to ability, ability may similarly be conceptualised as a way of 'doing' rather than of 'being' within established institutional arrangements. Further, institutional structures will dictate the social appearance of ability. Salih (2007) comments that the physical and cognitive functionality a person possesses was suggested by Butler to not be freely chosen by a person but rather individuals are constrained by a limited number of choices about how their ability is performed within a rigid and regulated social framework. Ability, like gender, is what Butler called a corporeal style, an action, or a number of actions the purpose of which is cultural survival (Salih, 2007). Those who are unable to act in terms of their ability in a socially acceptable manner are punished by society (Butler, 1990). As Butler (2002) commented, people understand themselves through norms which help conceptualise who they are. However, aspects of the self that fall outside of norms may not then be recognisable (Butler, 2002). People become attached to normative categories of social existence, meaning that how people see themselves is constrained by social norms (Butler, 2002).

Ability differences are performatively created through discourse meaning that alternate discourses could be ascribed to the ability experience (Salih, 2007). Judith Butler commented that bodies hold social discourses within them and argued that people live not only within social discourses, but through discourses (Salih, 2007). Discourses then exist in an interconnected manner between individuals and the society they inhabit but also embodied within the individual (Butler, 1993). Critical

research enables the examination of how ability, in this study Dyspraxia, is discursively situated and influenced by power relations, employing an epistemology underpinned by an awareness that it is not possible to study social life without being influenced by an ideology (Kincheloe & McLaren, 2011). Further, critical research seeks to transform institutional arrangements that may contribute to oppression in an effort to alleviate suffering (Kincheloe & McLaren, 2011).

This research aims to contribute to current and evolving academic narratives by applying the theories and ideas outlined above to the experience of Dyspraxia/ DCD in adulthood, prioritising, as much as possible, the perspectives and voices of people with Dyspraxia/ DCD.

1.4 Stigmatisation, society, and the lived experience of stigma

Goffman (1997) identifies stigma as being a difference or deviance, which society conceptualises through its rules and norms. People with Dyspraxia/ DCD possess a difference or deviance from what is held to be normal, which places them at risk of the stigma perpetuated by societal institutions. Ultimately, stigma is directed at people who, because of their differences, are negatively perceived by society. But stigma is not a static concept, rather it is a social process that is in a state of constant change, and that change is often resisted (Parker & Aggleton, 2007). Crucially, stigma is not an attribute that a stigmatised person has within them but rather it is a societal designation that has been attributed to an individual by others (Yang et al., 2007). Directly relevant to Dyspraxia and other SpLDs is the recognition that stigmatisation occurs in relation to a historical context which dictates how the stigma will appear and also its form in relation to particular cultural contexts and societal expressions of power (Parker & Aggleton, 2007). Understanding the historical context and the consequences of the possible stigmatisation experienced by individuals with Dyspraxia/DCD can enable the creation of improved means of mitigating negative effects because it is essential to identify how "stigma is used by individuals, communities and the state to produce and reproduce social inequality" (Parker & Aggleton, 2007, p. 17).

The general theoretical position adopted in this study will be to investigate how movement capabilities are defined in terms of normal and abnormal ability, with the ideal subject typified as someone who has mastery over their production of movement (Parker et al., 1995). People with DCD/ Dyspraxia are positioned at the edges of what is perceived as normal and a set of behaviours are defined for, and ascribed to them (Parker et al., 1995). This study investigates how wider society perceives and treats people with Dyspraxia/ DCD and whether they are the targets of prejudice, experiencing "material and

psychological disadvantage, low self-esteem, stigma and depressed aspirations" (Vaughan & Hogg, 2014, p. 359). Perceived discrimination has been shown to have negative impacts on physical and mental health, to elevate stress levels and to be a precursor to the adoption of unhealthy behaviours (Vaughan & Hogg, 2014). Prejudice is defined as; "stigmatised individuals who possess, or who are believed to possess a characteristic or attribute "that conveys a social identity that is devalued in a particular social context" (Vaughan & Hogg, 2014, p. 342).

The attribution of power within society affords certain groups of people the right to speak, while denying the power of expression to others (Parker et al., 1995). Societal discourses are statements which enable people to speak about and define an object (Parker et al., 1995). These discourses exist in relation to the distribution of power and, in the case of Dyspraxia/ DCD, societal discourses are structured around definitions and perceptions of normal and abnormal (Parker et al., 1995), able and dis/abled. Notions of dis/ability reflect certain societal values. For example, individuals who despoil the environment and destroy other species for personal profit, manipulate others to their detriment in the conduct of management, destroy the long term productive capacity of an economy in the interest of short-term profit or use deceptive practices to obtain public office (Levenson, 1992, p. 55) are not considered by society to be abnormal, antisocial or pathologically dis/abled, but rather as belonging to the normal population.

Foucault (1980) argued that scientific disciplines such as biomedicine are cultural systems which amass evidence that is neither fact nor truth, but rather they are socially constructed entities created by powerful professionals. The accepted understandings attributed to scientific disciplines then, are both contextually dependent and provisional (Foucault, 1980). Foucault (1980) observed that, beginning in the late nineteenth century, European societal regimes of violence and coercion transitioned to a knowledge/ power regime based on social control or subjectification, which was reliant on the creation of compliant and conforming subjects (Foucault, 1980). The social production of difference or deviance is inextricably connected to established power/ knowledge regimes, with that which is 'abnormal' enabling the definition of what is 'normal' (Foucault, 1980). Stigmatisation and stigma occur "at the point of intersection between culture, power and difference" (Parker & Aggleton, 2007, p. 17), and investigating how these phenomena inter-relate, improves our understanding that stigma and stigmatisation are not just isolated events or indicative of individually held attitudes or cultural assumptions, but rather they are integral to the construction of social order. It is essential to understand how the interrelated social processes of power, culture and deviance operate and function (Parker & Aggleton, 2007).

Goodley (2013) comments that disability researchers are uniquely placed to study the oppressive behaviours of normative discourses and challenge ableist assumptions about what constitutes a 'normal' body. Goodley (2013) further asserts that, in the reframing of the embodied disabled experience to embrace inclusivity and the contesting of dichotomous assumptions of able and disabled, normal, and not normal, there is the potential for productive social ethical, politically influential and value laden questions such as:

> How are non-disabled bodies made more viable and desirable than non- disabled bodies? How do societal practices uphold the precarious higher status of non-disabled people through the abjection (rejection) of disabled people? In what ways do disabled bodies rearticulate what qualifies as a body that matters? (Goodley, 2011, p. 159)

Attempting to free individuals of the stigma and discrimination to which they are subjected is to challenge societal notions of equality and inequality (Parker & Aggleton, 2007). Recognising that societies are founded on various forms of inequality and hierarchy, questioning societal structures equates to questioning the basic tenets of social existence (Parker & Aggleton, 2007).

Sociological research, Tyler and Slater (2018) observe, has overlooked Goffman's claim that stigma is historically situated and influenced and further, that stigma is used as a means of control by socio-political arrangements. Goffman's conception of stigma is underpinned by normative social ideals (Tyler & Slater, 2018). Paton (2018) argues for the need for sociologists to "gaze up" at the macro-levels of stigma construction and better understand the "motivations and roles" of people engaged in stigmatising acts. Stigmatisation is central to the complex power struggles that individuals with a dominant status engage in to legitimise their claims to power within societal structures that promote continuing inequality (Parker & Aggleton, 2007). Individuals with Dyspraxia/ DCD are people subjected to economically and discursively determined social processes, most tellingly neoliberal capitalism. Responsibility therefore is placed on socially disadvantaged individuals, whilst also deregulating the education and welfare services that would assist them (Parker, 2014), resulting in the engagement by individuals in symbolic violence which Parker & Aggleton (2007) describe as:

> the process whereby symbolic systems (words, images and practices) promote the interests of dominant groups as well as the distinctions, and hierarchies of ranking between them, while

> litigating the ranking by convincing the dominated to accept existing hierarchies through processes of hegemony (p. 18).

Ideas around symbolic violence and hegemony can elucidate how stigmatisation is integral to the complex power struggles associated with social life and the social structures that promote inequality (Parker & Aggleton, 2007).

It has been argued that the role of the socio-political context in the construction of stigma, and the perpetuation of social inequality from the level of the individual to the institution, has been overlooked in sociological research in favour of understanding the effects of stigma at various societal levels, from the individual to the social group (Marks, 1999; Tyler & Slater, 2018). Tyler and Slater (2018) state that disabled individuals face oppression because they challenge the normative assumptions upheld by political, cultural, and social forces about the human body and mind. Thomas (2004a) argues that disability can be framed as a form of oppression that occurs through social relationships

Disablism allows for the challenging of medical sociologists and other proponents of the individual model who do not recognise that disability represents an experience of "social oppression or systematic social exclusion" (Thomas, 2004b, p. 581). An understanding of hegemonic processes can also facilitate an understanding of why individuals often accept and internalise the stigma and discrimination to which they are subjected (Parker & Aggleton, 2007). Stigma undermines the safety of the local world that an individual inhabits, challenging the values that they attribute to their daily experiences (Yang et al., 2007). Yang et. al. (2007) observe that there can be critical periods where either the stigmatised individual or the stigmatiser will become inculcated into what they call 'stigmatised careers'. The adoption of stigmatising roles occurs during everyday encounters and through the internalising of commonly accepted power or status arrangements within the local worlds people inhabit (Yang et al., 2007). Perceiving stigma as a moral experience reveals that "both the stigmatised and the stigmatiser are … grappling with what makes social life and social worlds uncertain, dangerous and terribly real" (Yang et al., 2007, p. 1534). Whether individuals adopt a stigmatising social role may be due to whether they are exposed to embodied disability or difference during their, likely, early social experiences.

This study applied the concept of stigma to those with DCD/ Dyspraxia because it is possible that, for children and youth with Dyspraxia/ DCD, whether they know they have a dis/ability or not, stigma may dominate their experience of socialisation. The lived experience of day to day life represents the 'moral

experience' of individuals and what matters most to them, be it status, economic resources, life opportunities, health, employment prospects or relationships (Yang et al., 2007). Begon (2021) draws attention to the idea that what matters is not what impairments a person has but rather what are the real-world limitations they experience and how can these be ameliorated so that they can effectively access education or employment. Yang et al. (Yang et al., 2007) argued that stigma "spans physical-emotional-social-cultural-domains [and that]:

> by threatening what is at stake in the social world, stigma endangers what is most valued in one's innermost being. By proposing a means by which the social world (values) crosses over into the self (subjective experience of bodily states and emotions), [their] framework incorporates how stigma has psychobiological manifestations that occur out of awareness and that stigma takes place in intersubjective space (p. 1531).

This study examines the ways stigma enables and reproduces existing social inequalities at the institutional level (Bonnington & Rose, 2014).

In the contemporary world, the concept of identity is integral to the experience of social life and these constructions of identity change constantly (Hall, 1990, as cited in, Parker & Aggleton, 2007). Yang et. al. (2007) propose that our experience of both societal norms and emotions are connected via mediating processes, which manifest through moral-somatic and moral-emotional pathways. In the moral-somatic experience an individual's physiology is affected by their social experiences, or in other words, daily interactions with societal values and norms influence a person's bodily states. Moral-emotional experiences refer to the interrelated nature of a person's emotional state with societal values. Goodley (2013, p. 640) observes that "ableist processes create a corporeal standard, which presumes able-bodiedness, inaugurates the norm and purifies the ableist ideal". Ableist ideals and assumptions may result in Dyspraxic people perceiving themselves as lacking.

Tyler and Slater (2018) comment that Goffman has contributed to understandings of stigma being socially constructed and further, that the effects of stigma need to be managed by a stigmatised self through mechanisms such as passing, concealing and identity management. People with Dyspraxia may perceive and judge themselves in relation to social expectations about what constitutes the 'able bodied Self', whether in terms of physical comparison or a failure to meet the expected and often subtle threshold of acceptable social interactions. However, as Vehmas and Watson (2019) comment, people have the right to choose how they respond to their own experiences without having ableist or

disablist perceptions imposed upon them. The experience of stigma or the resistance to stigmatisation are both subject to the changing constructions described by Castells (1997) as being:

> distinguished between legitimising identities, which are 'introduced by the dominant institutions of society to extend and rationalise their domination vis a vis social actors', resistance identities, which are 'generated by those actors that are in positions/conditions devalued and/or stigmatised by the logic of domination" and project identities, which are formed 'when social actors, on the basis of whatever cultural materials are available to them, build a new identity that redefines their position in society and, by so doing, seek the transformation of overall social structure (p. 8).

Stigma has the ability to legitimise how resources and status are distributed in a manner that favours a dominant societal group who have no interest in removing the stigma, because the stigma serves to justify the dominant societal system, by maintaining the status quo (Vaughan & Hogg, 2014). Understanding how stigma processes threaten the local life world of individuals is essential if successful intervention programmes, and the tools to effectively evaluate them, are to be created (Yang et al., 2007). The valuable contribution of Yang et al.'s (2007) work is the recognition that implementing interventions devoid of an awareness of the potential local effects for stigmatised individuals, may have less chance of success than intervention measures that incorporate the observations of daily life. For such observations to be successful, many methodologies and vantage points may need to be adopted to better understand how individuals are threatened by stigma in their local worlds. The goal of this study is to contribute to the current literature by investigating how stigma affects the life experiences of people with Dyspraxia/ DCD and to consider the best conceptualisation of Dyspraxia that captures those effects.

1.5 Understanding dis/ability

Dis/ability, and dis/abled people, are predominantly understood in relation to two competing theoretical models, namely the social and individual-medical models of dis/ability (Simmons et al., 2008, p. 733). Medically derived models of dis/ability are determined by the level of impairment, which dictates the degree of dis/ability. Important aspects of the medical model include:

> (1) the definition of disease as deviation from normal biological functioning; (2) the doctrine of a specific aetiology; (3) the concept of generic diseases, that is the universality of a disease taxonomy; and (4) the scientific neutrality of medicine (Mishler, 1981, p. 22).

The medical-individual model promoted by industrialised societies, medicalises dis/ability and further regards it as a personal tragedy of the individual (Oliver, 1996). This perception is used first, to justify often invasive intervention measures by professionals in the social welfare, health and education sector and, second, as an explanation for the dependence and social disadvantages often experienced by dis/abled individuals (Barnes, Mercer, & Shakespeare, 1999). The health sector regards dis/ability as a pathology, while, in terms of social welfare, dis/ability represents a social problem and in both instances, dis/ability must be prevented, treated or cured (Barnes et al., 1999).

By contrast, the social model of dis/ability explores social factors, such as social attitudes, organisation, and physical arrangements, to determine to what degree an impairment is dis/abling. The pathology-dependent approach adopted by the medical model assesses individuals in relation to an idealised 'normal' level of ability. People with a dis/ability are regarded as 'abnormal' and in need of expert help (Simmons et al., 2008). Conversely, the social model of dis/ability, promotes the removal of dis/abling barriers at a societal rather than individual level, affording greater accessibility to education and other social opportunities (Simmons et al., 2008). Advocates of the social model of dis/ability seek to address the challenges experienced by dis/abled individuals who are aesthetically displeasing in relation to social norms and assumptions about being able-bodied and leading to social disadvantage (Abbott et al., 2005). Dis/ability advocates have adopted the social model of dis/ability to conceptualise dis/ability, framing dis/ability not as belonging to an individual, but instead perceiving 'dis/ability' as being the result of institutional and environmental inequities (Simmons et al., 2008). The social model has been found to have significant limitations, however. For example, by not acknowledging the effects of an impairment (Terzi, 2005) the separating of impairments from dis/ability can mean dis/abling social arrangements are not addressed. Critiques of the social model include the neurodiversity movement, in conjunction with other populations, for example d/Deaf individuals and people with mental health challenges, who do not regard their conditions as disabilities or perceive themselves to be biologically impaired (Berghs et al., 2016).

For both the individual-medical and social models, the experience of dis/ability due to an impairment, is understood as a deviation from normative conceptualisations of an individual's health status (Dubois & Trani, 2009). Medical professionals, and researchers, overlook the subjective experiences of their

patients, prioritizing instead quantifiable measures (Marks, 1999). Conversely, advocates of the social model typically highlight a lack of social inclusion and dis/abling environmental barriers that, if addressed, would mitigate the experience of impairment and meaning that the social model does not differentiate from the medical model enough and further, supports its continuation (Marks, 1999).

The International Classification of Functioning, Disability and Health (ICF) model represents an attempted synthesis of the medical and social models, and as such is a biopsychosocial model allowing for the conceptualising of dis/ability as having both social and medical components (Reindal, 2009). The ICF model attempts to incorporate the difficulties experienced by neurodiverse individuals with their social world (Bottema-Beutel et al., 2021). The ICF has been increasingly used to evaluate the social relationships between individuals and their local environment (Dubois & Trani, 2009). However, the ICF has been critiqued for framing dis/ability, and limitations of activity, as a disadvantage, and omitting issues of social justice or oppression (Reindal, 2009). The ICF further conceptualises dis/ability in relation to statistically acceptable normative social requirements and because it omits concepts of wellbeing and QoL, rendering it unsatisfactory as a tool to help empower people with disabilities (Reindal, 2009). Critics of the ICF Framework assert, however, that it is unable to identify discrimination, the role of a person's environment in the creation of an impairment or assess whether, and to what degree, it is the result of government policies (Hammell, 2015).

The recent EACD (Blank et al., 2019) report indicates that there is a move by DCD researchers to incorporate the biopsychosocial model, with much recent DCD literature appearing to be along ICF lines. DCD studies continue to situate the pathology within the individual (Hammell, 2015), as depicted in the Elaborated Environmental Stress Hypothesis (EESH) and other recent DCD literature, which identify significant social and:

> Environmental barriers to participation… [with] occupational therapy researchers and clinicians remain[ing] pre-occupied primarily with measuring deficits, remedying dysfunctions, and encouraging clients to adapt their abilities to environments that afford inequitable opportunities (Hammell, 2015, p.81).

Cairney et al. (2013) created the EESH to explain how DCD can lead to secondary psychological difficulties for children, such as victimisation from peers, and the internalising of psycho-emotional difficulties. The EESH suggests that an increase in social supports, for example from family and opportunities for peer inclusion, as well as improving individual resources, such as identifying personal

strengths including "mastery, self-esteem and social competence", can reduce adverse psychological outcomes (Cairney et al., 2013 p. 228). The EESH is an example of how DCD research predominantly engages with DCD along biopsychosocial lines, prioritising how to address limitations possessed by the individual. The EESH, in keeping with most DCD research, does not appear to consider the role of socially embedded discriminative responses to difference in the creation of DCD as a primary stressor or the role of socially oppressive arrangements that may lead to secondary adverse psychological implications.

A goal of this study is to contribute toward, what the Dyspraxia Foundation (2023b) in the UK describes as: "a move towards research 'with' rather than 'on'" people with Dyspraxia/ DCD. The UN CRPD, adopted in 2006, is a human rights treaty created by dis/abled people on behalf of dis/abled people and is based on activism and research that embodies a "nothing about us without us approach" to conceptualizing dis/ability (Watson & Vehmas, 2019, p. 77). Article 8 states that signatories to the UN CRPD (2006c) must:

> adopt immediate, effective and appropriate measures to raise awareness throughout society – 'including at the family level' – regarding persons with disabilities to combat stereotypes, 'promote awareness of the capabilities and contributions of persons with disabilities' and 'foster respect for the rights of persons with disabilities'.

The UN CRPD further requires signatory countries to "adopt all appropriate legislative, administrative and other measures to implement the UN CRPD, and to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities" (Watson & Vehmas, 2019, p. 77). The UN CRPD has been described as a treaty promoting dis/ability rights that is comprised of elements of the social model of disability, in conjunction with a human rights model and Nussbaum's version of the Capabilities Approach (see following section for description of the CA) (Watson & Vehmas, 2019). Aotearoa New Zealand as a signatory nation, and in keeping with Article 3 of the UN CRPD, has established the Whaikaha – Ministry of Disabled People as an independent body to "promote, protect and monitor [the] implementation of the present convention to ensure that national laws, policy development, implementation and monitoring" (Watson & Vehmas, 2019, p.79) do not reinforce existing inequalities (Rose, 1985, as cited in Watson & Vehmas, 2019)

1.6 The capabilities approach

The CA, developed by Amartya Sen (1999; 2005), was prioritized in this study because both the individual-medical and social models of dis/ability overlook the lived experience of the individual person in dis/ability analyses (Marks, 1999). Fundamentally, the CA asks: what are people able to do and who are they able to be? (Robeyns, 2017). Wellbeing from the perspective of the CA is connected fundamentally to the freedom a person has to achieve what they choose to value in life (Sen, 1999). The approach is normative and has the capacity to evaluate and assess the wellbeing of individuals in relation to social arrangements and promote policy design that contributes towards positive social change (Robeyns, 2006). The CA was created as an alternative to international development frameworks which typically concentrate predominantly on measures of GDP as the primary indicator of a person's QoL. In the decades since its conception, there have been considerable developments of the CA and its applications in policy and research settings have been many (Deneulin & McGregor, 2010). Deneulin and McGregor (2010) observe that the CA has influenced policy development and the social sciences and emphasised that it prioritises wellbeing as the end goal of policy development. The CA will be drawn on throughout this study, especially in the overall discussion of the findings, as a means of studying the individual experience of dis/ability in relation to social structures. The CA in contrast to the ICF model can conceptualise, in keeping with the social relational model of dis/ability, the experience of dis/ability as being one of exposure to inequality and consequently to socially oppressive forces and discrimination (Reindal, 2009). Regarding dis/ability as a purely medical phenomenon consisting of a physical impediment or intellectual limitation is evolving to encompass the environmental factors (Lollar & Crews, 2003) that can affect a person's lived experience. A comparison of the prominent models that have been created in response to the dominance of the medical model is shown in Table 1, with asterixis in table fields depicting the scope of the various models relative to each other.

A strength of the CA is its ability to explore a dis/abling phenomenon like Dyspraxia/DCD in response to, what Berghs, Atkin, Graham, Hatton and Thomas (2016, p.2) describe as, the "normative values and assumptions, embedded in discursive practices, where failure to accommodate diversity and difference denies the experiences of people with disabilities, generat[ing] oppression and produc[ing] inequalities". Mitra (2006) argues that the CA is distinguishable from other models of dis/ability, including the individual model, social model, and the ICF, or biopsychosocial model, in their treatment of impairment and dis/ability for several reasons. First, the CA enables dis/ability to be differentiated into the levels of potential dis/ability at the level of opportunity and actual dis/ability at the level of human capability (Mitra, 2006). Second, the CA can conceptualise the considerable variations between people's experiences of impairment, or dis/ability, in relation to their personal characteristics,

resources and environment (Mitra, 2006). Third, the CA can incorporate the economic dimension associated with the experience of an impairment (Mitra, 2006). The CA allows for comparisons between the ability a person has and the ability they could have in an ideal, barrier-free, situation (Trani et al., 2011) Despite the rhetoric of neoliberal discourses that suggest success is due to self-determination and personal effort, individuals do not all have the same abilities to act or to access the same opportunities. People make choices based on the choices that are available to them. The CA is a means of understanding how capabilities may be constrained by the social, physical, and economic world's they inhabit (Burchardt, 2004). The CA was created to address the utilitarian focus of modern welfare economics, as a means of conceptualizing the economic, social and environmental disadvantages that prevent some individuals or populations from achieving equality (Burchardt, 2004) and to evaluate social justice in relation to wellbeing and QoL (Reindal, 2009).

Table 0.1 Comparison of disability models

	Medical Model	Social Model	ICF/WHO	UN Convention	CA
Individual Impairment	*	*	*	*	*
Society Structure		*	*	*	*
Interaction between		*	*	*	*
Individual and society		*	*	*	*
Concept of functioning		*	*	*	*
Collective dimension of disability		* As a Barrier		* As a Barrier Attitudinal/ Environmental barriers	* Barrier or Enabler Community/ Social Resources, Beliefs and practices IMPACT
Possibilities/ Opportunities					* Capability Set (Choices) And potential capabilities
Decision-Making					* Agency Person main actor in the process

Table 1. (Trani et al., 2011, p. 149)

The CA is comprises the concepts of functionings, capabilities, the capability set and agency (Sen, 1999). Functionings, as defined by Sen (1999), include the aspects of life that a person values being or doing, for example, having the capability to access meaningful employment, health, an education, a sense of safety and positive social relationships (Deneulin & McGregor, 2010). The concept of capabilities encapsulates the freedom and opportunities an individual has, to achieve the aspects of life that are meaningful to them. An inability to access capabilities is referred to by Wolff and De-shalit (2007) as a capability deprivation. The overall set of capabilities an individual can access refers to all the functionings and capabilities that a person possesses. Finally, agency refers to the ability a person has to pursue their chosen goals (Sen, 1999).

Martha Nussbaum (2003) has further developed the CA framework by creating a list of ten central human capabilities which are the right to: life, bodily integrity, senses, imagination and thought, emotions, practical reason, affiliation, related to other species, play, and control over one's own political and material environment and which she argues all people are morally entitled to in the interests of human dignity (Nussbaum, 2006). Nussbaum (2006) argues that if a person falls below the threshold for any of these capabilities then a failure of justice has occurred. Sen (2005) acknowledges that key fundamental capabilities will feature in every list of essential capabilities, for every society, but objects to a prescribed capability list on the grounds that the progression of social understanding through social debate and public consultation may be compromised. While Sen's conceptualization of the approach is as an evaluative exercise and general, unspecified framework, Nussbaum conceptualizes the approach philosophically and as a theory of justice rather than as an evaluative tool.

Sen's approach to the CA does not explicitly identify which freedoms are most important for policy development or how to address conflicts that may arise in response to differing stakeholder perspectives (Deneulin and McGregor, 2010). Sen has been critiqued for understating how wellbeing is practically conceived of in each social context, and for not acknowledging the limitations of human reasoning, with critics observing that the CA overlooks the potential conflicts that may arise between people in relation to unequal distributions of power (Deneulin and McGregor, 2010). Critics further argue that the CA must address conflicting understandings of wellbeing and the different capabilities people possess to conceive of, and attain, wellbeing relative to the different social situations they inhabit (Deneulin and McGregor, 2010). Despite the potential of the CA to positively influence social

policies in both developed and developing countries (Burchardt, 2004) , the CA has been critiqued for minimising the role of reasoning and the power dynamics and conflicts that underpin how meaning is socially constructed, which then allows reasoning to occur (Deneulin and McGregor, 2010).

The CA is interdisciplinary in nature and has the ability to incorporate the diverse and multidimensional factors that contribute to a person's QoL (Robeyns, 2017). Dis/abling influences on an individual can be understood, using the CA, as resulting from "(a) the nature of impairment and other personal characteristics (e.g., age, gender, race), (b) the resources available to the individual, and (c) the environment" (Mitra, 2006, p.241). According to Trani (2011) whether a social actor can use the resources and limitations they possess to achieve what they choose to value and the life outcomes they want is contingent on the ability to access conversion factors. Conversion factors exist at the four levels of the individual, family, community and region or nation state (Trani et al., 2011). Personal conversion factors are central to the individual, family or group and are made up of impairments, gender, age, literacy level, etc. (Dubois & Trani, 2009; Hammell, 2022). Social conversion factors are socially derived and are comprised of social norms and infrastructure, sexism, racism, public policies etc. "and discriminatory practices [and] power relations constructed on the basis of gender, race, sexuality, class" (Hammell, 2022, p. 3) and that, as such, are socially embedded and interconnected with a person's abilities and opportunities in relation to wider society. Environmental conversion factors include access to appropriate healthcare, public transport, education, buildings, etc. (Hammell, 2022; Trani et al., 2011). Deprivations can result from any of these factors, which can include intrinsic aspects of the impairment (Mitra, 2006).

Equality from the perspective of the CA is the ability to provide people with equitable opportunities to attain wellbeing and the inability to do so can be deemed a capability deprivation (Sen, 1999) and societal disadvantage. Baylies (2002) states that the CA can enable a more inclusive approach to the human experience, for all people, by evaluating whether certain groups have had their access to functionings or capabilities limited by public policies that state institutions have the ability to control. The CA allows for the understanding of people, not in terms of their Dyspraxia characteristics but, instead, in terms of the policy decisions, changes to infrastructure, access to resources, that are necessary to enable them to achieve equal access to (Trani et al., 2011). Vizard and Burchardt (2007) have further developed Nussbaum's (2000) list by utilising a rights-based approach. According to Vizard and Burchardt (2007), and based on the UN declaration of human rights, essential capabilities are:

> 1. being alive and experiencing physical safety and health; 2. possessing access to knowledge, the ability to understand and reason, and the ability to participate in society; 3. access to security and independence, in conjunction with a comfortable standard of living; 4. participating in activities that are valued and productive; 5. enjoying a social life as an individual and as part of a family; 6. being able to make, and influence, decisions and possess a social voice; 7. being and expressing oneself, possessing self-respect, and an awareness that the law will protect and treat you fairly (p. 5).

In contrast to current normative discourses, Sen's (1999) approach to dis/ability represents impairment as an aspect of human diversity rather than as an abnormality and, hence, can provide a framework that can challenge oppressive and discriminatory practices identified by dis/ability advocates (Terzi, 2005). Through its ability to explore the sociopolitical context, the CA has the capacity to comprehensively understand the mechanisms that contribute to "exclusion and oppression", as well as encapsulating the entire lived experience in relation to dis/ability, rather than focusing entirely on the disadvantages associated with an impairment (Dubois & Trani, 2009 p.198). The CA's strength is its ability to incorporate important insights from the social model and provide a robust theoretical framework (Burchardt, 2004; Mitra, 2006; Terzi, 2005) to better understand Dyspraxia/ DCD. Terzi (2005) argues that the CA is able to add to understandings of dis/ability and impairment by considering both as aspects of human diversity in relation to social institutions. The CA rejects both the medical-individual and social discourses and frames human diversity as a variable specific to the human condition and thereby enabling dis/ability to be understood as a form of capability deprivation (Reindal, 2009). The ability of the CA to focus on the capacities people have, as well as the opportunities available to them to enhance their own wellbeing, can potentially contribute to a more positive framing of the experience of diversity (Reindal, 2009). The CA then can provide an opportunity to better understand how the experience of Dyspraxia/DCD, for example, is more nuanced than simply reducing it to a medical problem.

This section has introduced the social phenomenon of Dyspraxia/ DCD in Aotearoa New Zealand and internationally and how it may be understood at both the personal and social levels. The medicalisation of DCD has been examined and the role of ablest and disablist social responses to the lived experience of Dyspraxia/ DCD. Stigma, stigmatisation, and their potential implications for the social experience of Dyspraxia/ DCD were also introduced. Finally, how Dyspraxia/ DCD is understood in terms of the medical and social models was also examined and the capabilities approach was suggested as the approach that will be adopted for this study. The capabilities approach will be used to

examine Dyspraxia/ DCD because it can conceptualise many aspects of a person's life that can contribute to their ability to attain the life they choose to value. The focus of the CA is broader than that of the commonly used measure of capital production to ascertain the degree of wellbeing in a population. There has been very little research to date about the effect of stigma experienced by people with Dyspraxia/ DCD and the effect of social misconceptions about Dyspraxia/ DCD among neurotypical populations. Dyspraxia/ DCD may be the least well understood of the four main SpLDs of ADHD, dyslexia, autism, and dyspraxia. The comparatively recent medicalisation of DCD by medical professionals and framing of incoordination as a pathology and developmental difficulty, likely contributes to misconceptions by neurotypical people in Aotearoa New Zealand.

Chapter 2: Methodology

Previous literature has shown that minority groups, such as those with Dyspraxia may experience oppression in response to contemporary power structures. I wanted to explore whether similar processes were occurring in relation to the emergent and sometimes contested phenomenon that is frequently called 'Dyspraxia' or 'DCD'. Ultimately, an exploration of the acquisition of physical movement capabilities across the human lifespan and in the Aotearoa New Zealand context, is an opportunity to explore society's assumptions and values. Each participant's account of motor coordination challenges is likely to directly reflect their relationships to current social reality and the individuals within it. Therefore, participant accounts cannot be separated from constantly evolving societal understandings and medical narratives about physical movement. This chapter will examine the methodology employed in this study to better understand the Dyspraxia/ DCD phenomenon, providing an overview of the research paradigm and overall design of the study and including the study objectives. The research procedures used and how participant accounts were managed in terms of length and how data was presented are described. Finally, this chapter will identify research limitations and challenges encountered in this study.

2.1 Research paradigm

Employing reflexivity is essential in qualitative studies to ensure that the influence of the researcher and the role of the researcher in how data are collected and analysed (Shaw, 2010), is accounted for and, in particularly, the nature of the personal relationship the researcher may have with the subject (Terry et al., 2017). Reflexivity in qualitative inquiry acknowledges that the researcher is not separate from the world they are studying and further highlights the power discrepancy that exists between the researcher and the population being studied, which is particularly relevant to marginalized populations (Goodley & Moore, 2000), such as neurodiverse communities. The research paradigm of this study and the beliefs underpinning the methodology employed were based on an axiological approach, or a focus on values (Brown & Leigh, 2018), that were derived from the recognition that few sociological studies of Dyspraxia/ DCD exist that prioritise the discourses of people with Dyspraxia. Therefore, one foundational value of this study was to prioritise the voices of Dyspraxic participants. Further, this study sought to understand the socially situated Dyspraxia/ DCD lived experience, engaging with the Dyspraxia/ DCD phenomenon critically and with an awareness that subjectively created social forces

underpin social arrangements. That is, how individuals understand social concepts has implications for how society is structured.

Critical theory was the general philosophical approach employed for the purposes of this research. The goal of critical research is to generate new understandings of the social environment (Kincheloe, 2008, as cited in Rehman & Alharthi, 2016). Further, employing a critical methodology and methods can help identify what changes may be needed within a society to address a given social phenomenon and ensure that equality and social justice is achieved (Rehman & Alharthi, 2016; Spencer et al., 2014). Methodologies commonly associated with critical theory seek to challenge erroneous cultural myths and knowledge to improve society and empower marginalized social groups (Chilisa & Kawulich, 2012). Scholars of critical theory have criticized both constructionist and post-positivist paradigms, in keeping with Marxist ideas, of adhering to dominant Western research paradigms resulting in the marginalization of the knowledge produced by other social groups (Chilisa & Kawulich, 2012).

Different ontologies describe the philosophical position of the researcher, for example whether the research is grounded in an assumption that there is one reality or conversely a multiplicity of socially created realities. This research is philosophically grounded in critical and neo-Marxist theories (Chilisa & Kawulich, 2012, p.6). Ontologically, my stance is to presume that the experience of Dyspraxia/ DCD is an embodied reality of cognitive and motor coordination difference and/ or deficit that exists within socially constructed narratives. Dyspraxia / DCD is both an embodied physical reality and a socially constructed experience. However, in prioritizing alternate discourses (such as the notion of neurodiversity) in relation to dominant medical framings the study adopts a critical view of current dominant social assumptions about how Dyspraxia/ DCD is discursively understood. Critical theory is presupposed on the idea that what is known arises subjectively and in response to social values and how power is, contextually and temporally, distributed in society (Spencer et al., 2014).Situating a phenomenon in a historical context can reveal the invisible aspects inherent within a given phenomenon (Chilisa & Kawulich, 2012). The basis of critical theory, or what has also been termed the 'transformative paradigm', is that influential individuals reproduce dominant social ideas that are prioritised over the knowledge possessed by other social cultures (Chilisa & Kawulich, 2012). Critical theory is typically dialogic and dialectical (Guba & Lincoln, 1994; Rehman & Alharthi, 2016). The interaction between the researcher and the subjects being studied is composed of a transactional dialogue that seeks to challenge contemporary social structures and identify ways that may improve social arrangements (Guba & Lincoln, 1994).

Axiologically, critical theory is adopted by researchers who regard research as a moral and/or political undertaking, one that requires the adoption of a value position (Chilisa & Kawulich, 2012). A critical methodology was identified, in keeping with Rehman and Alharthi (2016), as being the most appropriate means to study the phenomenon of Dyspraxia as an insider researcher. Use of critical theory is not predicated on the need to employ a comprehensive research theory but rather accommodates epistemologically the perspectives of an investigator's own knowledge as being a valid basis for critiquing social arrangements (Spencer et al., 2014). Epistemologically (within critical theory), the researcher is assumed to subjectively influence the area being studied, with both the researcher and object of the research regarded as inter-linked (Guba & Lincoln, 1994). Critical theory effectively "challenges the traditional distinction between ontology and epistemology; what can be known is inextricably intertwined with the interaction between a particular investigator and a particular subject or group" (Guba & Lincoln, 1994, p. 110).

Capitalism is underpinned by socially perpetuated positivist ideas that define how people understand the world (Agger, 1991). To participate effectively in capitalist labour systems, people internalize values that limit their ability to ideologically imagine all the possibilities that might be available to them in modern society (Agger, 1991). Critics of positivism argue that it is both inadequate as a political theory and as a philosophy, reinforcing the status quo and promoting conformity through social and economic arrangements (Agger, 1991). Critical theory enables the questioning of how the social world is organised allowing researchers to consider how social circumstances could potentially be changed from how they are. The contribution of critical theory is to "develop a mode of consciousness that breaks the identity of reality and rationality, viewing social facts not as inevitable constraints on human freedom but as pieces of history that can be changed" (Agger, 1991, p. 109). Habermas (1985) argued that Western philosophical thought, including critical social theory, needs to shift from subjective and individualistic paradigms to theories based on the examination of communication so that ideologies can be critiqued. Critical theory has methodologically contributed to social science by enabling researchers to be more aware of the empirical assumptions that they bring to the research process. Habermas (1971) observed that the researcher is vulnerable to what he calls 'interest'. Interest influences how research may be constructed, executed, and interpreted.

This section has outlined the research paradigm utilised in this study. The next section will present the research design that was used to study the phenomenon of Dyspraxia.

2.2 Research design

A qualitative methodology has been used, involving semi-structured interviews with adults with Dyspraxia/DCD and relevant professionals working in the field of Dyspraxia/DCD. It was integral to this research approach that individuals with Dyspraxia/DCD be given the opportunity to describe their own lives within their social worlds. Quantitative studies are currently the most popular method of studying DCD with previous studies basing their criteria for selection of study participants on the need for a diagnosis of DCD (Blank et al., 2019). Many researchers have used biopsychosocial methods to investigate the phenomenon of DCD (Blank et al., 2019).

Qualitative methods identify and characterise aspects of a social phenomenon that fall outside the purview of medical model discourses, for example understanding alternate framings of an experience such as the definitional discrepancies associated with the terms Dyspraxia or DCD and their respective social implications. (Baum, 1995, p.495). According to Baum (1995), the value of qualitative research is its ability to conceptualise health issues in the public sphere, investigating and explaining how social interactions between individuals may affect a given health phenomenon. Social model approaches, in contrast to medical model narratives, are defined by a focus on: public health; collectivist approaches to public health issues and consumer or community control of research endeavors (Baum, 1995). This study used qualitative inquiry to explore the interactions between Dyspraxic people and their social world to render visible the socially embedded inter-related aspects of the Dyspraxia/ DCD experience. These social experiences and interactions only become visible using qualitative methods because people can tell their stories about their personal lived experiences. Qualitative research highlights how social structures affect the experience of Dyspraxia. Dominant social discourses and structural arrangements in relation to Dyspraxia/ DCD were explored to understand: "How do these dominant narratives position various actors? What are their implications for identity and agency? What do these narratives render invisible or untellable?" (McKenzie-Mohr & Lafrance, 2017, p. 196).

The present study utilizes a participatory qualitative research approach, a major advantage of which is its ability to capture the complexities of a social phenomenon like Dyspraxia/ DCD. A semi-structured interview approach was chosen so that participants could identify what was important to them about their Dyspraxia/ DCD experiences. However, there are certain drawbacks associated with the use of qualitative methods. The comprehensive nature of qualitative inquiry necessitated that a small sample was chosen because of the significant time involved in subsequent data analysis. Consequently, not all

participants with Dyspraxia who were enthusiastic about volunteering could be included and five later volunteers were politely excluded from participating and not interviewed.

The research process and participant cohort were divided into two distinct stages. Data for the first stage were collected through interviews with 23 adults who have Dyspraxia and for the second stage by interviewing 26 professionals, the majority of whom had significant expertise about Dyspraxia in the Aotearoa New Zealand context. Informed consent was collected from all participants in the study, who were informed, at the beginning of the interview, that they could stop the interview at any time (see consent form in Appendix B).

The Lincoln University Human Ethics committee signed off both the proposed data collection. All 49 subjects were recruited via email, requesting participation in a study about Dyspraxia through the dissemination of an information sheet about the study. Participants were accessed through the Dyspraxia Support Group, two Inclusive Education tertiary providers and through snowball sampling (Burns, 2000). Dyspraxic participants were chosen based on their willingness to participate. Professional participants were selected based on their knowledge of the health and education sectors, neurodiversity, and Dyspraxia. When inviting the participants, the purpose of the research was clearly explained in the research information sheet (see Appendix A). Prior to data collection, all participants received an explanation of the project. Participants were thanked for their time and effort and for being happy to participate in this study. On obtaining written informed consent from all participants, an interview was carried out (see Appendix B). Data were gathered over a six-month period and transcribed over a subsequent nine-month period. The purpose of interviewing relevant professionals was to provide an institutional and social context for the stories told by the people with the lived experience of Dyspraxia and to identify the professionals' understanding of Dyspraxia. As a researcher, I acknowledged my own life experiences in relation to Dyspraxia/ DCD through the inclusion of a situated standpoint (see p. xi) that addresses my background and perspective. Arguably I am an insider researcher in the field of Dyspraxia/ DCD, drawing on my own experiences to design, execute and interpret this study. The objectives that were developed to better understand the lived experience of participants with Dyspraxia, as part of the research design process, are presented below:

2.2.1 Objectives

The goal of this study was to answer the following research objectives which were formulated after reviewing the literature. The objectives are:

1. To identify the lived experiences and life outcomes of participants with Dyspraxia/ DCD, particularly in relation to predominant biomedical social narratives and,
2. To identify the repercussions of contemporary social conceptualisations of Dyspraxia/ DCD, in terms of social arrangements in Aotearoa New Zealand, and how Dyspraxia/ DCD is socially understood and responded to, across the lifespan, but particularly in adulthood.

This section has described the research design of this study and the objectives that were chosen to explore the Dyspraxia phenomenon. The next section will outline the research procedures that were used.

2.3 Research procedures

The research procedures undertaken in this study include how both Dyspraxic and professional participant samples were accessed and recruitment of interview participants. Challenges associated with recruitment are also presented and the structure of interviews, including where interviews were located. The Dyspraxia/ DCD participant sample, who participated in this study, is described in the section below.

2.3.1 Dyspraxia/ DCD participant sample

The Dyspraxia participants were selected based on their identification as adults having Dyspraxia. Nineteen of the participants interviewed had a formal diagnosis/ assessment of dyspraxia, as well as four participants who self-identify as having Dyspraxia, yielding a total of twenty-three accounts of individuals living with Dyspraxia who were recruited for this study. The number of participants with Dyspraxia interviewed was 23 because this was the maximum number identified through discussions in supervisory meetings that could realistically be interviewed for a PhD thesis. Consequently, prospective participants who were enthusiastic about participating in the study, and who responded after the first 23 interviews, were politely thanked and informed via email that the study was at capacity. While all Dyspraxic participants bar four had been formally assessed for Dyspraxia and had possessed significant motor coordination issues in childhood and still experienced motor coordination challenges as adults. These self-diagnosed adults have not chosen to be formally assessed/diagnosed

themselves. The fourth participant in the self-diagnosis sample was diagnosed with dyslexia as a child but chose to participate in the study because she had also experienced challenges with motor coordination in both childhood and adulthood. The Adult DCD Checklist (ADC) is a self-screening questionnaire (Kirby et al., 2010) used in this study to assess motor deficit challenges in four adults who self-identified as experiencing coordination difficulties (see ADC checklist in Appendix D). The four ADC participants identified that they experienced significant difficulties with DCD / Dyspraxia as adults and were therefore included in this research. The following quote is an example of one participant's answers to the questionnaire I used. The ADC was utilised to ascertain whether four participants, who self-identified as having Dyspraxia, experienced motor coordination challenges as adults Pseudonyms were used for all participants, including for Fiona who states:

> I'm really coordinated these days and with most things I was coordinated but not with team sports. I can throw and catch accurately well, catching not so good… so I'll put sometimes…. Would I say I bump into things? Frequently… Do I avoid hobbies that require good coordination, never and sometimes are too far apart … Do I have difficulty parking the car? Yeah, parallel parking I always have to go in front ways and even then, I'm usually parked too far out. Fiona (D/SD 30-40)

The age range of participants was skewed to people in their 20's to early 30s, a demographic that represented over half of Dyspraxic participants, and likely in response to increased societal awareness in the past decade about Dyspraxia and the attribution of the Dyspraxia label by experts in neurodiversity. The remainder of participants were aged between 35-45, one was aged between 40-50 and one participant was in the 50-60 age range. Most of the cohort had been diagnosed or assessed for Dyspraxia in keeping with Aotearoa New Zealand's continuing use of the Dyspraxia term in professional settings. The participant in the 50-60 age range had been diagnosed with clumsy child syndrome as a child, when Dyspraxia and motor coordination difficulties had not been medicalized to the point of having the definition and aetiology that they do now. An outlier participant was a participant who had received extensive and effective early intervention and who did not identify significant difficulties in adulthood. However, she identified as having Dyspraxia, and her challenges in childhood were significant and therefore her account was included in the subsequent analysis. To provide a socially situated context for Dyspraxic participant accounts 26 experts in the field of Dyspraxia, neurodiversity, DCD, health and education were interviewed and details about the professional participant sample are presented below.

2.3.2 Professional participant sample

To understand how Dyspraxia/DCD is understood from a professional capacity, twenty-six professionals who work within the Dyspraxia/DCD sector were interviewed. Eligibility of professionals who matched the selection criteria was based on their professional expertise in neurodiversity or insight into aspects of the Dyspraxia lived experience. The number of participants in each stakeholder group was dictated by, firstly, the researcher's ability to access participants and, secondly, the need to prioritise, where possible, the most important stakeholder professions who work with people with Dyspraxia/DCD. The professional fields of eight stakeholders who work in relevant medical, professional contexts, and who cannot be identified to preserve their anonymity, were interviewed in response to biomedical discourses which dominate social understandings of Dyspraxia/ DCD. Four occupational therapists were interviewed in response to the significant role of occupational therapy in ameliorating motor coordination functional deficits.

Professionals in the education sector were a significant stakeholder group because education is an important theme in all the accounts of the adult participants with Dyspraxia/DCD. Five teachers and five professionals providing dis/ability services in the education sector were interviewed because all participants with Dyspraxia/DCD related comprehensive narratives about their experiences in Aotearoa New Zealand schools. Interview participants also included Teacher Aids, Specific Learning Difficulty (SpLD) teachers, dis/ability service providers, educational psychologists, primary school teachers, high school teachers, and Special Education Needs Coordinators (SENCo) and a Resource Teacher of Learning and Behaviour (RTLB). SpLD teachers were interviewed because often they have been teachers in the education sector and are therefore uniquely placed to understand issues such as the relationship between families trying to support their children and what the education system is able to provide.

The number of professional interviewees was initially intended to be 23. Because previous studies have focused more on the parent experience of predominantly children with Dyspraxia, interviewing parents was initially ruled out in the interests of keeping the study to a manageable size. Toward the end of the data collection process, however, it became apparent that capturing the parent perspective would yield an important viewpoint and, to that end, four interviews were conducted with parents of adults with Dyspraxia. The interviewing of parents accounted for the higher number of professional discourses relative to the participant sample with Dyspraxia. The recruitment of both sample groups, those with Dyspraxia and professional participants is presented in the section below.

2.3.3 Recruiting interview participants

Professional participants and those with Dyspraxia were recruited using a convenience sample, with some snowball sampling. Recruitment was undertaken by contacting two gatekeeper organisations. Both organisations distributed a request for study participants to their wider databases and many of the participants who identified as having a diagnosis of Dyspraxia were contacted this way. Interviews were organized via email and phone. The self-diagnosis sample was predominantly composed of parents of children with dyspraxia or people whose children were at the same school as the author's children. There is likely an influence on the study from the relatively homogenous group of four self-identified participants from the same school. These individuals were approached either in person or by phone, to see if they would like to participate in the study, with all subsequent contact occurring via email. Access to individuals in the education sector was achieved by contacting gatekeeper individuals at different institutions, who were known to the author, and who were able to pass on details about the study to other educators. SpLD teachers, educational psychologists and occupational therapists were initially recruited through gatekeepers known to the researcher and subsequent participants were sourced through a snowball sampling technique (Burns, 2000). Participants in the education sector who were interviewed and who work with people with Dyspraxia, included Primary School teachers or High School teachers whose teaching specialisation involves physical activity that might prove difficult for individuals with Dyspraxia.

Participants from diverse professional fields who work with people with Dyspraxia were accessed through either cold calling or emailing them the details of my study. Parents who were on the database of one of the gatekeeper organisations also responded to my request for study participants and this group later made up the sample of parent stakeholders. Challenges encountered during the recruitment process are described below.

2.3.4 Recruitment challenges

One difficulty that was encountered in the recruiting of participants included the refusal of an important gatekeeper organization to disseminate the details of my study to their professionally experienced staff. The reasons given were that their staff were overworked and under-paid and therefore unable to participate. After this disappointing setback I reworded the recruitment email,

making it informal and personable, and from then on there were very few refusals. Another polite but significant refusal was a key stakeholder at the MoE who had been recommended to me but who said they were too busy. There is, however, documentation from both the MoE and the Government that outlines their approach to, and understanding of, Dyspraxia which will inform my research and represent their relative positions in relation to Dyspraxia. All qualitative data about the government ministry level response to Dyspraxia was obtained from secondary sources. In the next section how interviews were structured and the locations that were used to conduct the interviews are presented.

2.3.5 Interview structure and locations

Interview locations were selected in response to the needs of the participants (Yardley, 2015) Interviews were conducted in a variety of settings, including at various Christchurch café's, on the premises of both gatekeeper organisations, at primary and high schools, by phone and over Skype or the Facebook Messenger App. The location and time for the interview was dictated by the preferences of the participants. Interviews were recorded and later transcribed with the full knowledge and consent of the participants. There were three instances where participants did not show up, but these interviews were rescheduled and conducted later.

A semi-structured interview style was used to encourage, as much as possible, the collection of data that was rich and descriptive and composed of the interview participant's life stories and unique knowledge in relation to Dyspraxia. Interviews were conducted using mostly descriptive questions, although sometimes opinion questions were utilized to prompt the participant to provide greater detail. To capture their unique understanding, participants with dyspraxia were asked broad questions such as: 'Tell me about your experiences with Dyspraxia? Can you perhaps tell me a story about having Dyspraxia?', or in the case of professionals, 'a story about working with people with Dyspraxia?' (see interview schedules in Appendix C.1 and Appendix C.2). Verbal prompts were sometimes used as an aid to questions that did not elicit a response and especially if a participant was not initially talkative or to gain more data and enable participants to elaborate further on themes. Empathetic listening was employed in keeping with a person-centered approach (Rogers, 1995).

To identify their perceptions of Dyspraxia in Aotearoa New Zealand, the participants were asked open-ended questions to assess how various individuals, those with Dyspraxia and those who work with individuals with Dyspraxia, understand the socially situated experience. Open-ended questions led to a variety of subsequent questions about Dyspraxia experiences, that were mostly phrased in terms of

“What do you mean by X? Could you elaborate on X further?’, to generate additional data. Questions were not directive, an exception being the four self-identified participants with Dyspraxia who were also asked to complete the ADC checklist (Kirby et al., 2010). A second exception to the use of more directive questions occurred during attempts by the interviewer to make each participant feel as comfortable as possible, which led to the asking of more prescribed questions on several occasions, and typically in response to the distress exhibited by several participants as they recounted their stories. The ADC checklist (see page 214) was used to ascertain that their experiences with motor coordination challenges were such that it was relevant for them to participate in this study. The first question was designed to find out how they conceptualise their lived experiences with Dyspraxia and prompt them to disclose narratives of significance to them. Subsequent questions acted as additional prompts to help participants further reflect on what is important to them with regards to their Dyspraxia with open-ended questions asked until the participant had nothing further to add. Participants were given the opportunity to ask questions of the interviewer at the end of the interview process in case they had any. The next section describes how the data collection process was managed during the course of this study.

2.4 Management of the participant accounts and length of interviews

This section describes how data generated in interviews was managed in relation to both Dyspraxic, and professional, participants. There were some interesting interview situations where participants both had Dyspraxia and were also parents of children with Dyspraxia. Whether I included their interview accounts in the first stage of the research or in the second, depended on the content of their interviews and the data that was collected. For example, while three of the four self-diagnosed participants who have Dyspraxia are also parents of children with motor coordination challenges and other learning or behavioural difficulties, I chose not to include them in the stage two parent sample. This was because most of their interview accounts pertained to their own experiences with motor coordination difficulties and not those of their children although these were mentioned. Most interviews with participants with Dyspraxia were an hour long but there were several interviews that lasted for an hour and a half and one conversation with an enthusiastic participant that was two hours long.

On one occasion, two professionals wanted to be interviewed at the same time. Given that our conversation was over an hour and they each spoke for about half that time, I chose to count them as two separate accounts. On two occasions the principal person I was interviewing asked a second

professional, who was in the same room, for their opinion about an aspect of Dyspraxia. In these cases, even when the opinion was fifteen or more minutes in duration, I did not count the second professional's additional information as an account. I made sure to get a signed consent form from the second professional, however, so that their insights could also contribute to my understanding of Dyspraxia and be included in this study. Another interesting situation that arose was a two-hour long interview with a professional who has worked extensively with people with Dyspraxia and who has Dyspraxia themselves. Due to the wealth of data collected about this participant's personal experiences with Dyspraxia, as well as their professional account I decided to include them in both stage one and stage two of my participant samples.

Several other interesting scenarios eventuated as I collected data and conducted interviews. Two professional accounts, one with an occupational therapist and the other in a field that, to name would compromise their anonymity, were also parents of children with Dyspraxia. Both these participants spoke at length about their experiences as parents. Initially, I did not include these accounts in the parent stakeholder group because, while both interviews were close to an hour and a half in duration, most of their interviews related to their work as professionals in the field of Dyspraxia. After analysing both transcripts, I decided to add both accounts to the parent sample. While an estimated half hour of their interviews pertained to their experiences as parents, their stories did better inform my understanding of the parent stakeholder group. While I have included these two parents in the parent stakeholder group and they make up two of the six parents I have referred to, these two parents have not been counted twice in the overall number of participants in the stage two sample. Another interesting interview with a parent occurred when one parent, who was enthusiastic about sharing their experiences with Dyspraxia, was joined by their partner who was equally enthusiastic. I chose to count this one-and-a-half-hour interview as two separate accounts of parent stakeholders because they were both present and both contributed and, perhaps surprisingly, their accounts were markedly different from each other. Notes were made after each interview was conducted, documenting where the interview was held, when and other observations that were relevant to the research. Analysis of the data generated by this study is described in the section below.

2.5 Treatment of data

The method of analysis is presented in this section and how language is used in this study. A literature review was conducted of studies that covered the areas of: DCD, Dyspraxia, dis/ability, the social model of dis/ability, medicalization, neurodiversity, education, stigma, the capabilities approach, and

ableism. Published studies were gathered from multiple sources at various points in time and in response to the evolving nature of the data analysis. Article references were frequently searched further for additional relevant publications to build up an inter-disciplinary understanding of the experience of Dyspraxia/ DCD in Aotearoa New Zealand and in response to prevalent themes. This study draws on participant accounts and recognizes them as experts in their life experiences with Dyspraxia/DCD. This section will look at the methodology of thematic analysis which was employed in this study to better understand Dyspraxia/ DCD's socially situated nature.

2.5.1 Method of analysis

Analysis was based on the conceptual framework proposed by Braun and Clark (2006) of thematic analysis. The approach to thematic analysis outlined by Braun and Clarke (2020, 39) of "familiarisation; coding; generating of initial themes; reviewing and developing themes, refining; defining and naming themes; and writing up" was followed. Thematic analysis is flexible in that it is compatible with most theoretical approaches and is suitable for the interview method of data collection used in this study (Terry et al., 2017). Data sources were interviews transcribed by the researcher from audio data and field notes collected by the researcher. The epistemology employed was constructionist and looked at the sociocultural influences that shape individual accounts, identifying the underlying conceptualisations, assumptions, and ideas (Braun & Clarke, 2006). The themes that were derived from the data were identified, coded and analysed by looking at the entire data set to enable the identification of the most significant and predominant themes (Braun & Clarke, 2006). All interviews were transcribed, and descriptive notes were made. The interviews were then re-read and coded into an Excel spreadsheet, before codes were amalgamated to identify significant themes. Themes were further defined, and names changed during the coding process. I undertook all coding and analysis of the data. The final data set was analysed using the six phases of thematic analysis put forward by Braun and Clarke (2006). The data were initially coded descriptively. Regularly occurring patterns in participant accounts emerged and underlying "ideas, assumptions and conceptualisations" were identified (Braun & Clarke, 2006, 85).

Thematic analysis enabled a flexible and comprehensive analysis of the complex data set and complemented the reflexive approach chosen. Thematic analysis also promoted "a participatory research paradigm" and was able to elucidate "similarities and differences" within the data set while also enabling both a social and "psychological interpretation of the data" (Braun & Clarke, 2006, 97). Thematic analysis was also able to address the relatively large sample sizes (Braun & Clarke, 2020) of

participant accounts N- 23 and N- 26, respectively. Themes were analysed using a contextualist approach, that sought to understand individual experiences in relation to the social context they inhabit (Braun & Clarke, 2006).

Familiarization of the transcribed data was achieved through active re-reading. Initial codes were then generated using a detailed and inclusive approach, to prevent an anecdotalist interpretation based on limited research data, and coding was applied in a systematic manner across the whole data set. Individual data was sometimes coded several times to accurately reflect content in the coding process. Excel spreadsheets were used, creating a visual representation of the prevalence of codes and themes across the whole data set as well as within each individual account. Mapping the data this way provided an indication of a theme's importance to participants and the prevalence with which it occurred. One limitation of representing the coded data on spreadsheets is that, while the prevalence of codes was able to be measured diagrammatically, the size of the account pertaining to each code, many of which were significant in length, was not represented. Preliminary themes were then created, and all relevant data were sorted into these themes and sub-themes. Themes were reviewed to ensure that a good balance between the analysis and participant extracts was achieved, and that a narrative was created that is convincing and organised. Themes were further defined, and theme names refined to capture the essential meaning of each, before being assessed in relation to the overall narrative of the thesis. The final stage of Braun and Clarke's (2006) thematic analysis framework is the production of the manuscript and the creation of a concise, coherent body of work that hopefully does justice to the participant accounts included in this research and successfully relates the analysis to the literature review and research questions. Quoted data in this study were used in the empirical chapters both illustratively, providing examples, and analytically, which refers to discussion of aspects of the data, to contribute to achieving the study aims (Terry et al., 2017).

Thematic development was an iterative process over many months with codes grouped together into appropriate themes. Appropriate themes were identified by remaining aware throughout the analysis of the purpose of this study which was to do justice to the sets of categories described by Dyspraxic participants and identify those themes which best represented participant lived experiences. The coding process was extremely thorough to respectfully engage with participant accounts and the themes that were prioritised were those identified by participants as being important to them. The thesis was restructured numerous times through many productive discussions in supervisory meetings to ensure the thesis structure respectfully represented participant accounts.

It was reflexively acknowledged that certain perspectives of Dyspraxia were more prominent in the data. For example, participants with Dyspraxia who were socially competent, relative to adults with significant difficulties in adulthood such as comparatively less organizational ability that may have prevented them from participating. Similarly, adults for whom Dyspraxia posed few challenges due to the degree of support they'd received, or the severity of Dyspraxia, were also less likely to identify as Dyspraxic and be represented in the data set. There is no way to accurately establish where participants with Dyspraxia are situated in terms of the 50-70% of children with DCD estimated to experience some form of DCD in adulthood (American Psychiatric Association, 2013). However, the prevalence of social difficulties recounted in all discourses of participants with Dyspraxia across the lifespan was suggestive of a multiplicity of Dyspraxia experiences. A quarter of Dyspraxic participant accounts recounted almost exclusively negative social experiences that they equated with Dyspraxia and represented key participant accounts. It was important to be aware of these accounts because people with severe Dyspraxia and/ or other significant social disadvantages such as secondary psycho-emotional difficulties were less likely to volunteer to participate. The remaining three quarters of accounts were more nuanced in terms of ascribing positive or negative social outcomes to the Dyspraxia social experience.

It is important to state that the data generated by this study was not influenced by a research design that was created using the CA. Instead, the CA was used to 'cross check' how the qualitative data generated through participant interviews related to concepts of personal wellbeing and flourishing. The CA was applied to the data in this study retrospectively and the approach did not inform the methodology chosen. The CA allows a research question to be answered in many ways, due to the underspecified nature of how it can be applied (Robeyns, 2006). The interview questions and transcripts generated a significant amount of data that can be used to conceptualise capabilities and functionings. The prevalence of the concepts such as human capability and agency, within individual accounts, were assessed in relation to the overall data set and contributed to the development of the research themes discussed in this study. Having presented the method of analysis, the rationale for language used throughout this study will also be explained below.

2.5.2 Language used

A typology of participant codes has been used to indicate whether participant quotes are from professionals or Dyspraxic participants (see p. x) Motor coordination difficulties will be referred to as Dyspraxia/DCD except in circumstances where professionals or participants explicitly refer to one or

the other. In keeping with, particularly Autism advocacy in the neurodiversity movement, this research will adopt language to promote the interests of people with Dyspraxia. Many participants identified as Dyspraxic; one identified as being a person with Dyspraxia and the cohort of four adults in their forties identified difficulties with incoordination but did not use the label of Dyspraxia. Professional participants familiar with DCD were predominantly those working in movement and medical fields. Participants from the education sector were largely unfamiliar with the term DCD.

The following table has been adapted from (Monk, 2022) and the terminology here will be applied throughout this study. The Autistic community uses identity-first language to acknowledge that Autism, like Dyspraxia, "is inseparable from who they are: influencing the way they experience the world and is an integral part" of their identity (Monk, 2022, p. 7). As shown in table 2.1 below, the 'D' in Dyspraxia has been capitalized throughout this study, in the same way that the A in Autistic is capitalized by the Autistic community, and out of respect for participants in this study, the majority of whom, identify as being Dyspraxic. This research uses the term 'neurotypical' to describe the Dyspraxia/ DCD population in comparison with their typically developing peers.

Table 0.1 Terminology used in study

Reject Misleading Terms and Replace with Dyspraxic—Preferred Terminology

Instead of...	Consider using...
Development Coordination Disorder	Dyspraxia
Person with Dyspraxia	Dyspraxic
Dyspraxia symptoms	Dyspraxia characteristics
Normal person	Neurotypical (if not neurodivergent)
Co-morbidity	Co-occurring/ co-existing conditions

Reframe Understanding of Dyspraxia and Dyspraxic experiences

Instead of...	Consider using
Severe/ Mild dyspraxia/ DCD, High/Low functioning dyspraxia	Describe specific support needs
Quantifying dyspraxia/ DCD on a linear spectrum	Describe strengths and challenges
Someone does not look like they have challenges with coordination, and associated learning challenges	Consideration of Dyspraxic masking
Dyspraxia cure, treatment, or intervention	Focus support on Dyspraxic wellbeing

Rethink How to Empower and Support Dyspraxic People

Instead of...	Consider using...
Special needs, Learning impairment	Neurodivergent
Mental age	Actual age
Superpower, twice exceptional	Strengths and support needs
Dyspraxia people and their families, carers and whanau	Dyspraxic people supported by their families, carers, and whanau Dyspraxia people and those who make up their support network

Table 2. Adapted from Autism NZ (Monk, 2022)

For several quotes, notes from my research diary were used to provide greater context for participant accounts, for example to better convey the feelings of either the participant or myself as the interviewer. Due to the interrelated nature of the findings, I decided to combine the analysis with a discussion of the findings weaving both together throughout the empirical chapters. Limitations encountered during the research process are discussed in the next section.

2.6 Research limitations

For the most part, conducting interviews with participants was a privilege. I met many interesting people and listened to many interesting stories. There is the potential for individuals at either end of the spectrum of the Dyspraxia experience to be less likely to participate in Dyspraxia research. Those for whom Dyspraxia poses little to no challenge in adulthood, who have strategies and/ or are good at masking, may achieve an apparent degree of unremarkable and normal functioning. At the other extreme participants may face significant challenges in their social worlds which could consequently prohibit them from joining a study. The participants mentioned at either extreme represent two sub-populations, within the Dyspraxia population, that may be less likely to come forward to participate. Over half of participants disclosed that their reason for participating in this study was in response to what they perceived as a limited understanding of Dyspraxia in the Aotearoa New Zealand context. Furthermore, most participants expressed a hope that, by agreeing to be interviewed, they would be contributing to improving how Dyspraxia is understood in Aotearoa New Zealand. Research challenges experienced by the researcher are presented in the section below.

2.7 Research challenges

The process of interviewing often required a high degree of empathy, while interacting with participants, and the creation of a relationship based on trust for the duration of the interview process to enable participants to comfortably recount their life stories. Three participant interactions stand out for their intensity, in relation to the expression of grief within the participant narrative and, thus, were of an emotionally demanding nature for me as a researcher. On several occasions, prioritising the creation of a secure interview environment for participants required extremely careful management.

A further challenge encountered by this researcher is that many dominant academic perspectives do not encompass my experience of 'Dyspraxia' particularly in adulthood and in relation to the cognitive aspects I associate with Dyspraxia. Questions I found myself asking as the research progressed

included: Did I have DCD as a child? As a child I had motor coordination difficulties, but I've since attained most significant motor coordination milestones, like learning to tie my shoelaces and ride a bike. Much of the academic literature about DCD, says that any cognitive challenges I may still have as an adult, such as finding the courage to begin unfamiliar physical tasks and sequencing difficulties, is not an aspect of the diagnostic category of DCD but rather are co-occurring difficulties. In the write up phase of this research I struggled to read research articles about, predominantly, DCD that portrayed poor motor coordination as a physical dis/ability because this conceptualisation did not adequately encapsulate my life experiences with Dyspraxia.

The difficulties described above were thrown into sharp relief by two significant experiences during the research which nearly resulted in my discontinuing the research. Interestingly, these two significant encounters were with professionals who are experts in physical movement and yielded fascinating insights into current narratives about Dyspraxia/ DCD. There was a positive side to both experiences in that they greatly improved my understanding about how Dyspraxia/ DCD is framed and understood. The first experience was attending the 12th Developmental Coordination Disorder (DCD) International Conference in 2017 in Perth, Australia. Many of the academics at this conference argued for the exclusion of cognitive difficulties from the experience and aetiology of DCD. This stance contrasts with most professionals working with motor coordination difficulties in the Aotearoa New Zealand context, particularly in education related fields, who do incorporate associated cognitive challenges into conceptualisations of Dyspraxia. Another researcher I met at the conference, who has Dyspraxia/ DCD and who was also doing sociological research into Dyspraxia/ DCD in the UK, told me I would have to have a 'thick skin' to interact with professional people who had unshakeable confidence in their medically derived conceptualisations of DCD, and she was right. The comparatively more advanced advocacy occurring within the autism community was also made glaringly apparent to me at the 2017 DCD-12 conference. There, an expert in autism, who was also a guest speaker, spoke of the strengths associated with the experience of autism stating: "People with Autism have strengths. But that seems to be different to DCD, which you're all looking at and which seems to be a wholly negative experience". I am paraphrasing and conveying the essence of one comment in an, otherwise, inspiring presentation about Autism. The second time I questioned whether I should continue with the study was a deeply personally challenging interview with a professional participant that led to significant self-doubt about my capabilities as a researcher I even spoke disparagingly of myself during the conversation and afterwards I felt as though I had no legitimate right to continue doing my research. The role of medical narratives on the lived experiences of people with Dyspraxia will be looked at in the following chapter.

Chapter 3: The implications of biomedical framings on the lived experience of Dyspraxia/DCD in Aotearoa New Zealand

This study begins with an investigation of the influence of the medical model in Aotearoa New Zealand society, beginning with an exploration of the narratives of health sector professionals. The medical model has been defined by its focus on medical care, the identifying of disease, individualism, and the prioritizing of researcher control in research settings (Barnes & Mercer, 2010). The experience of health however, is now understood as more than the absence of disease but rather is conceptualised as the product of interactions between factors such as how power and resources are distributed in various social, economic, political environments (Orsini and Smith 2010). Social scientists have called for the prioritizing of other kinds of knowledge over the privileged position of science to promote greater social equity (Pellicano & Stears, 2011). This chapter will explore dominant medical narratives as they apply to the lived experience of Dyspraxia by looking at how medical framings influence Dyspraxia in society. Specifically, the role of medical definitions and aetiology, diagnostic practices and pathways and the implications over the lifespan of Dyspraxic participants will be looked at.

3.1 The dominance of medical narratives in relation to Dyspraxia/ DCD

The narratives that follow in this section are drawn from one participant interview whose account conveys a professional perspective that is suggestive of the influence of socially situated biomedical discourses. The quote below suggested how professionals may share knowledge in social environments, acting as social translators for the medicalised experience of health as opposed to the people with lived experience of various health conditions, such as Dyspraxia:

> The paper I gave there, I was a keynote there, was trying to get people to think about dyspraxia like learning a second language because that's one of my own areas of expertise and also came from learning to play clarinet and saxophone in my 50s. I told everyone they ought to try something like that because you can only imagine, and I don't want to be offensive about this, but I felt dyspraxic in trying. So, I kind of worked through the idea of the world seeming like

> unfamiliar territory for children who are trying to navigate with part of the information they need and then unreliable access, in the sense that, you know often when you're learning a second language you say something and as soon as it's out of your mouth you go" wait a minute that's not right". Anyway, it was essentially a long metaphor I suppose but I was also trying to normalise it because learning a new language or a . new instrument and stuffing up is what everybody does, so why are we making a fuss about people who have something that someone has given this name for but potentially feels similar. Does that make sense? You might not agree with that. Belinda (PP-M+E)

The metaphors used above may not convey the likely complexity associated with the lived experience of Dyspraxia/ DCD, particularly its embodied nature and the reality that it is not a life choice, unlike the decision to learn an instrument or another language. Further, it justifies the need for people with Dyspraxia to have a central role in the societal narratives that are created about them to avoid the minimisation of their experiences, as illustrated by this professional's use of impoverished and potentially misleading metaphors.

The medical-individual model defines the experience of disabilities as a deficit and this terminology can influence how non-dis/abled (Brittain, 2004) individuals respond to neurodiverse populations, such as those with Dyspraxia/ DCD. Biomedical approaches based on positivism are linear and reductionist and reliant on identifying constituent parts, measurement, and causality. Constructivist framings argue against the reducibility of health issues into their constituent parts, prioritizing holism and contextual factors as the means to best understand phenomena. One of the aims of this study is to employ sociological methods to explore how professionals respond to, and conceptualise, the social experience of Dyspraxia. To that end, I approached this professional participant for an interview, and introduced myself in the interview setting, as an 'insider' sociology researcher, who also has Dyspraxia. The assumption of medical authority suggested by the manner of delivery of this professional participant was also articulated:

> Maria: Physiological dysregulation, that's not a term I know.
> Belinda: You really haven't done any research into the background of dyspraxia have you?
> Maria: Well, no I did
> Belinda: I find this really distressing.
> Maria: Hmm I…
> Belinda: And you're doing your PhD?

> Maria: My aim is to interview 20 professionals such as yourself, but everybody comes at it from such a different point of view and I guess the common language thing is important but even reading the literature, nobody seems to agree either on what Dyspraxia/ DCD is. And going to that conference in Perth was very overwhelming as a student and researcher because that was very different to how I saw the experience of Dyspraxia as being because it was very much developmental coordination disorder focused. Belinda (PP-M+E)

The quote above isn't representative of a biomedical framing perse but uses emotional rhetoric but rather depicts a myriad of framings and significantly, seemingly, the participants own attitudes to sociological inquiry. According to Chapman and Carel (2022) the biomedical response does not incorporate the lived experience or assess analytically how a neurodiverse condition is socially situated or constructed. The likely predominance of medical narratives is suggested by Pellicano and Stears (2011) who have reported that, within the neurodiversity space, very few Autistic scientists have engaged in Autism research from an insider perspective. Published research by medically trained researchers who have Dyspraxia was absent, except for Walker, Shaw and Reed's (2021) study with one contributing researcher identifying as having Dyspraxia. Conversely, no sociology studies were found that were written by a researcher who identified as having Dyspraxia.

According to Lincoln and Cannella (2004) part of the value of qualitative studies is the ability to reveal social practices that are oppressive and lack equity. Terminology and aetiological framings possess greater social validity than the lived experience of Dyspraxia and further, with even sociological research needing to engage with Dyspraxia/DCD through medical discourses to have epistemological validity. Neurodiverse perspectives may be ignored in favour of medical framings with one participant in a study of Aspergers in adulthood stating, "everybody is an expert bar the person with the diagnosis"(Griffith et al., 2012, p. 14). My responses to the assumed authority of this medical professional could be termed what has been described by other neurodiverse individuals as a narrative of resistance (Gabel & Peters, 2004; McDonald et al., 2007; Snyder & Mitchell, 2001). The accounts in this section are suggestive of the medical model's ability to confer social authority on medical conceptualisations of an embodied experience vis a vis the medicalization process (Conrad, 2007) which is illustrated by the following professional when she said:

> Belinda: You know I'm patron of the [names institution]
> Maria: No, I didn't. That would be why they recommended you as a good person to talk to.

> Belinda: And that was because I know [names influential Dyspraxia advocate in Aotearoa New Zealand].
> Maria: (Looks unfamiliar)
> Belinda: That name hasn't come up at all? (Said incredulously)
> Maria: I'm not working with the [names NGO} as such.
> Belinda: No but that shocks me actually that people have forgotten that…she has a book called [names book] so she formed the [names NGO]… in [names city] probably 30 years ago and is retired now.
> Maria: To be fair they may have mentioned her in the interview. Belinda (PP-M+E)

A frequent critique of the medical model is that medical professionals, who are experts in diagnosis, treatment, and the curing of illness, should not be endowed with the authority or power over the lives of people with dis/ability or how society perceives them (Humpage, 2007). Every person interviewed in this study was regarded as having an important contribution to make to the story of Dyspraxia/ DCD in Aotearoa New Zealand and no one account was prioritised as being more important than any other (Todres et al., 2009).

According to Baum (1995) debates between medical and social framings about health are based on the dichotomy that exists between methodological differences employed by positivist and constructivist ontologies. Many researchers and professionals who adhere to the medical model regard qualitative research as being subjective and imprecise relative to what they consider the hard sciences which are deemed to be objective, despite many social scientists also employing quantitative methodologies (Baum, 1995)

Professionals can make assertions, for example in the quote below, about having a common understanding and language but DCD is a socially contested term, as indicated by the preference of the Dyspraxia Foundation UK (2023a) to retain the term Dyspraxia and, similarly, professionals in Aotearoa New Zealand (see section 3.3) in contrast to DCD academics who promote the term DCD (ref):

> I suppose that one does have to be careful about diagnosis because there is a lot of muddle around the edges of several of: dyspraxia's one, ASD's another, ADHD's another, where well it's a bit like being bilingual. If you think you're bilingual, you're bilingual. If you think you have dyspraxia

> well then, I suppose you've got dyspraxia, but it doesn't help the muddle if you haven't got some idea of the territory that you're covering. That's really all I want to say. Belinda (PP-M+E)

The account above speaks to biomedical systems of classification, reflecting the perception of medical professionals, who may act as gatekeepers, directly or indirectly, influencing whether people who identify as having motor coordination difficulties, can gain recognition and thereby public support. However, the negative attitudes toward non-medical, non-professional framings of Dyspraxia were not universal. Nevertheless, the professional superiority of medical conceptualisations of Dyspraxia was obvious with most professional participants defaulting to deficit-based framings of the Dyspraxia lived experience.

Professionals play a significant role in improving the life outcomes of people who experience movement challenges through the provision of interventions and/ or the conducting of research. However, socially ubiquitous biomedical narratives likely have implications for a person's interactions within their social world and in relation to other societal actors and institutions. The value of this study is that qualitative research, unlike quantitative research prioritizing as it does experimental inquiry and outcomes, enables the exploration of the ways that social participation and the distribution of power in society are negotiable, making visible these processes through detailed qualitative observations and questioning (Baum, 1995). Qualitative research can provide an understanding of how people make sense of their experiences with health (Baum, 1995). Subsequent sections in this chapter will explore the implications of biomedical framings of DCD/ Dyspraxia on the response of the Aotearoa New Zealand healthcare sector specifically to the Dyspraxia/ DCD phenomenon.

3.2 The definition and aetiology of DCD in relation to Dyspraxia

The remainder of this chapter describes the emergent phenomenon of Dyspraxia/ DCD in relation to the role of biomedical narratives in Aotearoa New Zealand and in particular, in the health sector. Professionals working within the individual-medical model have created definitions, diagnostic parameters, and intervention measures to provide help to people, predominantly children, with motor coordination difficulties in Aotearoa New Zealand and internationally (Blank et al., 2019) and a further 50-70% of adults who may still have diagnosable DCD (American Psychiatric Association, 2013). The section that follows explores the relationship between the definition and aetiology of DCD and the term Dyspraxia and the Aotearoa New Zealand social context. One participant account provides a

good example of how Dyspraxia may present in childhood, observing that Dyspraxia may not be immediately visible to individuals in a child's life:

> A hidden disability that is neurological and it affects the child's ability to plan out in sequence… motor skills. So, we see lots of difficulties learning new motor skills and that happens from a very young age. So, in the first few days, in infancy, it could be a baby learning to breastfeed, learning that suck, swallow, breathe rhythm. So that's the first kind of indicators… so sitting up, crawling…these children find it more difficult to learn the cross-pattern crawling, and they'll quite often do bum shuffling or commando crawling or not crawl for very long before they're up and walking but when they're walking you see lots of problems with falling over a lot. So, these sorts of difficulties, you see through the lifespan so when I talk to parents and I'm interested in how they found new motor learning like even starting to go onto solids, learning to use a swing for the first time, learning tricycles, all those kinds of things. Mary (PP-M)

The childhood presentation of Dyspraxia/ DCD is now extensively understood by researchers, particularly internationally (Blank et al., 2019), and, findings suggest, by neurodiversity experts working in movement related fields in Aotearoa New Zealand. Despite many recent DCD studies employing an ICF framework (Blank et al., 2019) based on a DCD etiology derived from the DSM-5 (American Psychiatric Association, 2013), most studies have tended to focus on clinical and rehabilitative practices (Cerniauskaite et al., 2011) and the implementation of the ICF continues to be narrow (Berghs et al., 2016). Where the ICD-10 identifies DCD as a specific developmental disorder, the DSM-5 has attempted to incorporate the large swathe of recent findings which show that DCD continues for the duration of an individual's life (Purcell et al., 2015). The DSM-5's diagnostic criteria have attempted to incorporate the ways that motor coordination difficulties might manifest in adolescents and adults, and are as follows:

> Criterion A: The acquisition and execution of motor skills is substantially below that expected given the individual's chronological age and opportunity for skill learning use;
>
> Criterion B: The motor skills deficit in Criterion A significantly and persistently interferes with activities of daily living appropriate to chronological age and impacts academic/school productivity, prevocational activities, leisure and play;
>
> Criterion C: Onset of symptoms is in the early developmental period;

> And,
>
> Criterion D: The motor skill deficits are not better explained by intellectual disability or visual impairment and are not attributable to a neurological condition affecting movement (Purcell et al., 2015, p. 295).

Purcell et al. (2015) have observed that symptoms from non-motor domains are not included in the DSM-5, including difficulties with executive functioning or an increased tendency toward obesity (Wagner et al., 2011) and adverse psychological effects, relative to the neurotypical population, which have been correlated with DCD (Cousins & Smyth, 2003; Hill et al., 2011; Mandich et al., 2003). Recent studies of adults with DCD/ Dyspraxia, have identified cognitive difficulties such as "executive functioning… activities of daily living… changes in routine… and social interaction and engagement" as being of far greater significance than impaired motor coordination (Purcell et al., 2015, p. 298).

While several professional participants stated that the terms DCD and Dyspraxia may be used interchangeably, the EACD recommendations (Blank et al., 2019) explicitly state that use of the term Dyspraxia is not endorsed, with the EACD strongly promoting DCD as the preferred term:

> Those two terms are used interchangeably internationally now. It used to be that dyspraxia was more about the planning of what you could do in terms of how you were going to move your body and that used to be seen as the distinction between developmental coordination disorder and dyspraxia. That it was these children with dyspraxia that find the planning difficult, and that term seemed to be missing in the diagnosis of developmental coordination disorder. But through the years there have been new terms. It used to be called clumsy child syndrome so the terms change. I think internationally they're looking at dropping the term dyspraxia so there's a global language of developmental coordination disorder. Mary (PP-M)

Aotearoa New Zealand differs from international contexts that prioritise the use of DCD over Dyspraxia. As the DSM-5 definition illustrates, claims by several participants that the terms DCD and Dyspraxia can be used interchangeably now, does not mean that executive functioning difficulties, for example, have been incorporated into the term DCD. Not all DCD experts in this study, however, agreed with the assumption that the terms Dyspraxia and DCD can be used interchangeably. Several professional participants suggested that experts knowledgeable in Dyspraxia in Aotearoa New Zealand

disagreed with current definitional, and aetiological, conceptualisations that exclude cognitive difficulties and argue instead for the integration of motor coordination and cognitive deficits:

> What I don't understand about people who want to siphon off coordination disorder as if it was separable when it happens in a small child. And Amy's a paediatrician [referring to a DCD expert in the UK] and it's not like she doesn't meet this and all of her books and her Centre and all of that, you look at what she's actually providing. She's providing cognitive mechanisms: lists of things people can do, little pictures that people can organise themselves by. So, what part of you takes that up, well your thinking brain takes that up: OK, I'm supposed to do this, I've done this, OK now I'll move onto the next thing. Belinda (PP-M+E)

That current conceptualisations of DCD/ Dyspraxia are contested, is likely an example of the definitional and etiological conflict that can exist around developmental disorders (Conrad, 2007). A similarly contested, and possibly under researched, developmental condition, one often associated with motor coordination difficulties, is sensory processing disorder (SPD) (Tavassoli et al., 2018). SPD does not appear in the DSM-5 as a stand-alone diagnostic classification but rather as an aspect of autism spectrum disorder (ASD) (American Psychiatric Association, 2013). Study findings suggest yet another alternate framing of SPD, used by professionals in Aotearoa New Zealand, with one occupational therapist describing SPD as a preference:

> When we do these sensory assessments, we talk about somebody's sensory profile. It's who you are, it's your makeup, it's not a disorder, so whereas…it used to be seen as sensory processing disorder. And that's no longer the case, it's just seen as your personal preferences. Mary (PP-M)

The professional observation above suggests how social perceptions of different developmental conditions, for example in clinical settings in the Aotearoa New Zealand context, can change over time, in keeping with Conrad's (2007) ideas about the medicalization of social phenomena.

The social phenomenon of Dyspraxia/ DCD has relatively recently been conceptualised. The following account illustrates how the medicalisation process, and social perceptions about motor coordination difficulties, may change over time. Elle (PP-M/D/ED/DP 40-50), who trained as an occupational therapist at a time when occupational therapy, which today deals extensively with children with DCD/

Dyspraxia, did not have a clear understanding of DCD/Dyspraxia described temporal change in relation to Dyspraxia in terms of:

> Maria: So, first, it was specific learning difficulties that you were diagnosed with and, later, after you finished your [occupational therapy] training in the 80s, it was dyspraxia?
> Elle: Yes. And that was after I'd had my kids. So that would have been in the 1990s and I went to a dyspraxia conference, and it all made sense (laughs).

Previous research of DCD has predominantly focused on childhood, but DCD researchers claim that many of the recommendations and information that is applicable in childhood will likely also be relevant for adults, for example diagnostic procedures (Blank et al., 2019), One participant suggested that there may be comparatively fewer studies about Dyspraxia/ DCD in adults because:

> It's a relatively new field and so it's easier for us to ask parents about the motor milestones of their child. So, it's harder for an adult to know when they started crawling and [their] parents might not even remember and then probably most adults have been able to adapt their functioning so that they're able to accommodate what they struggle with and also there's less demands because you're less engaged with sports. Mary (PP-M)

According to Broyles, McAuley and Baird-Holmes (1999) the language employed by the DSM-5 about impairment, focusing as it does on professional perspectives of the dis/abled experience rather than those of dis/abled people themselves, prioritizes individual vulnerability in a paternalistic manner. Additionally, the ICF research model has been critiqued for its disablist underpinnings and tendency to default to normative social assumptions and values, describing the experience of impairment as being "a deviation from a statistically assumed norm and relative to the capabilities of a person who does not have a similar health condition (disease, disorder or injury)"(Berghs et al., 2016, p.23). Results from this study suggest that dominant biomedical narratives which pathologise DCD may not be representative of the lived experience across the lifespan, as illustrated by the following quote:

> I think dyspraxia is a much better word. When I was a kid, I had classic DCD. It really was developmental coordination disorder. Now I'm an adult I think dyspraxia's a much better word for it because it incorporates relationships and work and money. Simon (PP-E+M/D/ED 40-50)

It is a widely held view that the definitions and aetiology attributed to the term DCD are representative of the experiences of motor coordination difficulties in adulthood (Blank et al., 2019). Most previously published studies, however, have not engaged with the lived experiences of the adult DCD/ Dyspraxia population. In contrast, this research suggests that the challenges and perceptions of Dyspraxia in adulthood differ markedly from those associated with childhood. Further findings will be presented in Chapter 4. in support of this argument. The EACD recommendations, by contrast, acknowledge that the 'patient' representatives who contributed to the EACD report, and who articulated the expectations of stakeholders with Dyspraxia/ DCD, were actually derived from parental input and not from stakeholder groups comprised of Dyspraxic adolescents and adults such as The Dyspraxia Foundation UK (Blank et al., 2019). While the EACD stated it hoped to rectify the lack of engagement with people with Dyspraxia/ DCD in the future (Blank et al., 2019), Dyspraxia may not be fully understood from a clinical perspective without incorporating the perspectives of Dyspraxic people which Sarah (PP-M) alluded to in the account below:

> You know dyspraxia because you work with it but we're on the other side of the looking glass. You don't know what it's like to have it and only we can know that. So even though you know quite a bit about it", this is him talking to me, "we know the most about it, so you have to ask us what it's like".

In summary, motor coordination deficits in childhood have been extensively studied by DCD researchers (Blank et al., 2019). Conversely, a lack of research exists about the adult experience of Dyspraxia/ DCD (Blank et al., 2019), likely rendering the experience of Dyspraxia/ DCD in adulthood less visible. In contrast to current DCD literature that etiologically frames DCD exclusively in terms of difficulties with motor coordination, Aotearoa New Zealand DCD/ Dyspraxia experts maintain that the role of cognition is integral to the experience of Dyspraxia/ DCD. This claim will be considered in more detail in the next section.

3.3 Conceptualising Dyspraxia/ DCD in Aotearoa New Zealand

As discussed in the previous section, the term DCD is assumed by DCD researchers to be representative of the experience of motor coordination across the lifespan, with 30-50% of people (Blank et al., 2019) who would have qualified for a diagnosis of DCD in childhood no longer regarded as experiencing DCD as adults. This claim is based on the DSM-5 definition of DCD which excludes the cognitive processes that may be associated with Dyspraxia, prioritising motor coordination deficits. In

Aotearoa New Zealand adherence to the term Dyspraxia, was suggested (in the findings) to be preferred over the current DCD definition and attending aetiology accepted in international literature. In the section that follows, the predominant use of the term 'Dyspraxia' in Aotearoa New Zealand by Dyspraxia experts in both medical and education settings will be explored.

Study results suggest that Aotearoa New Zealand has retained some of the complexity associated with the experience of Dyspraxia/ DCD over the lifespan by incorporating both motor coordination and cognitive aspects in professional settings. One medical professional illustrated how Dyspraxia is conceptualised in Aotearoa New Zealand by describing Dyspraxia as being:

> A neuro-developmental disorder affecting gross and/or fine motor control and coordination. So, to get a diagnosis that's the diff., that's the thing you need to have. This [dyspraxia] affects all sorts of processes, the process of ideation, motor planning and execution. So, coming up with an idea, planning for the movement and executing. So somewhere along the line the messages are travelling along the pathways but they're not making the connections that they need to. So, it's actually quite hard to define, it's not a simple thing but those kinds of processes when you think about it, they are to do with tasks and daily functioning. Every day so it's not just the coordination part of it, there's also the neuro stuff going on as well. Ginny (PP-E)

Despite recommendations by the EACD (Blank et al., 2019) to adopt the term DCD, the Dyspraxia Foundation UK (2023a), representing people with Dyspraxia, has chosen to retain the term Dyspraxia stating that the term Dyspraxia better represents the lived experience rather than DCD. That the term Dyspraxia is also the preferred term of advocacy groups composed of, and representing, adults with Dyspraxia does not appear to be acknowledged by most international DCD researchers with some study exceptions including Walker et. al. (2021).

The most recent EACD identified that adults with Dyspraxia can experience difficulties with "executive function, attention… anxiety, as well as… [sometimes] depression and low global self-esteem" and have challenges with the organization of "everyday activities such as managing money, planning ahead, and finding and arranging belongings" (Blank et al., 2019 p.277). Despite acknowledging the significant co-occurrence of cognitive difficulties associated with motor coordination challenges, a widely held belief is that these conditions may be differentiated from DCD (Blank et al., 2019). One professional described this perception in the following account:

> I think the other thing that has been significant and is actually still is ongoing, on a global scale is the DSM-5 that has basically turned dyspraxia into a coordination disorder and what that has done is that it has removed from the notion of dyspraxia that New Zealand has always operated with, and … that it's not just in motor planning, it's also in ideational planning, it's also in cognition for most children. Belinda (PP-M+E)

Study findings suggest that the co-occurrence of motor coordination and cognitive difficulties is the primary reason for Aotearoa New Zealand retaining the broader conceptualisation of Dyspraxia. According to Leonard (2016), the motor coordination and cognitive aspects associated with Dyspraxia should not be separated, despite the current prioritizing in diagnostic procedures of motor deficits, as illustrated by Cameron (PP-M) when he observed:

> That kind of dyspraxia, where there's nothing else but the motor coordination is highly unlikely for us to see. We're much more likely to see a child who's struggling with communication, possibly struggling with motor coordination of verbal mechanisms as well as gross motor stuff, challenges of fine motor control, challenges organising thinking. And when you look at human development and the role of movement in the development of cognition, you can see why these things go together".

Further, there is evidence from cognitive psychology to suggest that cognition is integral to the acquisition of new skills (Luria, 2014) and including those motor coordination deficits.

In addition, a significant critique of the medical model is its inability to address the presence of co-occurring conditions, or a multiplicity of conditions (Berghs et al., 2016). According to Payne and Ward (2020), there is a need to extend research beyond motor coordination to include self-efficacy in response to non-motor domains in adolescence, including executive functioning. A wide range of cognitive and visuospatial issues have been associated with DCD and these could be explained as being other neurodevelopment and co-occurring conditions or described as learning difficulties (Leonard, 2016). However, if symptoms associated with DCD are regarded as interrelated and understood in terms of embodiment then the integrated nature of motor difficulties, perception and cognition difficulties is more obvious (Leonard, 2016). It has commonly been assumed that it is unusual to see children who only have difficulties with DCD, an estimated 14% (Green et al., 2006). Research suggests that additional behavioural and emotional challenges, associated with DCD, include peer difficulties 53%, emotional difficulties 70%, behavioural issues 43% and deficits in

attention and activity 78%, with 11% exhibiting all these challenges (Green et al., 2006). One participant in the Aotearoa New Zealand context described co-occurring conditions in terms of:

> Significant dyspraxia is something that impacts multiple systems and the challenges of organisation within the child often start with knowing what they need to do so there's an executive function component to it and understanding the world that they're in and then how to organise their body in space in order to do what they want to do. So, the consequence, of course, is that children are often frustrated, they often don't have the language to say why they're frustrated, they don't know why they're frustrated. Belinda (PP-E)

The EACD recommendations state that the Dyspraxia definition adhered to by the Dyspraxia Foundation (UK) incorporates other non-motor difficulties and is therefore broader than the definitions attributed to DCD (Blank et al., 2019). The EACD further states that the term DCD should be used in all published research to refer to the individuals being studied, and that study participants must meet the current accepted criteria for a clinical diagnosis of DCD (Blank et al., 2019). Such recommendations are suggestive of claims making, in keeping with Conrad (2007). The ability of DCD researchers to influence what claims about the DCD/ Dyspraxia experience are legitimate within the shared social world is likely an example of what Wardrope (2015, p.343) calls social constructive power, the ability of privileged societal groups to legitimate certain claims about the world. It is a widely held view that marginalisation and the unequal distribution of privilege in society, can disempower certain social groups and exclude them from participating in the creation of the social resources, or structures, that affect them (Wardrope, 2015). According to Wardrope (2015), the converse of exclusion is the dominance of individuals who are privileged to decide who has access to social resources and how these resources will be arranged and further dictating what claims are perceived as legitimate. Accounts of professional participants, often included criticisms international moves by DCD researchers to separate cognitive processes from those of the body, observed:

> You've seen that there's a cognitive piece, you know, the ideational piece and then there is a motor piece. If you're only going to have dyspraxia defined here, what do you do with [the ideational piece]. Now in New Zealand we have argued for decades that it's part of it, and that there'll always be some element of it and as I say if you look at the evidence of the relationship between movement and cognition and communication, only in very rare cases are they separable. Most children learn about the world by moving about in it. If they've got challenges of moving about in it, then they're not learning about it in the same way. I'm not saying it's

> necessarily inferior, but they will be learning about it in a different way. So, if you're going to do that then you either have to have them both as part of the definition or you have to say no this is dyspraxia over here, and then this is the DCD. I don't understand why you don't involve them both. Belinda (PP-M+E),

DCD research that is predicated on the DSM-5 definition, likely contributes significantly to improved understandings of motor deficits and best practice intervention strategies (Blank et al., 2019). However, the use of differing terminology for motor coordination difficulties has been found to mean different things to relevant stakeholder groups, such as developmental Dyspraxia and developmental coordination disorder having been shown to be understood differently by relevant stakeholder groups (Miyahara & Register, 2000). Different social conceptualizations are likely compounded by the adherence to different definitions by medical, social and education professionals (Reid, 2005) with the potential for wider social implications. The following account below is suggestive of how a narrow professional definition may confuse parents, teachers and medical professionals who are not familiar with Dyspraxia or DCD and possibly contributing to reduced social recognition and/ or remediation:

> That's the thing about DSM5, DSM anything, DSM 1,2,3,4,5 is trying to find boxes to place around people, because, and that's the really interesting question, why do we have to do that? Why are we not looking at the individual needs and the individual presentations of individual children and saying what do you need in order for a successful life? Do you need support in daily living skills, do you need support in reading and writing, whatever it is? We don't do that, what we say is "OK well, and it's partly politics, we only have funding to support children with…." and now fill in the blank. So that forces people to go out and get a diagnosis and some parents are comfortable with that and they go: OK I'm happy to have my child diagnosed with dyspraxia, autism or whatever it is because it's a gatekeeper. It now opens the gate to support. Belinda (PP-M+E)

The quote below does not acknowledge the significant co-occurrence of Dyslexia with Dyspraxia but, nevertheless, it does provide a good representation of what the experience of Dyspraxia/ DCD may be like. Similarly, Sarah (PP-M) highlighted the complexity of Dyspraxia and how it may affect many life domains:

> It [dyspraxia] affects them more holistically in their life, it affects them across more areas of their life than dyslexia. So, a child with dyslexia might have difficulty with reading and spelling

> and writing but they can go and run around the place and play sports. Their coordination is fine, their fine motor skills are fine, they can plan and organise their day. They can tie their shoelaces, they can brush their teeth, they can do all of the daily living things and it doesn't impact their whole life or across all the areas of their life like dyspraxia does. Dyspraxia affects you from getting up in the morning and having to unbutton your pyjamas to having your breakfast and having to eat when your fine motor skills aren't good whereas dyslexia doesn't. Let's change the wording and say: 'It affects you across all areas of your life', whereas dyslexia is specific to learning. Sarah (PP-M)

It has commonly been assumed that while dyslexia is typically understood through an education lens, participation in education settings is only one aspect of living with dyslexia (Gerber, 2012; Wilson et al., 2009). Similarly, while Dyspraxia is typically understood through a medical lens, study findings indicate that the etiology attributed to DCD through the biomedical model may not be representative of the lived experience of Dyspraxia/ DCD across the lifespan. The linguistic choices made within a society reflect dominant social discourses and power arrangements (Bottema-Beutel et al., 2021). According to Bottema-Beutel (2021), predominant social narratives about neurodiverse conditions such as Autism are controlled by dominant social groups with all language choices representative of ideological social positions and therefore not neutral and devoid of judgement. The results from this study suggest that professional participants queried the use of pathologizing terms, asking whether such negative sounding labels need to be attributed to individuals with Dyspraxia or DCD:

> Mary: It's not wrong, it doesn't need to be fixed, it's just who you are.
> Maria: Developmental coordination disorder?
> Mary: Yeah, although I suppose we don't look at fixing it, but can we assist with making life easier to deal with, helping to meet these goals. I see what you mean with the term as well, having disorder at the end doesn't sound as good when you put it like that.
> Maria: (laughs)
> Mary: (laughs) I suppose that's ASD as well and probably a lot of people on the ASD spectrum would say 'well I don't like that it's got disorder' maybe that does need to be changed in terms of how health professionals are thinking and maybe a person comes under the autistic spectrum but it's, maybe it doesn't need to be seen as a disorder with a D on the end. It could just be seen as AS. Mary (PP-M/DP)

The linguistic response to Autism in scientific research, in keeping with Dyspraxia/ DCD, is one of deficit with researchers frequently using terminology such as "disorder, deficit, impairment and dysfunction to describe" how Autism is a condition that deviates from the norm (Pellicano & den Houting, 2022, p.6). According to Begon (2021) what matters is not what impairments a person has but rather what the real-world limitations they may experience are, and how these can be ameliorated.

In conclusion, the term Dyspraxia is used in Aotearoa New Zealand with Dyspraxia experts incorporating both cognitive and motor coordination deficits in their conceptualisation of Dyspraxia, an interpretation differing markedly from international DCD research. The narrower definition of DCD, compared to that of Dyspraxia, may give rise to an ineffective response by the health sector to the Dyspraxia/ DCD population by not making socially visible both motor coordination and cognitive difficulties associated with Dyspraxia, contributing to a lack of recognition in clinical settings.

3.4 Diagnosis of DCD in Aotearoa New Zealand

In this section, I will present a brief overview of medical participant opinions about how a diagnosis of DCD/ Dyspraxia is obtained in Aotearoa New Zealand. Epidemiological data indicates that, not only is DCD the most frequently occurring neurodiverse disorder that impacts day-to-day life, but it represents a significant challenge for individuals and one that warrants significant societal intervention to ameliorate (Blank et al., 2019). The professional account below indicated that despite a similar prevalence - 5-6% of a population having both ADHD and/ or 5-6% having Dyspraxia (Kadesjo & Gillberg, 1998) - that the diagnosis rate in Aotearoa New Zealand of Dyspraxia is significantly lower than for ADHD:

> We treat 25% of kids with ADHD but we treat 1% of the population as having ADHD, whereas we know the prevalence rate's probably 5% or possibly more. But with dyspraxia the level of diagnosis would be lower than that, a lot lower. It would not be a common label. Cameron (PP-M)

Dyspraxia may not be perceived, relative to other neurodiverse conditions, as being as debilitating in social environments and therefore not requiring the same degree of publicly funded support, which is described by Cameron (PP-M) when he stated:

> I don't think you can get a child disability allowance for a child with dyspraxia. But you will get one with ASD or ADHD or one of those diagnoses. But I think ASD can be the most debilitating of the developmental conditions and I think there is a bit of tendency to think that dyspraxia is kind of down the mild end, which is perhaps why it doesn't get funded, or it's not certain what should happen, but for some people it's going to be a significant impairment. Like with anything you get some that pool down the severe end and it has a massive impact. For dyspraxia it's probably lower than the number of people with ASD or ADHD.

Discourses of professionals working in predominantly health specialisations also described how diagnostic labels may ensure that individuals receive appropriate, targeted interventions for their condition and may enable access to public funding: Referrals appear to be supported by other professional evidence to help inform a medical practitioners decision as to whether a diagnosis is warranted, including movement battery tests, with several professional participants referring to the Bruininks-Oseretsky (BOT-2) (Deitz et al., 2007):

> We use the Bruininks, it's called the BOT-2. You start with fine motor precision, so looking at scissor skills and colouring in and then fine motor integration, looking more at how your visual integration skills work with your motor skills. And it's across the age span, so it's a standardised assessment that's used across the age span. I think it's from quite young from age 3 up to adults (Mary PP-M)

According to Lingam, Hunt, Golding, Jongmans, and Emond (2009) severe DCD, defined as significant difficulties with activities of daily living (ADL) for children of typical intelligence, has been attributed to 2% of children with a further 3% experiencing some motor coordination functional challenges with daily living. Whether the prevalence of severe DCD is also 2% in adults is unknown but, given the likely acquisition of motor milestones and addressing of developmental delays, the prevalence of severe DCD may be lower and possibly contributing to the 50-70% prevalence of DCD (Blank et al., 2019) suggested by research to continue into adulthood. The BOT-2 can identify the motor coordination difficulties attributed to DCD but not the cognitive challenges associated with Dyspraxia. The BOT-2, consequently, may not be a relevant indicator of the need for publicly funded support for adults who do not exhibit severe DCD symptoms but do continue to experience cognitive challenges associated with Dyspraxia.

The experience of dis/ability is, to varying degrees, socially constructed, as is the degree to which the dis/abled experience is exacerbated by being ignored, compounded, or ameliorated by social forces (Baylies, 2002). Baylies (2002), further states that where the state can address socially created disablement, it is right that the public sector should employ its political will to do so. Study findings infer that the health sector is under-resourced in terms of providing, crucial, state funded support for the Dyspraxia/ DCD population in Aotearoa New Zealand. Ginny (PP-E) described the complexity of obtaining support in Aotearoa New Zealand in terms of:

> To get a diagnosis of dyspraxia, it's a process of eliminating other intellectual impairments, speech and language, cerebral palsy, and the people to do that are usually developmental paediatricians or the neurologists. In saying that they're not easy to get. There's not a lot of private ones and to get into the [public] system is a bit hit and miss. You need to go to the GP and get a referral to the hospital or the child development unit and hopefully see the right people. It's not consistent in New Zealand, which is really challenging.

The majority of professional participant accounts state that access to medical practitioners knowledgeable in DCD/ Dyspraxia is inconsistent in Aotearoa New Zealand with a lack of private and public professionals who have the expertise to diagnose. There were suggestions from most medical professional participants that parents may have to seek out private diagnostic pathways if they cannot successfully access help for their children through the public medical system:

> If they've [someone looking for a diagnosis of dyspraxia] got money they can go privately. And depending on where they are in the country, some multi-disciplinary teams are available and they're able to diagnose. Some parts of the country they'd have to travel to other places to diagnose. So, it really depends on where you are and whether you've got money and whether you get into the [state] system or not. Ginny (PP-E)

Several professional accounts indicate that access to teams of professionals, who are qualified to diagnose, is inconsistent throughout Aotearoa New Zealand. Further, several Dyspraxic participants and a similar number of professional participants describe financial and geographical constraints in contravention of Article 25 of the UN CRPD which calls for governments to: "provide … health services as close as possible to people's own communities, including in rural areas" (United Nations, 2006a)

A few professional participants described how a team approach is important to prevent DCD/ Dyspraxia being misdiagnosed: “We have had a boy who has been diagnosed with dyspraxia, but it was a form of muscular dystrophy that he had. So that's why a team approach is important, and under a paediatrician” (Cameron PP-M). While international professional guidelines recommend that a qualified medical team of professionals diagnose DCD, to ensure the correct diagnosis (Blank et al., 2019), results suggest access constraints, and inconsistency between professionals qualified to diagnose DCD throughout the country. One professional participant in the medical sector described the complexity of attaining a Dyspraxia diagnosis in terms of:

> One of the things that myself and Merrin often talk about is more and more kids are coming through with a diagnosis of autism when they’ve actually just got sensory issues or dyspraxia. The diagnosis and labels are getting mish-mashed up, and it’s because people don’t understand them [developmental conditions] properly. Sarah (PP-M)

According to Turowetz and Maynard (2016), a diagnosis of Autism is achieved through the use of subjective behavioral observations, rather than the use of precise biomarkers and involves comparing a child’s behaviour with attributes expected from a normatively conceptualized broader population. Results suggest that a Dyspraxia diagnosis may be similarly determined.

Adding to the complexity of obtaining a diagnosis of Dyspraxia is a likely co-occurrence with other neurological conditions (Blank et al., 2019) leading one professional to observe: “a diagnosis isn’t as accurate as we’d like to think. On paper they’ve got this, and they’ve got that but it’s a variety of different issues that you find” (David PP-E). Findings suggest that a diagnosis by a medical professional may be subjective with diagnostic criteria potentially differing between medical practitioners, as suggested by Cameron (PP-M) when he stated:

> Cameron: So, ADHD is probably in 40% of kids with dyspraxia, learning disorder....40-50%
> Maria: So, you distinguish learning disorder from dyspraxia, dyspraxia being the motor coordination issues.
> Cameron: Um. Well, they’re often associated so if it was us, we would probably diagnose ADHD, dyspraxia, and dyslexia. That kind of combination would not be uncommon. I didn’t answer your question, so just on the ASD aspect. There is overlap with ASD, like not all kids with ASD have coordination problems but there’s a large number of them that do and with all these things, they exist on a continuum. So, if you and I saw a kid, the kid who stood out amongst 1000 normal kids

> as having ASD or dyspraxia then you and I would probably agree on it. We agree that that kid has significant difficulties in that area, but we talk about continua. Say it was a dyspraxia continuum from severe to mild, and… ASD… and you have ADHD, and there are learning disorders, and all these things are on different continua and often we'll get a kid who has a question around dyspraxia and ASD, and they commonly go together but sometimes the ASD aspects are more significant than the dyspraxia aspects.

DCD is likely significantly under-recognized by professionals in the healthcare sector both internationally (Wilson et al., 2013) and in Aotearoa New Zealand. The medicalisation of a phenomenon like Dyspraxia/ DCD occurs conceptually, institutionally and at the level of doctor-patient interaction, in varying degrees and in a variety of ways (Conrad, 2007). At the level of doctor-patient interaction the medicalisation of DCD may be incomplete, with study findings strongly indicating that medical professionals outside of fields that specialize in motor coordination deficits, predominantly the disciplines of "kinesiology, occupational therapy, paediatrics, physiotherapy and psychology" (Blank et al., 2012, p. 217) possess limited knowledge about DCD, reducing the likelihood of a correct diagnosis. The potential for inappropriate referrals by health practitioners exists due to the motor coordination difficulties identified, at the point of entry, not being associated with an underlying motor skills deficit (Purcell et al., 2015).

Despite the high prevalence of Dyspraxia in the general population, professional participant accounts suggest that more people may be diagnosed by education psychologists than by medical professionals using the criteria in the DSM-5. Mary (PP-M) alludes to the complex role of the education and medical fields in the diagnosis of Dyspraxia when she stated:

> Mary - I think that people do make that diagnosis without having had the full motor assessment.
> Maria - People being?
> Mary - Maybe psychiatrists or the paediatricians.
> Maria - Educational psychologists?
> Mary – Yeah. (PP-M)

A finding of this study was that claims of a 'diagnosis' of 'Dyspraxia' in the Aotearoa New Zealand context, may be being conflated with that of assessments by education psychologists. Study findings strongly suggest that the terms diagnosis and assessment with regards to Dyspraxia are used interchangeably in the Aotearoa New Zealand context. A medical diagnosis is required to access state

funded assistance in the Aotearoa New Zealand health care sector. An education psychology assessment is needed to access publicly funded support in the education sector. An aspect of the medicalization process is the legitimation of a claim where a medically defined condition, i.e., Dyspraxia/ DCD, is socially enacted rather than being merely rhetorical (Conrad, 2007) through such institutional processes as access to a diagnosis and appropriate intervention measures. The reasons precluding access to institutional support have been described previously, including an inability to access medical specialists knowledgeable about Dyspraxia, as well as geographical and financial constraints. Despite most participants having been assessed for Dyspraxia by education psychologists and informally given the label of Dyspraxia as part of this process, almost all participants with Dyspraxia spoke of having been 'diagnosed' with Dyspraxia. Exceptions include two participants who had been formally diagnosed, four adults who self-identified as having Dyspraxia, with most professional participants also referring to diagnoses of Dyspraxia in relation to assessments for the condition. The lack of access to a diagnosis through the Aotearoa New Zealand health sector may be the reason that a diagnosis and assessment are conflated.

Most professional participant accounts state that it is unusual to see a person who only has difficulties with Dyspraxia, which is illustrated by one participant who commented:

> Dyslexia, dyspraxia and dyscalculia and the middle line is sensory processing and communication difficulties and attention difficulties … ASD, Asperger's, Anxiety and Depression, something like that, and ADHD, full blown ADHD. And every kid who's got dyspraxia has got some of the rest of them. Simon (PP-E+M/D/ED)

One finding is that Dyspraxia is diagnosed in the Aotearoa New Zealand context through a process of ruling out the presence of other conditions which may also have motor coordination challenges as one of their symptoms. Cameron (PP-M) described the diagnosis process in terms of:

> We'll … say "you know, they've got dyspraxia" but if they saw another person, they may well get another opinion. So, these things are often opinion based rather than being definite. It just becomes difficult with the continuum and no clear cut-offs and even with dyspraxia, you might get kids who are really, really good at gross motor control but their fine motor control is terrible or they're really good at organisation and memory, which some people think are quite core to the condition, but very dyspraxic in other regards. You just get different flavours of dyspraxia as well which does make it kind of difficult as well.

The assertion above that Dyspraxia may be many conditions highlights the complexity of the neurodiversity experience. Neurodiversity is based on the idea that human variation is the species norm, framing such diversity as a valuable aspect of the human condition (Chapman, 2021) and a cultural identity, with the potential to also be a dis/abling social experience (den Houting, 2019). Proponents of the individual-medical model and neurodiversity advocates recognize that additional support may often be necessary to mitigate the difficulties associated with neurodiverse experiences like Autism (Nicolaidis, 2012), which is also likely for Dyspraxia/ DCD. The inability of the Dyspraxia/ DCD population to easily access a diagnosis in Aotearoa New Zealand, as indicated by study findings, is a capability deprivation denying Dyspraxic people the ability to access publicly funded supports and inhibiting the ability of a Dyspraxic person to access, in Sen's (2012) terms, the life they want.

This section suggests that diagnostic practices for Dyspraxia/ DCD are in the process of being institutionalised. Financial and geographical constraints, the need to access privately funded medical expertise, inadequate practitioner knowledge about DCD/ Dyspraxia, a limited number of experts qualified to diagnosis, inaccurate diagnosis and the subjectivity of a DCD diagnosis were the reasons stated for the problematic nature of diagnosis access that emerged from the analysis. The theme of more people being 'diagnosed' by educational psychologists than medical practitioners recurred throughout the dataset with many participants conflating having a diagnosis with having an assessment in the Aotearoa New Zealand context, with the two terms frequently used interchangeably. A common view among professional participants was the need to access privately funded assessments over state-funded or privately funded diagnoses, possibly in response to the difficulties of accessing a diagnosis compared to the greater accessibility of education psychologists. Further there is the significant need for an educational psychology assessment to access SACS in the education sector which will be discussed (section 5.3). Another significant aspect of the Dyspraxia/ DCD experience in Aotearoa New Zealand is the response of the health sector to the Dyspraxia experience and which will be explored in the next section.

3.5 Diagnostic pathways in Aotearoa New Zealand

The previous section looked at how difficult it may be in the Aotearoa New Zealand context to obtain a formal diagnosis, this section describes the implications of social understandings of Dyspraxia/ DCD, focusing on the response of the health sector to the Dyspraxia/ DCD phenomenon. Most participant discourses suggested that few people with Dyspraxia will receive a formal clinical diagnosis, with

subsequent implications for how many people with DCD/ Dyspraxia are able to access publicly funded support. Mary (PP-M) described how a child may access state funded support in the following account:

> I suppose the children in our service…there's been some behavioural issues at school or at home that's led the parents or the school to make a referral to the child and family service and it tends to be more around their behaviour. And then it will be picked up and they'll come to an OT and get the referral, but I think the majority of children won't be picked up because their parents have never really seen it as a huge problem. Mary (PP-M)

Access to publicly funded early interventions requires a medical diagnosis of DCD, as outlined in the DSM-5 (American Psychiatric Association, 2013), and is contingent on the successful navigation of the medical referral process and the awareness of relevant stakeholders that a problem exists. Results from this study suggest that interactions with institutional settings in Aotearoa New Zealand may not address the unique combination of characteristics that typify an individual person's impairment or identify the unique difficulties that they may struggle with. Belinda (PP-M+E) discussed the potential implications of a narrow definition of DCD relative to that of Dyspraxia on the social worlds of people with Dyspraxia when she stated:

> The most important thing is that the parents who are raising the child understand why the children find things so difficult and acquire skills and strategies for themselves and encourage the child to develop their own strategies and they're just the same ones that Amy [DCD researcher with a professional perspective in line with international definitional recommendations] argues for. So that the consequence of her narrower definition is possibly less concerning than the definition per se might suggest but it still means that parents and teachers, if they haven't got their heads around it, may not think to do certain strategies that would help… There is a high co-occurrence of executive functioning difficulties, sequencing of thoughts or other difficulties like auditory processing disorder, in people who also experience below average motor coordination which may account for a child being unable to follow multiple verbal instructions. These other difficulties may not be picked up if the narrower definition is being used.

Study findings have previously suggested that the use of a narrower definition of, or conceptualisation of, DCD may contribute to the limiting of social understanding and implementation of appropriate social mitigation measures that a broader conceptualisation of Dyspraxia may afford.

Almost all participants, both those with Dyspraxia and professionals, emphasised that Aotearoa New Zealand has an almost socially prevalent, limited awareness and understanding of Dyspraxia/ DCD, which is illustrated by one participant when they observed: “if you improve understanding, then you might be able to get somewhere [toward helping people with Dyspraxia]. But if you walked out into the street and ask[ed] what Dyspraxia is, no one would know” (Olivia PP-E). It has been reported that DCD is frequently not recognised by experts in both the health and education sectors internationally (Missiuna et al., 2007; Missiuna et al., 2006; Wilson et al., 2013). Similarly, study findings suggest that Dyspraxia/ DCD is poorly understood, not recognised and not addressed by the Aotearoa New Zealand healthcare system, with Cameron (PP-M) observing:

> Cameron: In New Zealand it's hard to get a diagnosis. The awareness of dyspraxia or developmental coordination disorder is not that high. And then the pathways for diagnosis are not at all clear. So, within the public system there isn't really a pathway. There's [names early intervention provider]… Yeah. They don’t do a lot of out-reach. And I asked a while back because, in Canterbury there are things called health pathways which are referral pathways for common conditions. So, there's one for ADHD for instance, anxiety-disorders, ASD and there isn't really one for coordination problems. So, I asked the paediatricians, what did they think, and they pretty much said: "Look they’re under the pump, it's not an area where we feel that we can offer a lot of resources but if we get referrals for kids with significant difficulties, we're likely to have a look at them". So that makes it very difficult. If it was possible to get a pathway for these kids and help them get an assessment. But then there would be issues with resourcing.

The results of this study suggest that there is perceived to be limited public resources for DCD/ Dyspraxia in Aotearoa New Zealand and that a health pathway for Dyspraxia may be lacking. Healthpathways is an online referral system used by Te Whatu Ora Health New Zealand (McGeoch et al., 2015). According to Nussbaum (2006), a society should strive to ensure that people with impairments are able to access the same level of capabilities as other members of society. The social arrangements that individuals with Dyspraxia/DCD, and their whanau must navigate, are suggested by study findings, to prevent the ability to access the same capabilities, as outlined by Vizard and Burchardt’s (2007) list (see section 1.6), as their neurotypical peers. The lack of health pathways for Dyspraxia/ DCD is in the Aotearoa New Zealand public political sphere, in Nussbaum’s (2006) terms, suggestive of a failure of social justice and of the equitable distribution of social resources.

That Dyspraxia/ DCD is a recent discovery of biomedical professions (Leveto, 2018) may be one reason for the seeming lack of societal engagement, suggested by study findings, with the Dyspraxia/ DCD population. One professional participant described social perceptions of Dyspraxia relative to other conditions in terms of:

> They [people with autism] get more respite care through [disability service provider]. People with autism will tend to get that because of that diagnosis, but people won't tend to get it with dyspraxia. So, I suppose it's understanding from the Government's perspective what that [dyspraxia] actually means. It shouldn't be based on a label, it should be based on a needs assessment, based on the needs of the actual child. So maybe access to more resources, maybe also GPs need more training to recognise and be able to refer on. There're also huge waiting lists so even if you do there are not a lot of occupational therapists or speech and language therapists out there. If they're lucky they may get some therapy, but it'll only be very short. Often, children with dyspraxia, unless they've got very bad dyspraxia, probably don't meet the criteria and probably aren't eligible for any government therapy. The Ministry of Education, I don't know, everyone's doing the best that they can do. There's no easy answer. I don't know. Anna (PP-E)

In addition, research results suggest that Dyspraxia may not be perceived as being as significant as other neurodiverse conditions in Aotearoa New Zealand. Hutchinson (1995) notes that while neurodiverse cognitive or functional characteristics may result in some difficulties with ADL, the experience of dis/ability may occur in response to societal structures not responding effectively to the needs of a given population. The participant narrative above suggests that there may be alternate social responses to the Dyspraxia/ DCD experience than those based on a diagnostic label, such as an individualised needs-based response.

To conclude this section, a common theme was that of limited access to a diagnosis and/ or publicly funded medical support through current referral processes within the Aotearoa New Zealand health sector. All participants suggested that Dyspraxia is poorly understood in Aotearoa New Zealand society which may be the cause of a, commonly articulated, theme that improving social understandings is necessary to improve social responses to Dyspraxia. While a small number of those interviewed agreed that motor coordination difficulties in the clinical setting are frequently not associated with an underlying motor skills deficit, a key theme articulated by a few medical

professional participants was the observation that the lack of provision of an individual needs-based health pathway for Dyspraxia/ DCD inhibited an effective social response.

3.6 Dyspraxia over the lifespan in relation to the medical model

Epidemiological approaches to the studying of health are currently grounded in reductionist thought and the employment of causal factors to generate statistical analyses about a given phenomenon (Baum, 1995) which is indicated by the predominance of DCD studies based on the medical model. An academic focus on diseases or disorders means that positive and healthy aspects of a given population may be overlooked because difficulties are prioritized in both academic research and public health debates (Baum, 1995). Several professional discourses and current DCD research indicate that primarily medical fields specializing in movement may prioritise motor coordination difficulties in keeping with their specializations, not addressing the cognitive aspects of the Dyspraxia experience. Mary (PP-M) illustrates the ability of medical fields to separate the motor coordination aspects from the socially situated experience of Dyspraxia when she observed:

> I know it's quite complicated isn't it with the whole, because as an OT you can just focus on the motor skill part it makes more sense. But it does become more complicated: they can't keep all the belongings together or are always losing things.

Most qualitative DCD research appears to be predominantly of child and adolescent perspectives, such as O'Dea, Stanley, Coote and Robinson's (2021) meta-ethnography of childhood qualitative studies of DCD. It is a widely held view, found in the recent EACD recommendations (Blank et al., 2019), that for many individuals DCD continues into adolescence (Cantell et al., 1994; Visser et al., 1998) with 50-70% of children who had DCD continuing to have coordination challenges as adults (Visser et al., 1998). However, applying the same DCD aetiology used in childhood to adults may render invisible, particularly cognitive, aspects of the lived experiences of individuals who would likely have received a DCD diagnosis in childhood. What happens to the remaining 30-50% of adults who no longer have diagnosable DCD but whose socialisation process may have been greatly influenced by their DCD as children, or who still experience cognitive challenges in an open question, with one Dyspraxic participant making the point:

> I flicked my legs out and I was last in every race and that had social repercussions that lasted a lifetime but it's more, I think, just the idea that you become invisible once you get a handle on

> trying your shoelaces and that doesn't mean that at school that there aren't organisational things that you maybe do find hard. Mandy (D/SD 30-40)

In keeping with Mitra's (2006) commentary on dis/abling influences, the complex interactions between a person's Dyspraxia/DCD, personal characteristics, capabilities, and environment will dictate the dis/abling impact of their impairment and the degree, and type, of capability deprivations they may encounter.

Where it was once a commonly held perspective that DCD could be outgrown, longitudinal studies have shown that motor coordination challenges can continue into adolescence (Cantell et al., 1994) and into adulthood for those severely affected (Cousins & Smyth, 2003). The results of this study suggest that in Aotearoa New Zealand Dyspraxia experts operate from an assumption that people do not grow out of DCD but rather the nature of their difficulties change in response to their social and physical environment over time (Hill et al., 2011). One professional participant discussed how Dyspraxia changes over the lifespan in the following account:

> They say it's [dyspraxia] not something you grow out of…yeah and I think that even though there's a lot less new learning for older adolescents and adults there is some new learning like learning to drive a car and things like that so maybe there's adolescents will find it more difficult, and they'll need a lot more practice for it to become automatic and for it to turn into motor memory. Mary (PP-M)

Prioritising the DCD definition as being representative of the experience across the lifespan, may have adverse implications for individuals who may have had DCD as children, but who may become clinically invisible as adults. The experience of DCD in most research is situated along biomedical lines and within the individual, with DCD/ Dyspraxia regarded as the primary causal factor of the subsequent social difficulties an individual may encounter (Payne & Ward, 2020). According to Payne and Ward (2020), what is lacking from most DCD scholarship is an exploration of the social origin of many of the adverse experiences impacting on people with Dyspraxia/DCD.

In addition, study results suggest that Dyspraxia can be understood in terms of a spectrum: "there is mild, medium and severe and obviously you're on the spectrum of how dyspraxia affects you" (Ginny PP-E). Within Autism scholarship there are differing perspectives about the use of a spectrum (Jaarsma & Welin, 2012) but many researchers of Autism argue that a linear approach to the

experience fails to capture the complexity of individuals who exist on many continua, whether in terms of sensory processing preferences, degree of intelligence or the ability to adapt (Nicolaidis, 2012). Study results suggest that a linear approach may also obfuscate aspects of the DCD/ Dyspraxia experience and that there is the potential for "wide variations in functioning" with people inhabiting different ends of the continua at different stages of the life-course (Nicolaidis, 2012, p.507). According to den Houting (2019, p.272), neurodiversity is typified by "considerable variation and fluctuation in both capability and capacity" with neurodiverse individuals sometimes excelling in one skill on a given day but not the next. Defining and distinguishing between diagnosable neurodiverse experiences, and in terms of a spectrum of difficulty, doesn't incorporate the individual variation that exists in ability and which may have implications for whether they are able to access support and an acceptable QoL (den Houting, 2019).

The degree of Dyspraxia/ DCD experienced may have varying implications for QoL outcomes in adulthood, which was suggested by findings. However, structuring a phenomenon like Dyspraxia in a manner that is "hierarchical and linear" ie regarding of Dyspraxia as a functional spectrum of mild to severe, may obfuscate the socially constructed lack of access, suggested by finding, to the capabilities, in Sen's (1999) terms, that would facilitate success (Feely, 2016, p. 874). Wolff and De-Shalit (2007) refer to the inability to access certain capabilities as capability deprivations. Basing publicly funded interventions on a medical diagnosis, that likely prioritises the severity of symptoms over other indicators, may obfuscate the degree of difficulty experienced in the social world of the Dyspraxic person. Elle (PP-M/D/ED/DP) illustrates how the severity of Dyspraxia may not be the only causal factor of social difficulties experienced due to Dyspraxia when she commented:

> He [Elle's son] fooled us. You wouldn't have thought he had dyspraxia because he was riding a two-wheeler bicycle at 3 and, yes, he would come a cropper across his bike, but he was basically riding. But it's the organisational issues that tripped him up. I had to be very careful because he was mild whereas when I was diagnosed, I was moderate to severe. And there's quite a lot of difference with somebody who has mild dyspraxia. He seemed quite coordinated when he was little and able to run and swim and so forth but there were things that tripped him up and I'm not sure how much of it [his difficulties as an adult] is caused by the bullying that he's received but as all dyspraxics you do compensate with verbal skills. His writing was shocking, and fine motor skills is where his dyspraxia came in. I remember looking at his work and there was a D here and a B here and it was all over the page and none of it was making sense.

The quote above is an example of the difficulties a Dyspraxic person encounters may be as much due to the social response to, for example mild Dyspraxia, as the embodied experience of Dyspraxia. The above narrative highlights how discrimination in response to ablest social discourses from other individuals may contribute to adverse life outcomes the implications of which are as significant as cognitive, or motor coordination difficulties associated with Dyspraxia. Study results suggest that there is complexity inherent in conceptualizing motor deficits in terms of mild to severe, with adverse life outcomes associated in participant narratives with even mild Dyspraxia/DCD, as illustrated by one participant's discourse about the difficulties experienced by her son:

> And he would like to go and train as a mechanic, but he's possibly had too much negativity to get over the hurdle of reading and writing. He went from being a fine athletic young man to carrying too much weight. Which was a symptom of the bullying. James used to hide in the library if I was late to pick him up because it was a safe place, the only safe place. Elle (PP-M/D/ED/DP 40-50)

The individual experience of Dyspraxia/DCD is unique to each person, with one participant drawing attention to the fact that motor coordination difficulties can differ, even within the same family: "As [key Dyspraxia advocate in Aotearoa New Zealand] says: 'Having a learning difficulty gets passed on from one generation to the other but the degree of difficulty is quite independent of what the parent has had'" (Elle PP-M/D/ED/DP). The professional participant below alluded to a binary division in society in relation to typical and atypical ability, observing that this distinction is subjective:

> There are strategies that we can all adopt to cover for whatever our own fallibilities are and then there's the fact that this [dyspraxia] is a continuum, there's no hard and fast line between people who have any kind of diagnosable developmental disorder, if you can use that word, and typically developing people. What the hell is that? There's no line there so there are lots of people who would never be recognised. And I mean I meet people from time to time, you've probably met more of them who say: "I was 25 before I realised, I had autism, dyspraxia", whatever it is. So, how's that happen? Well presumably because the strategies, the support, the parenting, the understanding teacher, whatever, knew there was something that was different. Belinda (PP-M+E)

In conclusion, biomedical narratives may influence how institutions like the healthcare sector (Berghs et al., 2016) in Aotearoa New Zealand respond to DCD/ Dyspraxia with, possible implications for the social response and the ability of Dyspraxic participants to access the capabilities necessary to

promote QoL. A common view among medical professional participants was that Dyspraxia affects a person and in many areas of their lives. Adhering to the definition of Dyspraxia is suggestive of a less reductive framing than those based on the DSM-5, and which conceptualise DCD as being distinct from other co-occurring conditions. It has been reported in cognition studies that the body, mind and environment are inter-related in all situations (Iverson & Thelen, 1999; Smith, 2005). Most DCD research regards cognitive difficulties as separate from motor coordination challenges and few studies exist that incorporate cognitive aspects into the lived experience of Dyspraxia.

3.7 Conclusion

This chapter began with an exploration of medical discourses in the Aotearoa New Zealand context because all participants, whether those with Dyspraxia or professionals, are responding to socially dominant biomedical narratives. The medical narrative as the dominant way of conceptualising Dyspraxia/ DCD may therefore enable or inhibit access to institutional response. Reductionist perspectives of the embodied state have been found to be based on identifying symptoms, regarding the body as being distinct from wider social contexts, and not acknowledging the socially interrelated and complex nature of a given phenomenon in a manner that incorporates social, emotional and environmental factors (Todres et al., 2009). It is thought that the individual-medical model is experienced through interactions with medical professionals who act as powerful gatekeepers, dictating the degree of access people have to societal resources and benefits (Haegele & Hodge, 2016).

DCD research defines the DCD experience etiologically as one of motor coordination difficulties in conjunction with other co-occurring conditions (Blank et al., 2019), confining the conceptualisation of Dyspraxia/ DCD to a medical epistemology. Most professional participants suggested that the process of successfully integrating Dyspraxia/ DCD into current societal arrangements in Aotearoa New Zealand appears to be typified by confusion and complexity at the levels of definition, diagnostic parameters, intervention measures and institutionalization. There is evidence to suggest that social resources are prioritised toward medical responses to a pathology, rather than toward identifying the political or social changes that could benefit the life outcomes of a population (Clark, 2014). A common theme among healthcare professionals was the lack of capacity of public health institutions to successfully address Dyspraxia/ DCD. Another finding was that many healthcare professionals agreed that access to a diagnosis, and subsequent state funded medical intervention may be, at best

uncertain and therefore represents a capability that may often be often denied to Dyspraxic people, and which may have significant implications for their life outcomes.

Professional participants in the healthcare sector reported frequently recommending to whanau that they access privately funded pediatric and occupational therapy support. Several healthcare participants expressed concerns about the implications of inequitable access to social support for Dyspraxic children, particularly for financially disadvantaged families and the social barriers preventing access of privately funded specialist paediatric care. According to Goodyear-Smith and Ashton (2019), regardless of the philosophical assumptions underpinning the Aotearoa New Zealand health system, its commitment to universalism has not been achieved in practice in terms of equity for disadvantaged minorities. It has been reported that the healthcare sector is not delivering on its promise to provide equitable access and outcomes for all New Zealanders (Goodyear-Smith & Ashton, 2019) which may potentially compound the equitable access to support for Dyspraxia if the onus is placed on whanau and individuals with Dyspraxia. There is some evidence to suggest that the health sector's complex structure contributes to inequitable access in conjunction with the inevitable trade-offs made due to geographical location, "cost of service provision, quality of services, and the seismic reliance of services (i.e., the risk associated with centralized services)" (Goodyear-Smith & Ashton, 2019, p.439).

Current research focuses on motor planning and execution, such as the EACD recommendations (Blank et al., 2019) which differentiate cognitive aspects as being distinct from the motor coordination aspects associated with the DCD definition (as described in chapter 3). A key theme that emerged from the analysis was that, by defining DCD exclusively as a motor deficit in line with the DSM-5, the significance of the frequently co-occurring cognitive difficulties, identified by most participants, may be minimised. Most professional participant discourses suggested that biomedical framings may contribute to the obfuscating of the cognitive difficulties associated with Dyspraxia resulting in potentially reduced access to social supports. Due to the predominance of cognitive difficulties in adulthood described in most Dyspraxic participant discourses, the term Dyspraxia is a much better way of conceptualizing the lived experiences of my study participants in adulthood. Dyspraxia may affect many aspects of a person's life. The lived experience of Dyspraxia may be hard to define because it affects many processes, such as ideation, motor planning and execution, executive functioning, attention deficits, depression, anxiety, and low self-esteem, managing money, planning and organization.

To conclude, the results presented in this chapter imply that the dominance of the medical model within the Aotearoa New Zealand health sector has far reaching implications for how Dyspraxia/ DCD is conceptualised and responded to by Aotearoa New Zealand society. It is a widely held view that the experience of DCD, situated as it is along biomedical lines, is socially perceived as occurring within the individual, with DCD/ Dyspraxia regarded as the primary causal factor of the challenges an individual may encounter (Payne & Ward, 2020). Dyspraxia, as understood in Aotearoa New Zealand, is nevertheless conceptualized as a pathology comprised of both cognitive and motor coordination deficits, representing a broader conceptual framing than employed in some international contexts and in response to the complex interconnected relationship that exists between cognitive and motor coordination challenges. The next chapter moves on to consider how participants with Dyspraxia conceptualise experiences of Dyspraxia/ DCD in adulthood.

Chapter 4: The lived experience of Dyspraxia/ DCD in adulthood

The previous chapter explored the role of biomedical discourses in the framing of Dyspraxia/ DCD in Aotearoa New Zealand and the response of the Aotearoa New Zealand health sector to the Dyspraxia/ DCD phenomenon. This chapter investigates how Dyspraxic participants perceive the lived experience of Dyspraxia in adulthood. Furthermore, this chapter presents findings of how motor coordination and cognitive difficulties are understood in relation to medical model framings of the broader Dyspraxia definition used in Aotearoa New Zealand. This chapter will first discuss how the medical model may impact on how Dyspraxic participants perceive themselves in adulthood and in relation to their social worlds. Second, neurodiversity will be explored, focusing on three prevalent themes in Dyspraxic participant narratives, namely the roles of identity construction, social adaptation, disclosure and normative social structures affect the Dyspraxia lived experience.

4.1 Medical model conceptualizations of Dyspraxia in relation to the lived experience

All but one Dyspraxic participant stated that they experienced motor coordination difficulties as an adult and most Dyspraxic participants stated that they were less clumsy than they had been as children. Despite the outcomes and life trajectory of adults in relation to DCD being a comparatively under-explored research area (Barnett et al., 2011), research has found that handwriting difficulties (Kirby et al., 2008; Peters et al., 2001), fine and gross motor challenges (Cantell et al., 2003) and ineffectual time management (Tal-Saban et al., 2014) are typical of the DCD experience in adulthood. It has been widely reported that the ability to organize and drive a car (de Oliveira & Wann, 2012; Kirby et al., 2011) and succeed in gainful employment (Kirby et al., 2013) may be adversely impacted by DCD in adolescence and adulthood. All but one Dyspraxic participant described ongoing motor coordination difficulties as adults: “I still have trouble parallel parking; something is missing there I can’t. I need to judge a space and also left and right and I just can’t” (Marie D/SD 30-40). One participant, said of his motor coordination challenges, as an adult, that “the only thing with motor skills

that I do struggle with is walking next to someone, I bump into them" (Edward D/ED 20-30). Another participant described difficulties with "flexibility and balance and muscle tone because, compared to my friend who's not working out at all, she's so much more balanced than I am and more capable … than I am" (Bianca D/ED 20-30).

A predominant theme of many Dyspraxic participant narratives was that of being less clumsy as adults than they had been as children: "I don't think clumsy would apply [to me] today. It would have been 10 years ago but not anymore" (Andrew D/MD 20-30). However, all participants, but one, with Dyspraxia described circumstances in adulthood where they continue to experience difficulties with coordination, which is described by Claire (D-M 50-60) when she stated:

> I found housework, it takes me much longer than it takes any other person to do, and I tend to be absolutely meticulous about it but the last time I vacuumed the floor I tipped over the rubbish bin. So, what starts off as me vacuuming the floor turns into me having to pick up the coffee grounds off the floor or the time before last when I mopped the floor, I ended up knocking over the bucket of water so that then I ended up having to get towels up. So, everything turns into this massive job when it was supposed to be a little job.

According to Jones, Huws and Beck (2013) while Autistic students thought that Autism could only be understood by Autistic people, they further observed that each person with Autism can only comment about their own experience of Autism. Similarly, Dyspraxic participants describe possessing characteristics of Dyspraxia that reflect their own individual social and embodied experience of Dyspraxia, as illustrated by Ginny (PP-E) who observed:

> If you've met one person with dyspraxia you've met one person. The next person with dyspraxia might have some similarities but there'll be some real differences as well. So, one person with dyspraxia might find it really challenging to write, to hold a pen, to be able to get the information out on paper, whereas another person might be able to write OK and it's the gross motor that they have problems with. I mean we've had people with basketball scholarships overseas, so they're fine with their gross motor, but its other [difficulties]: processing information that they find more challenging, so they are really different profiles. Also, somebody with dyspraxia might have sensory processing disorder, they might have autism spectrum disorder, some of those things coming in, whereas another person might have a bit of ADHD, so there's a whole lot of different things that create an individual.

It is a widely held view that establishing a link between motor deficits and academic performance is difficult, but that handwriting challenges can impact on academic "achievement owing to slow, inaccurate, and/or illegible penmanship and output" (Blank et al., 2019 p.259). Most Dyspraxic participant narratives point to the social complexity inherent in the individual Dyspraxia experience and how Dyspraxia can be perceived as being indistinguishable by Dyspraxic participants from, for example, cognitive challenges such as learning difficulties:

> I had a lot of issues…I'm good at it now but I never got body language and inference and implied meanings of things either from other people or by doing them myself so that kind of…like I was bullied at primary school and that sort of…the personality effects, dyspraxia probably played more of a role at that point than the actual learning disability 'cos I…my reading is really good and I was reading at a really high level at primary school so because of that it sort of balanced out me not being able to write very well and it wasn't until intermediate that someone actually went 'oh I think you've got a learning disability'. Jack (D/ED 20-30)

Handwriting challenges were identified by a number of Dyspraxic participants as continuing to have significant repercussions for their QoL. The following participant suggested that his handwriting affects his ability to succeed in a tertiary environment, with potential implications for successfully attaining his qualification and indicating possible effects on his subsequent life outcomes:

> At Uni now, I'm majoring in Biology we have to do a lot of drawing and 'cos my motor skills and handwriting is atrocious I struggle with drawing like I can see the picture but when I go to draw it turns out really bad so I know that's a key feature of dyspraxia but like one of the assessments we had to draw like a flower and my flower was quite crap so I didn't pass that part of the thing because of the drawing and the inability to look at the picture and then do it by hand. William (D/ED 20-30)

It has been reported that challenges with DCD in adulthood can include difficulties with acquiring new skills (Blank et al., 2019). Several Dyspraxic participant narratives indicated that they may require varying degrees and types of social support at different stages of their lives which they may not receive, as described by Lucy (D/ED 20-30) when she stated:

> I just want to be independent, but I can't cook. For me, cooking terms like simmering, boiling, I have no idea what they mean. I have no idea what to do in the kitchen. I need to be shown and I need help and people say: "Well, I was never shown, I just practiced".

Many scholars hold the view that the acquisition of difficult motor skills in adulthood may be both stress inducing and time consuming (de Oliveira & Wann, 2012; Missiuna et al., 2008). The majority of Dyspraxic participants mentioned that difficulties associated with learning new skills may either be due to the coordination or cognitive difficulties that Dyspraxic participants associated with Dyspraxia. One professional participant described challenges learning new skills in terms of:

> When you go into a new job there's lots of new learning when you go into a new workplace, having to remember lots of people's names, having to learn the building, the layout of where you need to go and all the new learning that comes with taking on a new job. Maybe they'd be less willing to have changes within their career because that would be more difficult, and they'd want more stability. But I think that just because someone's dyspraxic they can't get there in the end of whatever it is, but they might need more practice. Once that practice is there, then they're fine and it's not an issue anymore but I think it's around the new learning that it's often seen. Mary (PP-M)

In conclusion, Dyspraxic participants and professionals conceptualise the experience of Dyspraxia in terms of the medical model, identifying motor coordination and cognitive difficulties that change over time and between childhood and adulthood. The majority of Dyspraxic participants commented that their motor coordination challenges in adulthood included difficulties with handwriting and learning how to drive, with implications for their ability to successfully navigate the state tertiary education sector and employment settings. Having discussed the motor coordination and cognitive difficulties identified by Dyspraxic participants in terms of biomedical framings let us now consider the relationship between the self-concept and the experience of Dyspraxia described by Dyspraxic participants in adulthood in relation to the social model and neurodiversity.

4.2 The neurodiverse experience of Dyspraxia/ DCD

The previous section explored the motor coordination and cognitive difficulties associated with the DCD experience in keeping with biomedical framings which regard Dyspraxia/ DCD as a pathologized deficit of the individual. This section will explore how Dyspraxic participants conceptualise, perceive,

and respond to their experiences with DCD/ Dyspraxia in terms of their self-concept. As previously stated in the literature review, most studies in the field of DCD have predominantly focused on children (Blank et al., 2019). Conversely, researchers have not dealt with the experiences of adults in much detail. Current reductionist biomedical framings of Dyspraxia/ DCD may problematize how DCD/ Dyspraxia is socially responded to by not incorporating the complexity that most Dyspraxic participants associate with the experience of Dyspraxia. A neurodiverse framing of the Dyspraxia experience will be prioritised to better understand Dyspraxic participant discourses in line with social model conceptualisations of disability. The social model encapsulates the whole person, regarding the individual as being composed of physical, psychological, and emotional aspects (Barnes & Mercer, 2010).

4.2.1 The role of identity construction

Adhering to individual-medical discourses about dis/ability may result in the experience of dis/ability becoming the defining attribute of a person and dictate societal perceptions of neurotypical people towards them (Haegele & Hodge, 2016). Study results suggest that the social validation of a differentiated social identity, whether made visible through inter-personal social interactions or the attribution of a medical label, may be a key precursor to developing a positive self-concept. Anna (PP-E) described how a person with Dyspraxia may be supported to adopt a positive self-concept when she states:

> I had a boy years ago and he sat next to me, and he just sobbed, and I said to him what's the matter and he said: 'Every year I sit, and I look around me and everybody can just sit and get on with their work, why can't I?' Now he needed to know. He absolutely needed to know. He was super bright and so for him it was really important but that's different to knowing that there's a reason and not using it as an excuse". Anna (PP-E)

Findings indicate that social acceptance beginning in childhood is likely central to the quality of a person's lived experience, such as social validation and social acceptance of difference. The value of support, such as through humour, is illustrated by Claire (D/MD 40-50):

> Things like learning how to ride a bike…it was so hard but once I got it, it was fine. I still did stupid things like bike into parked cars, but I could at least ride the bike. Learning how to swing. I had two siblings who were younger than me and who could swing but I couldn't figure out how to

> make a swing work. I mean I did eventually, but it took a lot longer. I was useless at ball games. Shoelaces I got but it took me a lot longer but balls, I just couldn't. I never got it. I still haven't got it, and I was always the one who was picked last. At the dinner table, because we always sat down, if I reached for something often, I would knock things over and Mum would say things like Claire do you have to knock things over and spill things all the time' and then she would say, 'yea, I guess you do' (laughs) and that for me was nice.

Dyspraxic participants likely need support in the form of understanding to enable the construction of a positive social identity. While this study aims to prioritise the experiences of adults with Dyspraxia/ DCD, participant narratives often recounted their childhood experiences in relation to Dyspraxia/DCD and the implications these experiences had had on their life outcome as adults. According to Ragins (2008), a positive support network can help a person reframe their identity in response to social narratives about disability, enabling them to regard themselves in a more positive way.

The results of this study support Parsloe's (2015) findings about Autism, that Dyspraxia is not something that happens *to* someone but, rather, is an intrinsic part of their self-concept. Many Dyspraxic participants in this study commented that Dyspraxia may be indistinguishable from their identity, as highlighted by Edward (D/ED 20-30) when he commented:

> The thing is you don't know what you'd be losing and what you'd be gaining because if it was going to take away any of my analytical, rational side I'd say no. The one part I don't like is the buffering. When someone says something to you, and you sit there blankly looking at them especially… I find it really bad in a one-on-one teaching situation because someone will explain something very succinctly and clearly, which, if you were processing the words, they would have made perfect sense but because I haven't made sense of the words, yet I look like an absolute idiot. I hear the words, but it doesn't make any meaning.

The perpetuating of an able-bodied social norm, discursively grounded in the medical model, can reinforce the attribution of social stigma and discrimination to neurodiverse populations through the process of 'othering' (Guevara, 2021). According to Guevara (2021) the term able-bodied encompasses both the physical and cognitive aspects of embodiment experience. Many Dyspraxic participants describe experiences that involved 'othering' themselves (Gülerce, 2014). This typically arose through perceiving and judging themselves in relation to social expectations about what

constitutes the able-bodied self, whether in terms of physical comparisons or a failure to meet the expected–and often subtle–thresholds of acceptable social interactions.

Some Dyspraxic participants were often confused about their identities in terms of normative expectations and whether to adopt a disabled identity. Most Dyspraxic participants describe how the experience of difference can cause them to look down on themselves because, as one participant observed: "with disabilities it just feels like there's something wrong with you" (Penny D/ED 20-30). Dyspraxic participants had different responses to the term disability. Tom (D/ED 20-30) illustrates how some participants resisted the term disability, stating: "To have a disability, it's not a very nice word, it's kind of offensive". The devalued social identity ascribed to disabled people results in an internalised self-concept that accepts varying degrees of inferiority in response to social discourses of deficit (Shakespeare, 1996):

> The messages we receive are very strong and clear and we have little access to different values which may place a more positive value on our bodies, ourselves and our lives. Our self-image is thus dominated by the non-disabled world's reaction to us (Morris, 1991, as cited in Shakespeare, 1996, p. 103)

A key result of this analysis was that adopting a disabled identity, to varying degrees, may reduce access to capabilities with subsequent implications for life outcomes. Edward's (D/ED 20-30) account below highlighted how an identity of Dyspraxia may lead to a reduced perception of ability and subsequent access to capabilities such as a preferred profession:

> I think my dyspraxia, because I've got dyspraxia. I thought I'm not smart enough or whatever to do physics and math, so I put it off for a lot of time. Even if you'd said, right from the get-go, if you'd said without limitations what would you like to do, I would have said physics straight away. But it took me a long time to realise that it's more about how hard you work than what limitations you have.

Attempting many courses of study or exploring many different careers before identifying areas where they felt competent was a theme common to several Dyspraxic participant narratives. According to Nussbaum (2000), studies have shown that individuals change or alter their preferences, to desire only what they perceive they can achieve, instead of wanting what they truly value. Most narratives of Dyspraxic participants reveal, in keeping with Cameron and Billington's (2015) findings about Dyslexia,

that people with Dyspraxia have to negotiate to varying degrees their self-concept in relation to labels and further to resist or accept social discourses, in media, from family, teachers or peers: "I wouldn't say I'm disabled cos' that's using a word normal people who don't have the dyslexia and dyspraxia [use?]". (Tom D/ED 20-30). The attribution of a biomedical classification may cause a person's self-concept to change in response to being attributed a label (Feely, 2016). In the case of Dyspraxia/ DCD this may take the form of the partial or complete adoption of an identity that defines their embodied state as one of having a disability, being disabled and the subjectivizing of themselves in terms of either I have Dyspraxia/DCD or I am Dyspraxic.

Study findings suggest that Dyspraxic participants engage in frequent comparisons with individuals who they perceive as not possessing a socially ascribed difference. Further, social interactions were found to make visible to Dyspraxic participants their differences relative to normative societal expectations, with Edward (D/ED 20-30) describing this in terms of:

> The thing that triggered me to become really sceptical [about his Dyspraxia label] was my handwriting because I couldn't draw, and I'd never really tried. I drew stick figures and I assumed that was the best I could do. Then one day I just thought I'd have a go and I was actually able to draw surprisingly well. It was just something I'd taken as an absolute limit; I'll never be able to draw and then I drew.
> M Because you couldn't write?
> E Yeah, I was supposed to have bad motor coordination and fine motor skills. So, I drew that self-portrait and that was a first attempt at drawing (He shows me photo on his phone)
> M That's incredible, you should keep doing more! (I am sincerely impressed)
> E That just made me question because I was like, hang on, I was supposed to not be able to draw and I don't even know if that was part of the original diagnosis, but I've taken it as a limit anyway.

In addition, findings suggest that Dyspraxia may be defined by Dyspraxic participants as either a deficit or a difference. The Deficit vs. Difference model proposed by Griffin and Pollack (2009) in relation to SpLDs, places deficits within a medical conceptualization, in keeping with the medical model, and differences, more in line with the social model of disability.

This study found that Dyspraxic participant accounts ranged from perceiving Dyspraxia as being an aspect of the identity, which was more representative of a difference, to participants who identified as

having significant deficits in adulthood. In keeping with Griffin and Pollack (2009), all Dyspraxic participant accounts yielded both deficit and difference orientated conceptualisations, that varied by degree, context and over time. Results suggest that an inability to handwrite in adulthood may be framed in terms of a deficit in Dyspraxic participant accounts, but the possession of a differentiated learning style relative to normative expectations of learning could be seen by Dyspraxic participants as a difference and in keeping with the uniqueness of every individual's experience of Dyspraxia. Neurodiverse experiences have been described in the literature as specific learning differences, rather than as specific learning dis-abilities, implying that people with SpLDs learn in a different way (Griffin & Pollak, 2009).

According to Bagatell (2010), Autistic people increasingly promote a social perception of themselves that directly contradicts medical discourses that frame the disabled experience as an individual tragedy, illness, or disease. Autism is increasingly being socially conceptualized as a neurodivergent human difference, in contrast to deficit framings promoted by the medical model (Bagatell, 2010). According to the Dyslexia Foundation of New Zealand (n.d.-c), Dyslexia is a different or atypical way of thinking that is neurological in origin and may have both strengths and weaknesses and occurs across a wide range of intellectual ability. Conversely, employing the term difference may not validate the experiences of individuals who possess more challenging SpLDs (Walker & Shaw, 2018). In keeping with whether a person identifies as having a deficit or a difference, studies have found that individuals who associate Autism as being an intrinsic aspect of their identity, are more likely to identify as Autistic (Kapp et al., 2013) Conversely, individuals who regard Autism as something separate from their identity, and more in terms of a deficit, may prefer to identify as being a person with Autism, regarding Autism as being something they may experience but that doesn't define them (Walker & Shaw, 2018).

That a person's identity may be indistinguishable from their experiences with of Dyspraxia/ DCD was a key theme with one participant observing: "Organisation is difficult for me but I don't know, I've never known if that was down to dyspraxia or just personality but I think that the ability to process, that's been my biggest one, forming meaning out of what's being said to me" Fred (D/ED 20-30). Kapp, Gillespie-Lynch, Sherman, & Hutman's (2013) study found that, by referring to themselves as Autistic, people with Autism claim the experience as a central aspect of their identities. In contrast to the biomedical approach, the Autism advocacy community now regards Autism as an alternate cognitive style, not a deviation (Leveto, 2018). The choice by Autistic people to use the term Autistic has been found to not preclude other aspects of who a person is but rather, acknowledges Autism as a core aspect of a person's identity (Monk, 2022). Similarly, most participant accounts indicate that Dyspraxia

is also an integral part of their identity, with most Dyspraxic participants identifying as Dyspraxic. The adoption of a disabled identity and active differentiating of the self in relation to normative expectations and despite societal attributions of deficit can contribute to greater QoL, a positive self-concept, the accessing of social supports and diminished psychological stress (Bogart, 2015). Further, a number of Dyspraxic participants state that they would not support deficit-based conceptualisations of Dyspraxia given the choice, conceptualisations which pathologise people's "characteristics, experiences and personality traits…as deficient" (Monk, 2022, p.10)

Individuals with Dyspraxia/ DCD deserve to experience social inclusion but they may also need to be treated differently to access the capabilities in their capability set. While it is important to challenge the reductive medical conceptualisations of disabled people in relation to their impairments, it is also important to recognize the importance of medical interventions and their implications for improving QoL (Shakespeare, 2005). Ascertaining whether a person is disabled based exclusively on a prescribed etiology defining an impairment may limit how their experiences are socially understood (Begon, 2021). However, most professional participants in this study commented that knowledge of Dyspraxia and self-awareness in relation to possible difficulties can lead to empowerment and self-advocacy and ultimately better life outcomes for an individual, which is suggested by Ginny (PP-E) in the following account:

> Some parents do find it hard to tell their children that they've got something called dyspraxia because they don't want to be different. Some kids can't deal with it and that's what the parents feel. Mostly we find that it's really empowering and that the earlier they can get information about this, about themselves, about how they work then it helps them grow into, and understand it, a really empowered individual who knows what they need. And then they'll be able to go to teachers and future employers and say: 'I have dyspraxia. This is how it affects me and these are the things I need support with.

Adults are sometimes able to positively reframe the Dyspraxia experience from one perceived as a deficit in childhood, to that of a difference in adulthood because of gaining greater agency and autonomy. Most Dyspraxic participant accounts support the findings of Missiuna et al. (2007) that some people with DCD are able to reframe their experience in adulthood, becoming more accepting of their experiences, and changing from a perception of DCD as a deficit to DCD as a difference, thereby contributing to their own wellbeing: "I think once I moved past it when I was 23, I started to drop the label and think well I'm Edward, I'm not Edward with dyspraxia" (Edward D/ED 20-30). Where

participants had achieved a measure of self-acceptance and stopped striving to meet standards equated with 'normal' functioning be they physical or social, they had managed to 'reauthor, liberate and achieve authenticity' (McKenzie-Mohr & Lafrance, 2017, p.192) for themselves. Goodley (2013) argues that, in the reframing of the embodied disabled experience there is the potential to promote productive social change by simultaneously forwarding inclusivity in conjunction with the contesting of dichotomous assumptions of able and disabled, normal, and not normal.

Findings further suggest that Dyspraxic participants are frequently able to exert more control over their social environments, possessing comparatively greater agency as adults than as children, as suggested by one professional who observed:

> So once you're in a job, you're in a routine and if you're in the same routine it's probably not a very noticeable thing in your life whereas I think it's much more noticeable for children that've got a lot of things happening that involve new learning and involve motor coordination skills, whereas if you're an adult you kind of have the choice to back away and not do any of that kind of thing if you don't want to. Whereas children tend not to get the choice and there's lots of new learning as well Mary (PP-M)

The ability to reframe the disabled identity in adulthood and develop a healthy self-concept was found to be contingent on the degree of wellbeing and resilience Dyspraxic participants possess in response to social interactions with other individuals.

Several accounts of Dyspraxic participants described realising that a previous label did not apply to them after all. In Tom's (D/ED 20-30) account below he realised that he was not stupid suggesting that adulthood can enable people with Dyspraxia to improve their individual resilience, and in keeping with Zwicker et. al.'s study (2018):

> What kind of annoyed me was that nobody asked me to get tested. I just assumed I was stupid, kind of thing, which really sucks. So that's why I didn't finish High School. I didn't want to go to Uni, there's no point I wouldn't be able to do it. Yeah, so it wasn't until I quit my job and travelled overseas that I realised, I'm not that dumb.

The iterative process of navigating the experience of Dyspraxia with oneself, in terms of self-concept, and the importance of overcoming challenges associated with Dyspraxia was an important theme of

this study. Studies have found that people with dis/abilities may experience a degree of wellbeing that is only marginally less than those of neurotypical people (Gilbert, 2006, as cited in Chapman & Carel, 2022). According to Reindal (2021), the ascription of negative or value-neutral judgements by a disabled person to their impairment characteristics has been found to be dependent on the social experiences within the social world. Forde and Smyth (2021) argue that there are no direct implications for a person's QoL in response to the degree of DCD or borderline DCD with their study further drawing attention to the importance of factors besides motor skills, as having a significant effect on QoL for adults with Dyspraxia.

The Dyspraxic participant accounts presented in this section suggest that conceptualising motor coordination difficulties exclusively in terms of motor coordination developmental delays fails to capture the complexity of their lived experiences. While Dyspraxic participants frame their Dyspraxia in terms of the medical model, accounts suggest, in keeping with the social model, that most Dyspraxic participants regard Dyspraxia as being an inseparable aspect of their identity. Harris et al. (2021, p.8) state in their study of Dyspraxia that "recognition of their clumsiness could be a source of unhappiness or anxiety and therefore they might rate this as a negative aspect of their identity, while for other individuals, recognition of their clumsiness might be just that – recognition – and they may feel fine about that aspect of their identity". Whilst a minority of participants in the current study mentioned that the attainment of motor skills in adulthood was stress-inducing and time consuming (see section 4.2), most Dyspraxic participants identified having greater agency, and more control over their social environments, as adults.

To conclude, how Dyspraxic participants conceptualised their experiences with Dyspraxia was varied and occurred in relation to normative social expectations with most Dyspraxic participants regarding Dyspraxia as being an aspect of their identity. Dyspraxic participant accounts were suggestive of engagement in a lifelong process of identity construction in relation to their Dyspraxia. The following section examines this dynamic process further through highlighting the various ways Dyspraxic participants describe engaging in adaptive social behaviours to manage their experience of Dyspraxia.

4.2.2 The role of social adaptation and Dyspraxia/ DCD

In this section it will be argued that the Dyspraxia experience changes markedly between childhood and adulthood, with a key theme being that Dyspraxia can affect every aspect of a person's life, resulting in the need to engage in a process of adaptation in response to social factors. It has been a

widely held view that the non-motor cognitive challenges associated with DCD include executive functioning difficulties, disorganization and an impaired ability to plan (Tal-Saban et al., 2012). It is imperative to identify the restrictive elements in a person's social world and that individuals may encounter over their lifetimes (Begon, 2021). Simon's (PP-E/D/ED 40-50) account alluded to how the important it is to recognise how Dyspraxia changes over the lifespan and that the lived experience of Dyspraxia changes significantly between childhood and adulthood:

> At some point the dyspraxic children are going to grow up and I think it's quite important to know how it can transition over time. Definitely you could say, when I was little you could say it was more severe. I built skills over time so being an adult with dyspraxia is quite different to being a child.

Shakespeare (2005) draws attention to the need to better understand how disability is experienced over the lifespan and a recognition that it may not be experienced in the same way at every life stage. All Dyspraxic participant narratives imply that Dyspraxia can affect every aspect of a person's life, with the challenges they experience changing over time:

> I don't think dyspraxia ends, I mean it begins being really, really noticeable and you stick out like a sore thumb because it wasn't called clumsy child syndrome originally for nothing. But it does become more hidden because we do adapt to make our difficulties hidden. With Dyslexia it's a bit different because you're unable to read which is kind of a noticeable thing but when it comes to something that's beyond reading and actually surrounds your entire life, like the way you communicate, the way you walk and talk, socialise and actually perform every task differently with dyspraxia. It [dyspraxia] doesn't so much as end, it becomes more hidden". Andrew (D/MD 20-30)

Despite most Dyspraxic participant accounts describing motor coordination challenges in both childhood and adulthood it was the cognitive difficulties that dominated participant accounts of their experiences as adults. An important theme of this research, and one not conceptualised by medical framings, was that Dyspraxic participants associated both motor coordination and cognitive aspects as being part of their experience of Dyspraxia in adulthood in contrast to the current accepted medical aetiology and definition (see chapter 1). Jack (D/ED 20-30) illustrated the complexity of the Dyspraxia lived experience when he commented:

> I think the biggest things are, and you're obviously already doing this, is looking into the effects on adults as well as children because that's a massive gap that needs to be filled. Because even at the university there's basically no awareness of the ways it affects a person's personality or the way it affects my ability to sit and mentally write an essay. Like there's awareness for like, using a computer is harder than normal, typing, writing's harder than normal here's the dictation software, go write the essay but it's not like that, that's not the reason I struggle writing essays it's 'cos I struggle to sit there long enough to do them and I struggle to stop and go back if I get interrupted and there seems to be little perception of that, of the internal mental portion of it.

The social implications of Dyspraxia are suggested by study findings to be manifold, such as the common theme articulated by most Dyspraxic participants of having to navigate the social world with limited access to information and societal supports, with one participant observing: "You can know how someone with dyspraxia is going to move but you won't know how that's going to disadvantage them in society. Does that really help you understand how they're going to interact with their peers?" (Bianca D/ED 20-30). Study findings strongly indicate that cognitive difficulties are integral to the Dyspraxia experience in adulthood, suggesting that current conceptualisations of DCD may not be representative of the life experiences of Dyspraxic participants:

> The way that we had dyspraxia explained was: When we go and do something like, I'm going to go and do the dishes, I'm going to tie up my shoelaces, our brain automatically connects, and we do it. We go to that filing cabinet in our brain, pull out the right file and we get it done. What they explained to me was, not only does he not know where the file is, he's forgotten where the filing cabinet is. And then there'll be other times when it's right there. Sometimes Joshua will be doing stuff and then the next day he'll be doing stuff and I'll be like; how did you do that yesterday but not today? And it's because he forgot what happened. David (DP)

The previous account suggests that there may be limitations in current research that adopts medical model definitions and aetiologies, especially with regard to the ways that they may obfuscate the socially situated nature of the Dyspraxia/ DCD experience. Most accounts of Dyspraxia participants describe challenging interactions with their social worlds in relation to the cognitive difficulties they associate with Dyspraxia, such as executive functioning, as illustrated below:

> I'm organising to go away right now but I'm struggling to get organised to get all the things I need to do and to put into some kind of structure, or step by step process to make it happen, is really

> overwhelming and my brain…I'll sit here every morning and I'll make lists and try to figure out how am I going to do this today, what am I going to do to feel like I've achieved stuff? What's most important? It's like my brain isn't working properly … to put things in order with the important things happening first and the least important things happening last. So, when I hear people talking about it being a disability, I would say that yes, something in my brain doesn't function as I would like it to. Katherine (D/SD 30-40)

Another common theme of this study was the importance for Dyspraxic participants of an awareness of how they process information and learn to succeed. Learning how to operate in the world, as a person with Dyspraxia was a predominant theme in this study and one that was prevalent in many Dyspraxic participant narratives. Cognitive difficulties with verbal processing were identified by half of Dyspraxic participants as having adverse implications for adulthood. Half of Dyspraxic participants also describing experiencing spatial difficulties as an adult:

> Finding your way, I don't have a navigation system in my brain, or I have one which doesn't work on planet earth (laughs). If I'm explaining directions to someone it's really difficult. I need to do it with my closed eyes and almost imagine a map and say it very slowly, so I don't mix left and right up. Or I can't follow verbal directions. If you tell me to go left and then right, I will remember the first one and after that there is nothing. It just disappears. Any verbal explanation of something. When it gets too difficult my brain goes blank. Marie (D/SD 40-50)

Several participants with Dyspraxia identified a need for structure and a dislike of sudden changes in their social and work environments, managing and/ or minimizing circumstances in their lives that might require a quick adaptation to a situation, as indicated by Henry (D/ED 20-30) who said:

> I love formality, which is interesting, structure. I have to plan my day before I do anything. So, for example, today, I had my exam in the morning and then this, and I thought it would work in well and then I've got my meeting, which is 3pm till late, in the afternoon until late depending on what happens and then Friday, I'll be studying all day. Saturday/ Sunday work and in the evenings, I'll be studying. I have my day planned out. I don't like sudden changes.

The majority of Dyspraxic participants described how they may need to manage the processing difficulties they equate with Dyspraxia, actively attempting to discover strategies that enable them to succeed in their social world and how they relate to, and assimilate, information to experience life

successes. Developing a comprehensive awareness of how they learn and assimilate information was a common theme in many Dyspraxic participant accounts, as illustrated below by Edward (D/ED 20-30):

> I actually find lectures are not much good for me. I teach myself very well, but I find I almost need to make sense of their words, so if someone's talking to me, I need to think about it afterwards. It's almost like their words have no meaning until I've had time to make my meaning. And with lectures it's just a constant stream of words and they start saying their second sentence before I've processed their first sentence, and then their third sentence… And before I've made sense of anything, I've forgotten what the first sentence was and then they move onto the fourth and I forget what the second was… I have found that my challenges have changed. Now it's sort of…the processing thing is the big problem I deal with now. And it's a difficult thing to make coping strategies for, if you can't take in what you're being told you can't take in what you're being told and that matters in lectures.

Most Dyspraxic participants observe that, while the challenges they face in adulthood are different from the difficulties encountered in childhood, challenges with Dyspraxia still have the potential to create pronounced difficulties. Results further highlighted that the process of creating appropriate strategies was not always straightforward and/ or achievable.

A related finding was that Dyspraxic participant discourses described actively cultivating the skills that they identified as not having been attained in childhood, to access the capabilities that would ensure their wellbeing and QoL as adults. The ability to identify restrictive elements, and actively engage in acquiring strategies to overcome them, was described by most participants with Dyspraxia as being a significant difference between the childhood experience of Dyspraxia and that of an adult and represents a key finding of this study: "I had less coping mechanisms [in childhood], like I've learnt how I learn now". (Edward D/ED 20-30). The development of strategies to succeed in social environments, and a lifelong process of adaptation, represented a common theme with many participants exhibiting a high degree of awareness about their individual strengths and weaknesses. Similarly, students with Dyslexia have been found to create strategies to compensate for weaknesses they may possess (Ministry of Education, 2007). According to Parsloe (2015), neurodiverse individuals may need to prioritise the development of strategies to navigate a world that is designed for neurotypical individuals. All but one Dyspraxic participant described the need to manage their Dyspraxia as adults,

with varying degrees of success and in response to the demands of their social environment, as suggested by Claire (D/ MD 50-60) below:

> Claire: It was a doctor at the hospital, and I remember him asking questions of Mum and testing my reflexes.
> Maria: And any intervention after that?
> Claire: No and he said I'd grow out of it [poor motor coordination]
> Maria: And did you grow out of it?
> Claire: No. It's still a problem and it's definitely always been a problem like when I had to learn to drive.

The majority of Dyspraxic participant narratives provided evidence that participants often experienced successes in their efforts to adapt and acquire social, physical and academic skills that they have identified they needed. Claire (D/MD 50-60) described the process of strategy acquisition when she states:

> So, if you get a strategy and then you train yourself, you just go over and over and over then it just becomes automatic… So, when he [a doctor] said 'you'll grow out of it' what actually happens is once something becomes suitably automated, and you don't have to think about it in that kind of way then you can do it no problems. So, I think that rather than growing out of it, it switches to a different part of your brain processing. And it's the same for cars and driving.

The ability to adapt and create strategies is likely improved through early intervention, lessening the likelihood of ongoing adverse emotional experiences in adulthood (Nalavany et al., 2015). However, the majority of Dyspraxic participants suggested that access to early intervention was the exception not the norm with only a small number of Dyspraxic participants benefiting from access to professional intervention as children. Study findings suggested that constant adaptation to social environments and the creation of individually relevant strategies was mostly experimental with the process of acquiring strategies done in isolation and without external support. Penny (D/ED 20-30) described the potential confusion associated with creating strategies without support and on her own in the following account:

> My Dad says you should have strategies, but I don't know what those strategies are. I mean I just do things and I don't know that they're strategies, if you know what I mean … What are the

> strategies for dyspraxic people because everyone's different? … I've looked on the internet and google is helpful to a point.

Most Dyspraxic participants stated that it is not always obvious what strategies should be adopted as a person with Dyspraxia/ DCD. Conversely, a few Dyspraxic participant narratives described struggles to identify–or knowing how to acquire–the skills necessary to achieve positive life outcomes. Most Dyspraxic participants identified the need to have a comprehensive understanding of their individual strengths and weaknesses to successfully navigate Aotearoa New Zealand institutions and, further, that there is limited information available to assist them in identifying the sorts of strategies that may support their individual needs.

Adaptation and compensation strategies may likely evolve over time in response to different circumstances in a person's social world. Most Dyspraxic participants spoke of engaging in ongoing processes of trial and error to successfully identify the strategies and adaptations (or conversion factors, in Sen's (1999) terms that they needed to access capabilities to promote their QoL:

> One of the things I mentioned earlier was adaptation. I actually dropped loads and loads of courses in order to go for ones that played to my strengths. So, for instance, when I first started Uni, I was taking geology, statistics biology, I dropped out of all of them (laughs), so I played to my strengths. Well, I had the insight to know that because of my difficulties in certain aspects I typically just try to play to my strengths which is why although I'm very good at achieving in certain areas. I know that you put me in a different situation I'm probably going to be bad at it. Andrew (D/MD 20-30)

Dyspraxic participants also spoke of identifying their strengths and abilities through multiple changes in either their studies or even career paths to facilitate positive life outcomes. This process is illustrated by Edward (D/ED 20-30) when he states: "I've had multiple attempts at studying. I did a year of biochemistry. I've done psychology, environmental science, biology, computing [and] now I'm doing physics …Oh and personal training".

The lack of institutional support for the Dyspraxia population from either the Aotearoa New Zealand MoH (see chapter 3) or the MoE (see chapter 5), as suggested by most Dyspraxic participants, may represent a lack of access to capabilities (Sen, 1999). In order to achieve a degree of wellbeing and the life a person has reason to value, access to the resources, practical means, knowledge and abilities

that are available in their social, economic and physical environment are necessary (Burchardt, 2004). The provision of support for Dyspraxia is not straightforward but complex and varied which is described in the quote below:

> In the hustle of the classroom, it can take a wee while to work out, is that child shy, is that child a real extravert or is that child covering up for inadequacies that they perceive. Is this child being the class clown because they don't want anyone to know that they can't actually do the work? Is this child leaving the room because they can't do the work? So, it can take a while because they have a multitude of ways of covering it up and they get very skilled. Or is this child unable to read off the blackboard because they can't see it but for years, they've been copying their friends or someone next to them so no one picks up that they can't see. That's where you need [the] quality of your teachers. Laura (PP-E)

There could be a multitude of reasons for the need to disguise Dyspraxia and a multitude of aspects of the Dyspraxia experience that are being disguised meaning that there is complexity in identifying the various issues that may be occurring for an individual. One variable observed by several professional participants, for example, was a lack of resources in the state education sector which was found to not enable Dyspraxic learners to identify appropriate and individualized learning strategies as part of the provision of education in Aotearoa New Zealand. This point was illustrated by a tertiary educator when she observed:

> I've got one at the moment, who's pursuing it [funded support through having a current education assessment] from Workbridge and that's kind of a rare occasion that you get a student who's motivated enough … that they actually take some action around getting it [assistive technology] and practicing with it. When we re-register them, we review the year that's been and we talk about well you know, we talked about technology like text help; "how did you get on? Did you access it at all?" and probably a lot of them say no they've not done anything with it. You know I think it's the pressures that come with starting Uni. Yeah. So as Freda said they'd be much better to get to grips with that while they're at high school. Annabel (PP-E)

The seeming need identified by most Dyspraxic participants to create strategies to succeed may reflect the absence of an opportunity. That the neurotypical population does not need to create strategies to respond to the Dyspraxia/ DCD experience, by virtue of not having Dyspraxia/DCD, is an example of

what Burchardt (2004) identifies as a social inequality in response to how capability sets are distributed among individuals.

This section has analysed the need of Dyspraxic people to engage in adaptation in response to social factors, representing a common theme of adult accounts, and one identified as being a significant difference between the adult and childhood experiences of Dyspraxia. Common themes identified were those of acquiring strategies and an awareness of preferred individual approaches to information assimilation, for example in education contexts. Dyspraxic participants further observed that it was not always obvious, through experimentation on their own and without the provision of adequate social sources of information, what strategies would best support them. Most Dyspraxic participants indicate that the acquisition of compensatory abilities, to better navigate the school, state tertiary sector and workplace was engaged with independently and without social support. The adaptation response was found to evolve over time and in response to social circumstances, with half of Dyspraxic participants expending a lot of effort to identify their strengths through frequent changes of careers, for example.

4.2.3 Disclosure of Dyspraxia/ DCD

A key theme identified was the frequent need for Dyspraxic participants to compensate for their weaknesses, often going to great lengths to conceal their difficulties. Most Dyspraxic participants described the perceived need to strive to pass in a manner that approximated their neurotypical peers: "I know that I have it [Dyspraxia] and I know it affects me, but I want to be able to do everything just as if I didn't have it". (Tom D/ED 20-30). A person may respond to their impairment by adopting normal behaviours and concealing their difficulties, minimizing any challenges they may face in an effort to pass (Shakespeare, 1996). Further, half of professional participants described how inventive and resourceful people with Dyspraxia may need to be to navigate challenging situations in their daily lives:

> She seemed to be doing really well and it wasn't until she went to Intermediate [a type of school covering years 7 and 8] and she wasn't with her friends, she's a girl of course, and girls tend to be really good at covering their inadequacies and all of a sudden it just highlighted the fact that a lot of her friends were doing a lot of her work for her. Zoe (PP-E)

Walker et. al.'s (2021) study of the experiences of trainee doctors with Dyspraxia, does not use the term DCD, and addresses the complexity of the Dyspraxia experience by making visible the population of Dyspraxic people who are frequently successful at passing but who nevertheless experience

challenges due to their neurodiversity. People with neurodivergence often "consciously or subconsciously mask" their neurodivergent traits and often in response to the "exclusion, discrimination, and stigma" they encounter when they are unable to "fit in" with neurotypical people (Monk, 2022).

Analysis of the findings suggested that the ability of people with Dyspraxia/ DCD to conceal their difficulties through attempts to compensate, contributes to lack of recognition by professionals in the education and health sectors and a diminished likelihood that they will receive appropriate support. Mary (PP-M) describes the difficulties associated with accessing social support when she stated:

> Because those children who aren't so obvious aren't going to get to the services to do those assessments to try and identify what their strengths and weaknesses are and it is about do they compensate, are they able to compensate enough that it's covered up and not really picked up.

The process of masking can be stress inducing and tiring for neurodiverse populations (Monk, 2022). Several professionals noted that there may be many people with Dyspraxia in Aotearoa New Zealand who may not know that they have Dyspraxia but who may be aware that: "they were a bit different [relative to their peers] but didn't know why, and they could have had a miserable life for all we [as a society] know" (David PP-E). Neurodiverse individuals may attempt to 'pass' in society, however, to prevent adverse social repercussions. As Denhart (2008) observes about dyslexia, these attempts to 'pass' may be performed to mitigate fears of being perceived as less intelligent than neurotypical peers.

With respect to whether to disclose Dyspraxia to individuals in the workplace, Dyspraxic participants suggested that the decision was frequently complex and inter-related with managing how participant's social identities were constructed. A theme articulated by some Dyspraxic participants was that of a limited social understanding of Dyspraxia in the workplace with Amber (Amber D/ED 20-30) commenting that: "most people don't know what it is and just get it confused with dyslexia. And I've got my strategies to manage". Further, most Dyspraxic participants observed that they had learned how to manage their Dyspraxia related difficulties as adults, to varying degrees. However, this was not true for all participants. The need to manage social perceptions of other individuals was found to be a difficulty associated with Dyspraxia: "It was because he didn't know what to do, didn't want to ask anybody for help, because I think he's got this feeling that if he asks anybody for help, he'll look stupid but by not asking for help they think he's lazy" (Martin DP). Disabled individuals may be reluctant to disclose their

disability due to internalized stigma and in the attempt to avoid anticipated stigma, diminish their access to social support (Bogart & Dunn, 2019).

Whether an individual chooses to disclose a dis/ability requires an analysis of the risks and benefits associated with disclosure for example weighing potential benefits, such as access to workplace support, against potential risks (Brown & Leigh, 2018). Martin (DP) describes the risks associated with disclosure of Dyspraxia, that he has observed his son experiencing, in the following account:

> Sometimes he doesn't want people to know because he thinks they'll look at them differently, and he knows he's right and people have. So, he's learnt from experience: don't say anything, don't tell. Then other times he's happy to share.

Similarly, a few professional participant narratives identified a risk of exposure to stigma associated with the workplace and due to the ubiquitous lack of understanding of Dyspraxia in Aotearoa New Zealand:

> I think sometimes people can have the idea that it's limiting, and people can't do things and then as adults.... When do you say that you have dyspraxia? Do you have to say that you have dyspraxia? Cos then there's that whole thing that if you put that on your initial application are you just going to be put to the side because there is that perception that you're just being too difficult and not up to the job. But then if you don't disclose and your dyspraxia impacts on your ability to work you can then be dismissed because you haven't disclosed... it depends on the situation, dyspraxia may or may not impact on a situation and your ability to do your job. Liz (PP-E/DP)

Limited social understandings of Dyspraxia were suggested by some Dyspraxic participants to create a conundrum about whether to disclose Dyspraxia related difficulties to employers and is indicative of the complexity and uncertainty associated with the Dyspraxia lived experience.

People who can conceal their disabled identity may need to make decisions about whether to disclose with resultant implications in terms of costs and benefits at the level of both the individual and society (Chaudoir & Fisher, 2010; Corrigan et al., 2013). Results of this study suggest that Dyspraxic participants made the decision to disclose information about Dyspraxia in employment settings, for example, based on whether they perceived a need to manage the perceptions of other individuals. Simon (PP-E+M/D/ED 40-50) illustrates how his Dyspraxia may affect him in the workplace in the

quote below and describes the aspects of Dyspraxia that may require him to manage the perceptions of other social actors:

> The thing about me and a job is that I'm a very good psychologist and I'm a good therapist but I'm a crap office worker. And it's the really basic stuff like mixing up appointments or not quite getting written stuff done properly or losing a bit of paper that I have difficulty with, and they [employers] need to understand that, and it can sometimes take me a bit longer. It definitely takes longer for the induction as I learn the system and also, I can be quite hard on myself about any little mistakes that I make along the way in organizational planning.

Several participants with Dyspraxia opted for transparency in employment settings: "I don't think it's the end of the world if someone knows I'm dyspraxic. It's not like I'm an outcast of society or anything. I'm still a normal person, it's up to other people to gauge what they think of it" (William D/ED 20-30). William's account suggests that he is confident enough in himself and his skills that he is willing to disclose, knowing that he is unlikely to lose his job or confident enough that he could get another job. Participants were motivated to disclose their Dyspraxia to pre-empt any normative expectations that may be placed upon them, suggesting that disclosure can be a countervailing 'force' against the fear of being stigmatised. Disclosure then, may present a cognitive dilemma in that there may be adverse repercussions associated with disclosure or concealment. Fred (D/ED 20-30) described his complex relationship with disclosure in terms of:

> I do say in job interviews actually. I think it's better for them to know it upfront and even for some things…maybe it might make it harder to get the job if they thought it was going to impair your performance. But I think you need to know about it in order to take steps to deal with it and if you don't know about it, they'll sort of be expecting to function normally then when you don't do it, they'll think you're being slack.

Most accounts by Dyspraxic participants describe experiences in employment settings where they perceive that they do not possess a given ability, relative to the abilities they perceive neurotypical actors possess. People with invisible difficulties must make extremely difficult decisions about whether to disclose their difficulties to neurotypical people and risk stigma (Nalavany et al., 2015). Further, people with Dyspraxia have been found to be frequently exposed to social stereotypes and discrimination (Denhart, 2008) including normative assumptions that they possess inadequate social

skills, limited physical abilities and low intelligence (May & Stone, 2010). Lucy (D/ED 20-30) illustrates below how Dyspraxia, perceived as a dis/ability by social actors, and her intelligence may be conflated:

> Basically, the boss emailed [names employment agency] because he wanted to fire me because of having a limited mental capacity… which was really hurtful. [Because] my condition doesn't affect intelligence.

All individuals are situated "within a hierarchy of bodily traits that determine the distribution of privilege, status, and power (Garland Thomson, 1997, as cited in Loja et al., 2013, p. 191) with discrimination caused by societal assumptions that equate the impaired body with an inferior form of embodiment (Hahn, 1985). Results of this study imply that difficulties in relation to employment settings may include, in keeping with DCD research (Blank et al., 2019), difficulties attaining financial independence, learning new skills in the workplace and a sense of vulnerability around employment.

To conclude, Dyspraxic participants describe the need to make decisions frequently about whether to disclose their difficulties with Dyspraxia to individuals in social, education and employment settings. A repercussion of the ability to conceal challenges with Dyspraxia was suggested to result in a reduced likelihood of social recognition by significant individuals, who may be gatekeepers to support. Having discussed Dyspraxia in adulthood in terms of the motor coordination challenges, psycho-emotional difficulties and need to engage in adaptation, I will now move on to discuss the social origins of these aspects of the Dyspraxia.

4.2.4 The role of normative social structures

This section will look at the implications of normative social arrangements on how Dyspraxic participants perceive their social identity in relation to Dyspraxia. All Dyspraxic participants identified negative repercussions for their self-concept in response to social discourses about disability. According to Clark (2014), socially dominant framings of deficit overlook the relative nature of normative assumptions and the multiplicities of experience that are illustrated by Dyspraxic participants' narratives. Disability, Begon (2021) argues, is the loss of important opportunities, not the challenge imposed from without of being different to normative expectations. Social model theorists regard the use of categories created by medical professionals in order to define disabilities as being divisive, focusing on perceived abnormalities that people possess, a focus that then leads to an undervaluing of the person (Terzi, 2005). An important aspect of the Dyspraxia/DCD experience is

what Terzi (2005) refers to as the dilemma of difference whereby, the different needs a person has must be identified in order to access supports but a person risks social division through the attribution of a disabling label (Terzi, 2005). The act of separating neurodiverse experiences along biomedical lines and from other aspects of the self (Nicolaidis et al., 2011), may socially objectify the experience of Dyspraxia/ DCD and contribute to social understandings that denote a sense of the 'other', the 'othered' neurodiverse aspect of a person's identity, one separate and undesirable from other aspects of their self-concept. Accounts of most Dyspraxic participants indicate that to varying degrees they experience, in Terzi's (2005) terms, the dilemma of difference whereby, and at different life stages they may need to access social support. The adoption of a disabled social identity to access support, however, may also lead to social exclusion. Penny (D/ED 20-30) account illustrated the subtleties of how social exclusion may occur because of having Dyspraxia when she said:

> If there wasn't the whole normality, I would be a whole lot more happy with my Dad telling people that I'm dyspraxic when I was 10, 11, 12 years old… You know and that was the thing, but you know I was able to get extra help. I was able to get a reader/writer. That's the conundrum too with the term disability because the term disability gets extra help from the government but for the people who are disabled it doesn't necessarily help because there's social stigma attached to it and yes, they are disabled for want of a better word in relation to society because society is not helping them, but society could be helping them and at that point are they still disabled? And I think for the most part it's no".

Many researchers hold the view that neurodiversity as a concept adheres to the 'difference model', perceiving the neurodiversity experience as one of human diversity in relation to brain configuration and not as a disordered human state. Fred (D/ED 20-30) in the account below described his perception of disability as:

> I guess there's always been a lot of controversy around the word disability because some people see it as a pejorative, but I see it really just in a practical sense. I mean maybe not the whole condition but definitely aspects can be seen as a disability if it's making it harder for you to do certain things… I guess it's about a holistic interpretation rather than a simplistic [interpretation]. I guess it's very complex and some people see it as purely a medical condition but that's just one aspect.

While acknowledging the complexities they associate, and difficulties they experience, with Dyspraxia, some Dyspraxic participants described biomedical terms as not adequately encompassing the Dyspraxia lived experience. An ableist approach to the pathologised dis/abled experience is internalized by both dis/abled and non-dis/abled populations through the exposure of all individuals to a myriad of social narratives within society that promote a socially acceptable embodied norm (Brittain et al., 2020). One professional commented that:

> I think you want to fit into societal expectations, so you want your child to be normal, you don't want them to stand out, you don't want them to have difficulties. You want life to be easy for them … It would be much easier to be typically developing and be the same as everyone else and I think particularly in schools. Liz (PP-E/DP)

Most professional participants also describe the dilemma associated with social constructions of normality, for example observing that parents do not want their children to perceive themselves as being different or perceived by other individuals as having an 'abnormal' social status.

Results of this study suggest that the internalizing of socially constructed notions of deficit in response to medical framings of Dyspraxia/ DCD can negate the social framing of Dyspraxia as a possibly value-neutral and/ or diverse human experience. William (D/ED 20-30) described this complexity when he says:

> I've come to understand who I am and why I am this way and at times I do think why am I dyspraxic? Why me? Especially if I've had a crap day and I don't understand things so yes at times I do feel like 'why am I dyspraxic?' And I don't want to be. I don't think dyspraxia is a disability, it's just I understand the world differently, concepts and stuff. Like one person might understand it in one way but I understand it a different way. I'm aware that I think differently to the normal person.

Findings suggested that were Dyspraxia to be eliminated, several Dyspraxic participants observe that they would cease to be the same person, in accordance with Bagatell's (2010) Autism study.

The idea that there could be positive characteristics associated with the experience of Dyspraxia contrasts with medical framings that portray DCD from the perspective of an individual pathology. Most Dyspraxic participant discourses mention strengths, as well as weaknesses, with the following

participant observing that identifying as Dyspraxic was helpful both personally and professionally, allowing him to explain how his abilities might differ from normative social expectations about what a person 'should' be capable of:

> It helps me understand who I am and helps other people understand what I've got and although it's terribly confusing with dyslexia, dyspraxia, and dyscalculia it allows me to explain how I can be an overachiever in some areas and a complete idiot in others. Simon (PP-M+E/D/ED 40-50)

The Dyspraxia experience was framed by the majority of Dyspraxic participants as being perceived as different to a perceived normal experience: "Who am I to know what a non-dyspraxia person acts or feels like, you don't know. You're not able to figure out ever what it feels like to be a non-dyspraxic" (Andrew D/MD 20-30). Autism as an identity is far more developed than that of Dyspraxia/ DCD. Many Autistic people have embraced their Autistic identity, rejecting neurotypical perceptions of normal and adopting the view that Autism has both strengths and weaknesses and is a natural manifestation of human diversity across a population (Nicolaidis et al., 2019). Autism advocates seek to oppose and replace the discourses imposed on the Autism experience (Monk, 2022) Andrew (D/MD 20-30) describes below how a person's perception of their Dyspraxia can be re-conceptualised from a negative medical framing to one of a positive self-identity:

> Would I change? I don't think I would want to because I would be scared of knowing what I would be missing, what I would be losing and that's a thing that I think resonates with me the most is the fact that I know that I can see things, I do, I can see the world differently from people who aren't dyspraxic. Why give that up? Why lose it? What am I going to achieve? Would I become a mathematician that's able to enter into theoretical physics and enter into the world of Oxbridge? Probably not. And would I obtain any betterness in that? So, I think I would rather stay as I am (laughs)".

Despite the negative discursive framings of the Dyspraxia experience and the social implications of possessing a differentiated Dyspraxic identity, Dyspraxic participants frequently attribute value to the Dyspraxia experience.

Cognitive benefits associated with Dyspraxia include the potential for a high attention to detail, being thorough and accurate; possessing the ability to focus deeply on a task with a high degree of concentration and an ability to filter out distractions; the ability to absorb and retain information as well

as having an excellent long term memory and the ability to recall information; having expertise and in-depth knowledge in a subject and a high degree of skill; being honest, loyal and committed with a high level of integrity and; being creative with a distinctive imagination and expression of ideas (University of Edinburgh, n.d.). Further, every person with Dyspraxia will have their own unique neurodivergent profile of strengths and weaknesses. According to Walker et.al. (2021) people with Dyspraxia have been found to be able to create learning strategies based on their strengths. Fred (D/ED 20-30) described his Dyspraxia in terms of:

> I think I could perhaps be a lot more productive if I didn't have it but then I would be…(laughs) I guess there are a lot of people who aren't dyspraxic and perhaps I wouldn't want to be like people who don't have those skills or qualities that I do quite enjoy. I don't think I would really sacrifice the creativity, and passion and the very dedicated focus. I think those are what make me, me and I don't think I'd really be satisfied not having those traits.

Another strength associated with Dyspraxia by several Dyspraxic participants was that of having an intense focus. Claire (D/MD 50-60) describes her ability to focus as:

> I've always been like that, single minded and completely focused on one thing and it's something I admire in others. I had to train myself to multi-task. I divide up my day into different spaces, otherwise it doesn't work. So, when I'm in term time I find it virtually impossible to do any research and I find it almost painful to think about research when I'm in the teaching phase. I don't know if that's a dyspraxia thing.

Most Dyspraxic participants exhibit a high degree of self-awareness around how they learn representing a significant, frequently mentioned, theme in participant narratives. An awareness of how they learn may be a product of half of the participants with Dyspraxia being at universities meaning that they may be more likely than the general population to reflect on learning given its prominence in the university setting. Neurodivergence is considered one style of cognitive processing or way of interacting with the world among many diverse ways of thinking (Grinker, 2010; Wolff, 2009) with the atypical neurodivergent experience increasingly perceived as having not only weaknesses but also strengths (Pellicano & Stears, 2011). Bianca (D/ED 20-30) described her Dyspraxia in relation to her learning in terms of:

> Broader and slower, that's me. I struggle so much with chemistry. I'm sitting there going: 'This is the equation but I'm going, like Why? Why does that mean that? And If I properly understood it would probably make it easier but there's just no point' I remember last year my flat mate who is a chemistry genius and she sat me down one day and wrote out this equation because I was struggling with this thing, and she was like: 'This is how you do it. Now do five of them' And I'm like: 'OK, I'll do five of them' And then she adds in a new thing and I'm like: 'Why?' and she says: 'Don't ask why, just do it! ...It's not necessary'... She's probably right but if you can have that much wider scope of understanding then you'd probably be able to do it [chemistry] better".

A heightened tendency toward empathy was identified by a number of professional participants in keeping with Saban and Kirby's (2019) study of young adults with DCD who were found to possess more empathy relative to a typically developing population. Mark (PP-E) illustrated empathy in relation to Dyspraxia as:

> I stress to the parents that your child might have greater empathy for someone. I quite often notice that children with disabilities they do have this empathy that other children ... a natural empathy ... they say that children need to learn empathy and I think those children do learn it because they've had a journey themselves and they haven't had an easy road.

Accounts of strengths articulated by Dyspraxic participants were often in relation to the abilities of perceived neurotypical individuals around them and/ or the feedback they had received in the workplace, education, and/ or state tertiary sectors. Jack (D/ED 20-30), for example, observed that: "broad thinking's what they're trying to teach everyone to do [at university] anyway but I do seem to just get it a lot better than a lot of the others".

Another aspect of Dyspraxia identified by a few Dyspraxic participants, primarily those at state universities, was that of perceiving that they were better at critical thinking than other students who they regarded as being 'normal' learners. Normal learners in this context were people who Dyspraxic participants perceived may not question or interrogate what they are being taught to the same degree. Henry (D/ED 20-30) described his relation to learning relative to a normal learner in terms of:

> Like a normal person would be taught it [information about a topic in an education setting] and carry on whereas we [Dyspraxic people] look at it and think about it more, and relate it to certain things, looking at the big picture of how things actually work. It's quite hard to explain.

One participant described his relationship with learning in the following way: "I consider myself quite a rational analytical person and I think something about it [dyspraxia] forces you to reflect on things more and I don't know if it's part of it or not but the way my brain functions is completely non-linear" (Andrew (D/ED 20-30). Dyspraxic participant discourses frequently emphasised the differences they observed between the Dyspraxia experience and that of perceived neurotypical people, as illustrated by Edward (D/ED 20-30) who said:

> When I was doing psychology, it was like what is a narcissist? It's not like they have a thing called narcissism, it's that they're at the end of the bell curve of egocentrism. It's not like there is this whole new category, it's just that the further you get out to the end of the bell curve where people think about themselves you get a narcissist. So, I'm thinking maybe I just have a cognitive style that's at the end of the bell curve of processing speed. You know, maybe thinking slow, makes me think analytically.

Experiences with Dyspraxia are frequently described by most Dyspraxic participants in relation to a perceived differentiated identity relative to a perceived normal. Further, the majority of Dyspraxic participant accounts discuss the unique relationship that someone with Dyspraxia may have with the idea of being 'normal' and what it's like to exist with an awareness that you do not perceive yourself as being like most other actors in your social world. Andrew (D/MD 20-30) described his relationship with a perceived normal as:

> I've managed to have the knowledge of adapting to certain situations. I mean I know many people who, for me, I was able to adapt to situations that I found difficult. So, if I found myself in a situation that proved difficult for me because I had dyspraxia. For me I would just say 'this is a problem that's affecting me personally, what things can I implement and put in place to get back to normality'. This whole idea of normality".

Achieving 'normality,' or deviating as little as possible from what is perceived as normal, represents a common theme, as suggested by Andrew (D/MD 20-30) when he stated:

> It's the whole sense of normality. It's like here's the benchmark of the perfect person. Let's try and achieve that, at least that's what I find (laughs). That's definitely something I can totally agree with as well, especially the stuff about disorder. I remember, even one of the most

important psychology courses was 'Abnormal Psychology', Ab-normal, emphasising the normal and some sort of normality. The fact is everybody's normal it's just about realising that".

Several Dyspraxic participants objected to the social perception that some individuals do not possess a normatively acceptable status, likely in response to their own 'othered' social status. McKenzie-Mohr and Lafrance (2017) state that, when a social narrative has oppressive consequences for a population, the creation of 'counter narratives' can enable new stories that are supportive of their identities. According to Parsloe (2015) , individuals within the Autism community have begun to reclaim characteristics of Autism that distinguish them from neurotypical populations and embrace these aspects as positive traits associated with being an 'othered' identity. The concept of 'othering' represents an extraverted process and disidentification with an individual's life narrative. The alternative proposed by Gulerce (2014, p.245) of 'selfing' conceptualises a person's life history in an introverted manner, to create a personal sense of 'goodness, uniqueness and continuity' of the self. Despite the dominance of discourses that frame Dyspraxia/ DCD as a pathologized, personal tragedy (Barnes & Mercer, 2010), findings suggest that people with Dyspraxia resist deficit-based framings, conceptualising their lived experiences as both positive, value neutral and/ or negative.

In summary, much of the Dyspraxia experience is indicated by findings to occur in response to socially ubiquitous normative ideas with Dyspraxic participants frequently describing their Dyspraxia experiences in relation to other neurotypical individuals in their social world. A key finding was the frequent comparison Dyspraxic participants engage in with other individuals, who they perceive as normal, evaluating themselves in relation to their Dyspraxic identity and adapting to approximate behaviours deemed by the participants as being normal. Analysis of the results suggests that people with Dyspraxia are frequently confused about their social identity in relation to normative social expectations. Findings further suggest the need to manage their identities, minimising their Dyspraxia difficulties in some contexts and accentuating them in others in a constant process of negotiation in relation to social environments. Despite social narratives that repeatedly frame Dyspraxia as a negative experience, most Dyspraxic participants identified positive aspects with their Dyspraxia experience, embracing Dyspraxia as an intrinsic aspect of their self-concept. Findings suggest that the social mechanisms, or pathways, which would proactively enable Dyspraxic participants to identify possible strengths associated with the Dyspraxia/ DCD lived experience are absent. The need for positive Dyspraxic role models suggested by findings may be indicative of a need for Dyspraxic participants to have their social experiences validated in society and to achieve social inclusion. Further, some

Dyspraxic participant accounts suggest resistance to normative social structures stating their objection to normal abnormal social distinctions.

4.3 Conclusion

This chapter has explored the lived experience of Dyspraxia from the perspective of the Dyspraxic participants who participated in this study. The lived experience of Dyspraxia is inferred by findings to occur on a multiplicity of scales, whether contextually, physically and/ or cognitively. As a socially situated phenomenon, the Dyspraxia lived experience is too complex to be adequately conceptualised utilising the reductive medical model. Adhering to the medical model may result in grey areas of social understanding that are not discursively captured and rendered socially visible. One significant finding, not encapsulated by current societal discourses about DCD, is that of Dyspraxic participants reporting both motor coordination and cognitive difficulties in adulthood. In keeping with biomedical discourses, motor coordination difficulties were identified in all Dyspraxic participant discourses as being present in adulthood. A significant result of this study was that the experience of DCD/ Dyspraxia changes significantly over time, and between childhood and adulthood, from an experience dominated by developmental delays in childhood, to one predominantly associated with cognitive challenges in adulthood. Current definitions and aetiology may relegate claims of Dyspraxic participants that cognitive challenges are more significant in adulthood to a definitional, aetiological, and experiential grey area of understanding. Most Dyspraxic participant narratives suggest that Dyspraxia occurs in a social grey area which exists between individuals who possess an able social position and people who are dis/abled.

Being able bodied is always understood in relation to an opposing corporeal state, one where medical labels are attributed to the body, and/or mind, to individuals who are perceived to inhabit a space outside of a preconceived social norm (Campbell, 2019). The adoption of an idealised human norm is problematic in that the idea of a physical functional deficit, as it is portrayed for example in the DSM-5 (American Psychiatric Association, 2013), is largely subjective and founded on value judgements (Aftab & Rashed, 2021).

The process of internalizing oppressive narratives, for example those based on ableism, may cause people to other (Gülerce, 2014) themselves relative to the social world they inhabit and in relation to their own inner narrative, to a degree that impairs the attainment of an adequate QoL, as indicated by a number of Dyspraxic participants. The experience of ableism can create the experience of othering

oneself relative to one's own body and/or mind through the internalizing of oppressive narratives and making an individual "an outsider in their own life" (Tarvainen, 2019, p.297). Most Dyspraxic participant discourses contained accounts that were suggestive of 'othering' themselves, in relation to ableist social expectations about what is perceived as normal, to varying degrees.

The majority of Dyspraxic participants described creating their own ways of relating to their unique and individual Dyspraxia lived experience. For example, medical framings were found to not incorporate the complexity of the lived experience of Dyspraxia and its implications for a person's self-concept (see section 4.2.1). Further Dyspraxic participants described the negotiation of a social identity, that they perceived, differed from the neurotypical individuals around them. Families, neurodiversity experts and other people informed about Dyspraxia were identified as being less likely to attribute negative conceptualisations to the embodied experience of Dyspraxia. Additionally, most Dyspraxic participant narratives articulated the value they associated with being accepted by other individuals in their social worlds while possessing a motor coordination and/or cognitive difficulty.

Many Dyspraxic participants exhibited resilience and the possession of a self-concept that enabled effective engagement with social structures and the ability to access capabilities that were available to them. According to Leveto (2018), people with Dyspraxia/ DCD possess a different way of relating to the world around them when compared to neurotypical people and thus are differently connected to their world. Neurodiverse conceptualisations are significant because they can enable the Dyspraxia population to define their experience and identify strengths and weaknesses, which are rendered invisible by deficit-based medical framings. Neurodiversity can encourage society to value diversity in the same way differences in gender, race or sexual orientation are valued, with the neurodiversity concept encapsulating the reality of the strengths and weaknesses that neurodiverse people possess (Nicolaidis, 2012). Some Dyspraxic participants described being able to exert more control over social environments in adulthood, such as controlling the degree of exposure to change, and ability to create routines.

In conclusion, this chapter has looked at Dyspraxic participant responses to socially situated experiences in relation to Dyspraxia, that are influenced by medical model discourses. Results presented include Dyspraxic participant perceptions of ongoing Dyspraxia challenges in adulthood, the social attribution of a dis/abled identity, the engagement in adaptation, the association of weaknesses, value-neutral, or strengths with Dyspraxia and the perception of Dyspraxic participants of normative

social expectations. The next chapter will look at the implications of the socially situated nature of Dyspraxia/ DCD in relation to interpersonal social interactions.

Chapter 5: The social experience of Dyspraxia/ DCD

This chapter will explore the socially situated nature of the lived experience of Dyspraxia/ DCD. Relationships between individuals represent the interface between the ontological position held by a society and its implications for the life outcomes of individuals. The socialisation process is contingent on the successful navigation of moral-somatic encounters at the local level of the life world (Yang et al., 2007). These everyday encounters shape both the internal (see chapter 4) and external life world (see chapter 5) of the Dyspraxic participants in this study.

5.1 The role of family/ whanau support

This section will explore the role of families on the socialisation process, which represents a significant conversion factor, in Sen's (1999) terms, between Dyspraxic people and other individuals in their social environments. Most participant discourses suggest that there may be a range of support provided by families, in terms of the personal, social or environmental conversion factors provided. Some Dyspraxic, and professional, participants described families going to great lengths to provide support: "My father put himself on the Board of Trustees and he managed to get me moved into the classroom of a very kindly, warm teacher" (Elle D/ED 40-50). Several Dyspraxic participants also observed that family support has the capacity to be simultaneously supportive as well as strained, indicating that having a child with Dyspraxia may create stresses for families: "My parents were really good but at the time there was no awareness that it was affecting my memory or personality so there was a lot of confusion or conflict over perceiving me being rude or grumpy" (Tom D/ED 20-30). According to Logan (2009) life success for people with dyslexia in adulthood has also been found to be contingent on a high degree of support from families. Similarly, families were indicated by many professional, and a small number of Dyspraxic, participants to be key in accessing environmental conversion factors, such as addressing motor deficits in childhood through access to clinical settings. Sarah (PP-M) described the importance of family support as:

> They [people with Dyspraxia] do have to try harder, and the thing that really helped them all get where they are and achieve in the way they're achieving is that their parents worked with them the whole time. That's the main thing that helped them. They also acknowledged that it was helpful to have therapy or occupational therapy and they all noticed a difference in that but the thing that made the biggest difference is their parents going into bat for them every single year of school.

Eyal (2013) in their study of Autism identified the family as being the socially preferred site of diagnosis and interventions. Similarly, findings from this study situate the family as the main source of advocacy and access to diagnosis and interventions, which Penny (D/ED 20-30) described in the following account:

> I grew up in a really good household and went to a really good school and that had a lot to do with where I wanted to get in life. It was [named school] but I feel like if I didn't go to that school that I probably would have been happy to stay in my job in the supermarket type thing. And it sounds quite rude but my school did push me and I always wanted to strive for excellence and it did shape me and my dad didn't want to send me to the local high school, he was like: 'No way, you're going there!'.

In addition, study findings suggest that personal conversion factors were promoted such as the promotion of academic achievement by families. Several Dyspraxic participants indicated that accessing intervention in childhood was dependent on their parents being aware that they had difficulties and were subsequently proactive: "I was given help from an early age which benefited me a lot … I mean without any help I wouldn't be here at uni. The fact that I'm getting A's in all my courses shows that I am capable". (Andrew D/MD 20-30). Only one study participant did not associate Dyspraxia with any difficulties as an adult and this individual had benefited from a high degree of intervention and parent advocacy in childhood:

> She [the participant's mother] got me all this support. I had a lot of lessons, music, horse riding, swimming and video games that taught me typing and maybe that's why I could do a lot of planning and stuff because she spent a lot of time helping my brain go "yes that's how you do it". And it was when I was young, it was when I was 7. (Amber D/ED 20-30)

Findings described the provision of various degrees of, financial, social, emotional and/ or practical, support from primary support networks. Most Dyspraxic participant narratives describe how the support received from families facilitated successes as an adult, with several accounts indicating an awareness that, without support, participants' life outcomes may have been less successful:

> I know a friend of mine who is both dyspraxic and dyslexic and he never got the help I did, and he struggles, he really does. It's so bad he's even scared of getting lost and scared of actually being in new situations". Andrew (D/MD 20-30).

The experience of Dyspraxia/ DCD may compound the risk of social disadvantage relative to the general population. Most professional participants observe that if families are supportive then a child is more likely to access social conversion factors and facilitate their success in society:

> I know that, in my practice, that kids are going to do well if their parents get on board. If I know that I can get the parents on board to understand their child and what they need then that child is going to be OK. (Sarah PP-M).

Studies have shown that low parental expectations, in terms of education outcomes, of neurodiverse children and young adolescents results in reduced academic and post-school success (Doren et al., 2012; Shandra & Hogan, 2009): "I never had parents who were supportive and encouraging and so I always needed that validation and I was scared of not getting things right. So, I would prefer to not try, rather than look like a fool" (Fiona D/SD 30-40). An inability to access chosen opportunities is the point at which a person's impairment becomes disabling (Mitra, 2006). Several participants with Dyspraxia described how a low level of support from their primary support network may compound challenges with Dyspraxia and further impair their ability to thrive and succeed in life:

> I want people to understand me and my issues, but they don't because nobody understands dyspraxia. I found out at 18 from a complete stranger and I was completely neglected because everybody spotted it. My teachers spotted it, I knew there was something wrong because I struggled in High School but for your own parent, the person that raises you and looks after you to ignore that. If your child has a disability, you get help. If your child has a broken leg, you get medical treatment. If your child is assaulted, you see somebody. If your child has a disability that embarrasses them in school, you know, you get help. Because dyspraxia affects so many parts, it's not just verbal, its motor, emotions, socialisation, fine and gross motor skills. It affects your whole life. She knew that too. My disability is not invisible, every time I speak it's visible and people spotted it. And growing up I was really shy and sensitive, and I'd cry a lot and that's common for children with dyspraxia because they have trouble expressing themselves. But if your child shows signs, you get help. If your child is struggling to speak or at school, you don't ignore it because that's neglect, that's neglect. Lucy (D/ED 20-30)

Factors contributing to the inability of families to address additional needs in childhood and adolescence were due to being unaware, unwilling or unable to provide support. The result of inadequate assistance from families for a child or adolescent with Dyspraxia/ DCD, was indicated in several professional accounts and most Dyspraxic participant narratives to be the need to manage their difficulties alone. A result of a lack of support for Dyspraxia in childhood and adolescence may be an increased risk of adverse psychological consequences.

Dis/abled populations are frequently isolated from collective social understandings and supports (Shakespeare, 1996), with the experience of stigma compounded by the likelihood that most disabled people spend most of their lives relating to non-dis/abled people, whether in the home, education or in employment (Morris, 1991, as cited in Shakespeare, 1996). Further, dis/abled people may be isolated if no one in their families or community shares their disabled identity, (Bogart & Dunn, 2019) contributing to a lack of identification or engagement with conditions like Dyspraxia/DCD (Bogart & Dunn, 2019). Several professionals commented that a lack of understanding by families about Dyspraxia could also be a source of stigma:

> It's the support around those people and it's the understanding. Like I've got an 18-year-old girl with dyspraxia at the moment, and I think her dad thinks that it's about time she starts to … she's got regulation issues, and she can be inappropriate socially because of that. And he thinks it's about time that she's 18 now and for her, just because she's 18 doesn't mean that overnight it's going to go… At the end of school, they've finished school then they're quite socially isolated. There's not a lot out there, you know for young 18- or 19-year-olds if you don't already have a social group and you struggle with a social group". Abby (PP-E)

If the onus of providing support for Dyspraxia/ DCD is on parents who do not, or are unable to, provide it then this indicates that the Dyspraxic population may be at greater risk of cumulative disadvantage (Payne & Ward, 2020), relative to their neurotypical peers, as a result of having Dyspraxia/ DCD. Lucy's account below (D/ED 20-30) described an experience of Dyspraxia without familial support:

> And in terms of socialising, I was really shy and very sensitive. And I always afraid people wouldn't understand me, so I never asked questions. Going to school was really difficult, difficult to make friends. I struggled to keep up, writing, sports, socialising and then at the high School some teachers picked up that I couldn't write as fast and finish my exams. And then my

> horticulture teacher told my Mum about my issue and Mum was like: "Lucy has dyspraxia, but I never told her because I didn't want her to play up on it".

Conflict between primary support networks and neurodiverse young adults has been found to diminish the ability of neurodiverse children and adolescents to solve problems leading to avoidance behaviours (Mihut et al., 2022). Conversely, young adults who experience a close relationship with their primary support networks and who were subject to high parental expectations have been found to have higher levels of problem solving abilities and fewer avoidance behaviours, which may act as protective factors reducing the inequalities that exist between neurodiverse and neurotypical students (Mihut et al., 2022). Amber's (D/ED 20-30) account provided a contrast between her own experiences of family support in relation to a friend who did not receive support for Dyspraxia:

> I had a friend when I was at college, whose mother was a teacher and thought she was dyspraxic but wasn't going to do anything about it. And my friend was struggling a bit at school because in one way I didn't really need the help, it did help but I didn't necessarily need it for grades and stuff, but she was having some trouble with school, and you'd think with a mother as a teacher that they'd do something about it, and it doesn't seem cheap to get the testing.

The negative experiences associated with Dyspraxia/ DCD can be exacerbated, and in ways unique to every individual by the added complexity additional factors, for example familial dysfunction which Claire (D/MD 50-60) illustrated in the following narrative:

> Maria -How did you find relating to your peers?
> Claire: Not easy but everything gets muddled up, so all sorts of other problems get muddled up with that as well.
> Maria: Do you mind me asking in what way?
> Claire: Well, my father was an alcoholic.
> Maria: Ah family stuff
> Claire: Yeah. We had all sorts of family problems, so that got all muddled up with the not being able to do things [experience of Dyspraxia] and my brother and I were both reasonably bright, but he was dyslexic, so people kept saying that he was stupid.

Study results show that a degree of dysfunction in the family of a Dyspraxic person likely compounds challenges associated with learning and/or movement difficulties, as illustrated by Claire (D/MD 50-60) who states:

> Claire: I wanted a xylophone for Christmas, but my dad used to always say things to me like 'yea but you know that you're going to be totally useless' and I couldn't handle that at all.
> Maria: That's awful!
> Claire: And he would do that kind of stuff all the time. Or I'd say: "Dad, Dad, I'd really like to have a Netball for Christmas" and he'd say: "you'd never be able to catch the thing anyway". So, he was the Master of give up before you start and, in a sense, I knew he was right which kind of made it worse.

Limited self-efficacy, sometimes in response to the negative reactions of actors in their social worlds has been found to limit participation thereby increasing exposure to social isolation (Payne & Ward, 2020), compounding difficulties with Dyspraxia/ DCD experienced in Aotearoa New Zealand institutions and contributing to a diminished quality QoL. Katherine (D/SD 30-40) describes how the experience of Dyspraxia may be compounded by other difficulties in a person's social environment. Katherine (D/SD 30-40) makes the comment:

> I think my Mum, the way she walked in the world as a very insecure person. If she walked in the world as a very confident person and the same as my father, if he walked in the world as a very confident self-assured person, then I think I would be able to walk in the world as a very self-assured person. School would have been just the same, just as hard, but if I'd had that emotional support from my parents, I feel like I could have become successful younger. I feel like now, as an adult I'm only just starting to deal with that trauma of school and parental input and it's only now that I'm starting to look at it and starting to see that I am actually capable, and I could be successful. But I've never really believed up until now that I could be anything but a failure.

The lack of knowledge about Dyspraxia in Aotearoa New Zealand, as illustrated by the quote below shows how a lack of widely disseminated, information about Dyspraxia in Aotearoa New Zealand may prevent a parent from identifying their child's difficulties with Dyspraxia:

> I feel bad as a mother because once [names their child] fell off the jungle gyms and you did that sort of thing every day. And I started walking over to [names their child] and this parent comes

> sprinting in front of me and picks her up and says: 'You're such a bad mother, you're such a bad mother! You should have run to pick her up' Cos [names their child] were OK because it was something [names their child] did every day, but I didn't know it wasn't normal. And when this mother said that to me, I still think about that day because that was the difference between me as the mother of a dyspraxic child and a mother of a not dyspraxic child. Jane (DP).

That the difficulties with Dyspraxia that young children experience may be overlooked represents a common theme of this study. Sen (1999) identifies the importance of institutions, and their structures, for the opportunities that people have to expand their capabilities. Access to social conversion factors that are socially embedded and comprised of social norms and social infrastructure are interconnected with the abilties and opportunities that an individual posseses (Trani et al., 2011) A failure to diagnose people with DCD has been found to increase the risk of exposure to cumulative adversity (Cleaton et al., 2021). Similarly, not socially acknowledging, recognising, or assessing for, the cognitive challenges identified by study findings as being a key aspect of the Dyspraxia experience may also contribute to cumulative adversity, in the form of a lack of access to necessary support. Results suggest that the opportunities that would assist young children to utilise their functionings and access capabilities in their social environment, such as in education, may be inadequate and result in capability deprivation. Access to institutionalised assistance for DCD/ Dyspraxia in early childhood was found to be primarily contingent on whether primary support networks were aware of Dyspraxia and able to recognise motor coordination difficulties in their child. However previous findings have shown that a lack of access to knowledgeable practitioners, geographical and financial constraints may also limit access to appropriate interventions, regardless of whether Dyspraxia/ DCD is recognised as described in chapter 3.

Support for Dyspraxia/ DCD by families in childhood and adolescence was found to be a significant precursor to positive life outcomes in adulthood. Current social norms, as a social conversion factor, place the onus of support provision for Dyspraxia on families which may contribute to the small number of Dyspraxic participants who had accessed clinical interventions. Having explored the role of families on the socialisation process of Dyspraxic participants, the following section will look at the experience of social inclusion for Dyspraxic participants.

5.2 Dyspraxia and social inclusion in Aotearoa New Zealand

This section explores the role of social visibility on the Dyspraxia social experience and represents a common theme of this research. That Dyspraxia/DCD is not visible to individuals in the general populace and may be a significant contributing factor to the prevailing lack of understanding of Dyspraxia/ DCD in Aotearoa New Zealand, was a common theme articulated in most participant accounts. Such findings suggest that Dyspraxia is an emergent social phenomenon that is in the process of being socially constructed in Aotearoa New Zealand and, further, that many people do not know what Dyspraxia/ DCD is. One professional described the recent recognition of Dyspraxia as a condition in terms of:

> I think it's [dyspraxia is] so new, in terms of being on people's radars [in New Zealand] that I think some kids will be missed, even by parents as well. Like as a parent you're aware your child's quite clumsy and not that good at learning to ride a bike compared to the younger brother but I know that a lot of people in the community aren't aware of what the term dyspraxia means or that there is anything out there that describes their child as clumsy. It's just probably seen as who they are. Mary (PP-M)

Study findings suggest that Aotearoa New Zealand has only recently acknowledged Dyspraxia, with one professional participant stating: "New Zealand has started talking about dyspraxia now but it's relatively new. When was it recognised in New Zealand, was it less than five years ago?" (Belinda PP-M+E), and "not many people really know about it [dyspraxia] as well, when you talk about it, just in the wider community a lot of people don't know what the term means" (Mary PP-M). That Dyspraxia is poorly understood in Aotearoa New Zealand, was a theme that was overtly stated by most Dyspraxic, and professional, participants. This lack of society-wide understanding of Dyspraxia has implications for institutional responses with one educational professional observing:

> There's a lot of kids with dyspraxia that just fly under the radar. So, they're just left alone. Unless they have the behavioural problems and then there's the secondary problems on top of it [dyspraxia], they won't get the support that they need ever (Ginny PP-E).

Dyspraxia is suggested by findings to be in the process of being institutionalized (Conrad, 2007) in the Aotearoa New Zealand context: "When I started working in Christchurch 15 years ago, dyslexia wasn't understood and there was a push to get that recognised and understood and dyspraxia is probably 5-10 years behind that" (Anna PP-E). Conversely, progress is being made internationally to create guidelines, namely by the EACD (Blank et al., 2019), with several professional participants who had

trained internationally in neurodiversity specialisations commenting about the Aotearoa New Zealand context stating that:

> Allegra: Teachers can't train anywhere in learning disabilities. In the sense that this is learning disabilities, let's address it by doing this, this is how we will intervene.
> Maria: Is that just in New Zealand?
> Allegra: It's pretty much just in New Zealand. New Zealand is more than 50 years behind the rest of the Western world in this area. Allegra (PP-E)

Regardless of the availability of public resourcing for Dyspraxia/DCD in countries like Canada and the UK, professional participant accounts, and several Dyspraxic participant narratives, suggest that there appears to be greater social awareness about Dyspraxia overseas than in Aotearoa New Zealand:

> The University of South Africa was fantastic, you had to be a teacher and go through a selection process and do the course and I did it part time and then you had to work in a remedial school for a period of time in a multidisciplinary team. So, it was a really good training and I'm hoping that one day they'll do that here. Anna (PP-E)

In Aotearoa New Zealand extensive knowledge of Dyspraxia is often, as suggested by professional participants in both the health and education sectors, possessed by a limited number of professionals with requisite neurodiversity expertise.

The lack of institutional knowledge about Dyspraxia/ DCD is suggested by accounts to be compounded by Dyspraxia/ DCD being a 'hidden' disability, an observation that was made by over half of the participants in this study:

> The bulk of students we work with have hidden disabilities. So, there's a few in wheelchairs, a few that might have other mobility challenges, blind people, with the cane, with the dog, so you [other people] get an idea of what that's all about. But mental health you don't see, learning difficulties you don't see, bowel conditions you don't see, you don't see it. So, um I guess that's why people don't get it [dyspraxia]. Freda (PP-E)

Findings indicate that social perceptions of Dyspraxia in Aotearoa New Zealand are derived from normative assumptions that a person with Dyspraxia is expected to be like everyone else: "You look

normal and you're expected to be normal and it's only when you start moving or doing stuff that people think: That's a bit peculiar" (Bianca D/ED). Most participants identified the lack of an informed societal response to Dyspraxia/ DCD in Aotearoa New Zealand, as contributing to a failure to identify Dyspraxia/ DCD, with even well-educated, and well-resourced, parents sometimes unaware that their child is experiencing developmental delays or difficulties:

> Until I had my son, I didn't know what it was like to have a child who is coordinated and didn't have any dyspraxia. But I didn't realise and sometimes I look back as the parent of a dyspraxic child and I have regrets, and this is why I'm grateful to you because parents need more knowledge and education about it. If I'd known many years earlier that this is what happens with dyspraxic children, I think I'd have been a better mother. Not that I'm saying that I've been a bad mother because I've certainly given up things for her". Jane (DP)

Study findings further suggest that a large percentage of people in Aotearoa New Zealand may not be identified as having Dyspraxia/ DCD by parents, teachers, or medical professionals. "I spoke to someone the other day and I told them: 'My daughter's got dyspraxia, poor child' And she asked me: 'What's that?' And I was so surprised because she was a teacher … and I was like: 'You should know what that is!'" (Jane-DP). That people with Dyspraxia continue to be under-recognized by Aotearoa New Zealand's social institutions was a common theme mentioned by many professional participants, with one parent participant observing:

> There were fact sheets everywhere about dyslexia. There was nothing about dyspraxia for us and even the guy who diagnosed you with giftedness … Most of the children at the school [names their child] went to had dyslexia or dyspraxia. And there was just so much knowledge about dyslexia but there was nothing about dyspraxia. Jane (DP)

All Dyspraxic participants described instances of both institutional enabling or disabling, such as in the account above in response to the degree of awareness possessed by a social actor about Dyspraxia/ DCD. However, several education professionals strongly asserted that most individuals in Aotearoa New Zealand may not make a distinction between people with intellectual disabilities and a learning challenge, as illustrated by the parent of a Dyspraxic son below:

> He got invited to an event at the Horncastle Arena for special needs children. And it was a Christmas Party but when we got there, James was like: 'Dad. I'm not one of these people' 'We

> shouldn't be here. This should have gone to somebody with an actual disability'. You know what I mean. And it was weird because the teacher thought: 'Oh, well he's special needs and he can go because he's been a good boy'. Martin (DP)

Ableist perceptions frame people as either able, with the appearance of being normal, or disabled, and appearing different (Calder-Dawe et al., 2020). Those whose cognitive or motor coordination differences are minimal, disrupt this social separation (Calder-Dawe et al., 2020). Social stereotypes are likely perpetuated due to the lack of contact 'normal' people have with disabled individuals and the negative portrayal of disability in the media and in cultural settings, the result being awkward social interactions that are heavily influenced by social stereotypes (Bogart & Dunn, 2019). The lack of an informed social response to Dyspraxia coupled with the invisibility of Dyspraxia to most social actors in Aotearoa New Zealand is indicated by Emily (PP-E) who observed:

> I guess there doesn't seem to be as much information out there, as say for autism or cerebral palsy or more physical … someone with paraplegia and also that brings me to another point: you can't see dyspraxia and some days, somebody with dyspraxia might not have those challenges and another day they've got them quite severely. I think that's hard, it's often an unseen … children who are in the middle to high range of autism or who are in a wheelchair, you can see that, or someone's got a broken arm or broken leg, people can see it.

Individuals may conceal their dis-ability to avoid the attribution of stigma (Kranke et al., 2013). The invisibility of Dyspraxia/ DCD may be particularly compounded if a Dyspraxic person is adept at compensating for, and/ or concealing, their difficulties. Several Dyspraxic participants described having to justify their access to additional support such as Rachel (D/ED 20-30) who stated:

> When I tell them I have a learning disability they say: 'Are you serious? ARE YOU SERIOUS?!' And I'm like: 'Yeah'. Because they'll be like: 'Why have you got extra time?' Or 'Are you going to the exam with us?' And I'm like: 'No. I have it here'. And people just don't get it. They just can't get over the fact because I'm one of the top in my class. And they're like: 'That can't happen'. I found it really, really hard, probably in Year 10, Year 11, when I was getting extra time and I just hated it and people were like: 'Why does she get extra time?'

In keeping with Calder-Dawe et. al.'s (2020, p.150) study, findings also suggest that disabled people may endure: "invasive questioning and attempts to cure and impose assistance" by the public. Another

finding was that Dyspraxic participants identified being unable to meet social stereotypes about what the disabled experiences looks like. Previous studies have found that being perceived as being "able-bodied" may require justifying that an experience constitutes a disability (Calder-Dawe et al., 2020, p.150). Several professional, and Dyspraxic, participant accounts suggested that when regarded by able bodied individuals as not being disabled, that Dyspraxic people may need to prove and explain their disabilities to incredulous others. A study by Cameron and Billington (2015) of Autistic people found that they may need to manage their identities in relation to the capabilities and challenges they experience, requiring them to minimise their difficulties in certain contexts or emphasize them in others. Further, they may need to portray their challenges as being due to a neurological disability in some situations or regard their experiences as socially or environmentally constructed in others (Cameron & Billington, 2015).

Several professional accounts suggest that the socially invisible nature of Dyspraxia/DCD is a contributing factor to a lack of public investment:

> If I have Cerebral Palsy, I get all the help in the world. There's OTs involved and there's this involved and this involved, but if it's a learning disability or dyspraxia I do not get the help that the others would get, because you can't see it. Allegra (PP-E)

The challenges associated with Dyspraxia/ DCD are often perceived as being mild relative to other neurodiverse conditions and therefore not as deserving of intervention as individuals with conditions like cerebral palsy (Blank et al., 2019). A consequence of this is a societal perception that investment in assessments or interventions for DCD may not be socially justifiable (Blank et al., 2019). Further, the ability of people with Dyspraxia to 'pass' as normal can influence whether a family discloses their child's Dyspraxia to other individuals and is indicative of the dichotomy experienced by Dyspraxic people who may simultaneously, and successfully, adopt normative behaviours while experiencing socially invisible difficulties. Ginny and Olivia (PP-E) highlight the complexity associated with disclosing a socially invisible dis/ability as:

> Olivia: Parents don't want to label their child because they know that child's going to become an adult and that child's going to have to try and find work and there's prejudice and they don't want their child labelled. So, for us to get out there and garner publicity, people don't want their child…because they're mainstream children but they have difficulties, but they can fly under the radar.

> Ginny: It's kind of like the hidden disorder, dyspraxia is. It's not so obvious.
> Olivia: And not many parents would shout from the rooftops that their children have dyspraxia. It's always hidden. So, it's actually really sad".

A frequent theme of this study and articulated by Dyspraxic participants and professionals, was the active striving by people with Dyspraxia/ DCD, and sometimes their families, to actively conceal their motor coordination difficulties from other individuals likely in response to normative social expectations.

There are benefits of being perceived as normal, not the least of which is the avoidance of possible social stigma. As Elle (D/ED 40-50) commented: "You don't get many opportunities to share about dyspraxia and you have to be careful about who you share with because people put you in boxes". Several professional, and a similar number of Dyspraxic, participants identified that Dyspraxic individuals may be able to pass as neurotypical, or pass in some social situations and not others:

> Jane: "Dyspraxia, it's almost a hidden disability.
> Bianca: I've never let people know that I have dyspraxia.
> Jane: People look at you and think you're odd but you're actually not odd, you just have a disability.
> Bianca: But then I'll tell people that I have ADHD or dyspraxia or whatever and they'll be like: 'I wouldn't have had a clue. But then if I get close to people, I'll ask: 'Do you notice it?' And they'll be like, of course!" Jane (DP), Bianca (D/ED 20-30)

Possessing a concealable invisible difficulty may result in the internalizing of social stereotypes, and the social narratives associated with their difficulty, and may cause a person to anticipate stigma and discrimination were their identity known (Quinn & Chaudoir, 2015). Actual stigma then does not have to be experienced by individuals with invisible difficulties for them to experience psychological distress due to anticipation of stigma and discrimination (Earnshaw & Quinn, 2012). Autism research into neurotypical responses to labels, and behaviours, has shown that a diagnosis, communicated to significant individuals in a person's life reduces stigma (Brosnan and Mills. 2016), which is also identified as being significant for people with Dyspraxia by a quarter of professional participants:

> I think it's extremely important that we have those labels because those labels are the correct labels. If a child does not have the correct label, they get the wrong label. So, the teacher may

> say, or the mates may say: Oh, he's a lazy boy, he doesn't want to do writing or he's a dumb boy he can't do writing or that kind of thing and that's the incorrect and damaging label. The correct label, handled in the correct way, is very liberating for them (Allegra PP-E).

Similarly, participants may also be uncertain about whether the challenges they experience are part of their Dyspraxia or due to another reason which is further suggestive of Dyspraxia as being an emergent social process.

In conclusion, the lack of social validation and social recognition of Dyspraxia/ DCD may be a function of its ongoing status as an emergent social phenomenon. Results suggest that the lack of recognition of Dyspraxia may be due to Dyspraxia being a less visible embodied experience to influential individuals, relative to more visible social difficulties like deafness or AD(H)D. Analysis of the results reveals that the visible and/ or invisible nature of the Dyspraxia experience, takes place within a social environment based on a socially ubiquitous and unexamined ableist ontology with repercussions for the degree of social engagement and the provision of support for the Dyspraxia population. This section studied the role of visibility on the social response to Dyspraxia, now I will move on to discuss how neurodivergence impacts on the lived experiences of Dyspraxic participants specifically in the social world.

5.2.1 Social interactions and Dyspraxia/ DCD

This section studies how the experience of neurodivergence impacts the experience of socialization. Social capabilities are regarded as being the result of social interactions and the sharing of capabilities from one person to another (Trani et al., 2011) Many professional participants specializing in neurodiversity and Dyspraxia, in both medical and education fields, drew attention to the variability within the Dyspraxia population with regards to being able to successfully access capabilities, such as the ability to socialize and achieve a degree of wellbeing:

> For some people, it looks hard and painful and lonely and for other people there is amazing charisma (laughs). I definitely don't see a one size fits all for that [social skills]. But I guess if you need more time for processing in a social situation that's not always a given, extra time if you want to process your thoughts and information that's coming to you and some people are better at finding strategies and finding ways around that. And some people have gifts in humour that allow them to mask that or be socially at ease a lot more and some people might not have those

> little masks, which all of us have, but which might enable them to get by and buy you some processing time when you need it. Merrin (PP-M)

Study results suggest that the social experience of Dyspraxia is interconnected with a myriad of social factors and is socially complex, contributing to the attainment of wellbeing, or not, of both the individual and their family, as suggested by the account below:

> We were actually talking earlier because Ginny's daughter is a bit of a loner at school and one of Olivia's kids was the same and William was the same. And Sarah said to me: "Yeah but William is OK" and I said yes. So, it's my issue and it's the same with Ginny, you know, you want them to have friends. You want them to be constantly playing with other people, you want them to fit into that mold. And then you realise that it's actually OK. If the child is happy, they don't actually have to fit into that, so I think it's more that societal, but I think things are getting better and I think there are more people saying: "Actually I don't fit into this box and I'm really happy about it. Being a Unicorn". Liz (DP/ PP-E)

Another key result was that the experience of difference represented by Dyspraxia, while frequently negatively portrayed in relation to social expectations, was sometimes supported by social conditions, which is suggestive of what Sen (1999) describes as variations in the social environment. Several study participants with Dyspraxia described successful social interactions and social relationships with peers that are supportive and devoid of stigma or social exclusion but rather are typified by social acceptance of personal heterogeneities (Sen, 1999) or the social characteristics that may differentiate Dyspraxic social identities. Bianca (D/ED 20-30) described the value of social acceptance as:

> "You [the participant's friends] must just understand me for me and just like be treating me like normal. We all must be so used to my ADHD or dyspraxia or whatever", that no one points it out, no one notices it. It's just something to laugh at and it's really light.' And I have really supportive friends actually.

Bianca's quote is suggestive of societal changes that have reframed dis/ability from being perceived as a pathology to greater acceptance of dis/ability as an experience of diversity. Sen (1999) refers to social rules to describe what is acceptable and what is not in a given social environment. For example, social rules will exist within each family in terms of what is considered acceptable social behaviour and what is unacceptable. The social rule described by Henry (D/ED 20-30) in the account below is

that socialising with older people is not deemed appropriate in Henry's family. His account is an example of a familial social rule that does not support his socialising preferences:

> It's quite strange, I'm quite social with older people like my Mum hates it, so I don't socialise much because I do struggle to socialise with some people or I should say my peers, my age group… After this I've got a board meeting to go to for a rest home that I'm a part of and it's these opportunities that I thrive in but when it comes down to socialising and going out with my mates, I can't do it, I'm too anxious and I think that's part of my disorder. I do think that dyspraxia does limit me socialising with peers.

The quote above illustrates the importance of having a sense of acceptance. Previous studies about hidden disabilities have concluded that an inability to access peers who validate a person's identity, may negate the social comparison necessary to create a healthy identity (Festinger, 1954). According to Payne and Ward (2020), dis-abled people may be unable to locate individuals who are similar to themselves, thereby compounding their sense of difference. Analysis of the findings indicates, in keeping with Brittain et al. (2020), that the lived experiences of dis/abled people and their experiences of socialization are varied and not homogenous. For example, many people with Dyspraxia are very successful as indicated in the quote below:

> There are a lot of doctors with dyspraxia, but their social interactions are very nice and very fluid, and they do absolutely fine excepting that they might not have participated in team sports, or they might have avoided certain things that require motor skill when they were growing up. Like I've seen adults who've been diagnosed with dyspraxia who haven't got their driver's license, that kind of thing and just decide that it's not worth it. Cameron (PP-M)

Some Dyspraxic participants suggested possessing the added burden of having to mask how they move and interact socially, engaging in behaviours that are not normal for them to avoid social alienation. Penny (D/ED 20-30) describes how she attempted to adjust her behaviour to adopt behaviours she deemed normal:

> At the moment I am finding out who as I am as person, because I haven't done that yet, I spent so much of my life trying to fit in while I shouldn't've and I've got to that stage where I've learnt that…And then my sister says I'm too mature but then I'm immature to my peers because with dyspraxic I know that some of the things I might say a 17 or 18 year old might find it funny but someone my age could like, not. So, I'm quite wary of what I say because what I find funny, 23-

> year-olds could be like, well why are you saying that for that's a bit… so I've learnt from past mistakes".

The majority of Dyspraxic participant discourses exhibit an awareness of having socializing difficulties, relative to the perceived abilities of other people:

> But my sister, I make her nervous poor thing because she's quite social and has friends and she's really outgoing. We're completely different, she's got a boyfriend, I've never had a boyfriend, never been kissed…I mean I'm kind of awkward, what happens if I can't kiss properly? You know…when people talk about their boyfriends, I'm like I have no experience of this. Penny (D/ED 20-30)

The following quote by Andrew (D/MD 20-30) described the developing of a social strategy that is not necessarily ideal but a strategy nevertheless:

> So essentially, primary, and high school, even Uni today, there have been times when you do feel different… I mean I've always been the person that has needed to cling on to social groups because I'm unable to, or I was unable to, form my own social groups, form good social connections on a personal and group level. So, I would be like 'hello, can I tag along with you' I mean even today (laughs). It's very, very difficult. Andrew (D/MD 20-30)

How participants with Dyspraxia perceived their difficulties with socializing and social acceptance varied, with several articulating fears of social rejection. According to Sen (1999) environmental diversities, such as being overwhelmed in a loud social environment, can result in an inability to access capabilities, for example social inclusion, in social settings: "I find it extremely awkward, you walk into a bar and there's heaps of people, there's lots of yelling and all that kind of stuff, I just can't, I find it very awkward, so that's when I walk around trying not to be noticed" Henry (D/ED 20-30). Finding new social environments that enable social connection, for a person with Dyspraxia who may encounter stigma in other settings, may offer opportunities for freedom from stigma. A significant theme in the accounts of many participants was how sport participation was an important means of attaining social wellbeing in Aotearoa New Zealand, a focus that may limit the social inclusion of Dyspraxic people, reducing their ability to locate social settings that complement their interests and socializing preferences. Social skills may improve in response to social engagement in adolescence and adulthood being less dependent on the degree of motor dexterity possessed and any consequent sport

participation (Missiuna et al., 2008). Simon (PP-E/D/ED 40-50) described his experience of successful socialisation in terms of:

> If I can find a bunch of people who like to do something then I'm so much better as a person. And for me that's interesting because that's hotrod cars, trains and things like that. And nobody in those groups have got brilliant social skills".

Socialising challenges due to a perception of difference in relation to their similarly aged peers was a common theme in most Dyspraxic participant accounts, as illustrated by Andrew (D/ED 20-30) below:

> I think the one that stands out is the whole difficulty maintaining friendships. Not so much maintaining friendships but actually just meeting people 'cos I mean I'm always tried clinging on to groups that are already established and even today I'll walk around the undercroft and everybody's in these groups of friends and I'm like where are mine (laughs).

Dyspraxic participants described social exclusion being imposed on them by other individuals, or due to self-stigma and an inadequate self-concept, both of which may preclude social inclusion efforts. Claire (D/MD 50-60) describes the complexity that may be inherent in building social connections for some people with Dyspraxia when she said:

> Maria - What about friendships?
> Claire: Really, really bad at it. I'm really scared of contacting people; I don't know if that is dyspraxia but I am. I really don't like using telephones. So basically, my number of friendships was small in the first place and has dwindled to zero and if I like people, I get more scared of having anything to do with them. So, I'm almost worse with people I actually like, much worse. So funnily enough, some of my better relationships I've had with people who I don't have a lot of respect for, just because I really don't care.

The above quote highlights that Dyspraxia is an emergent social phenomenon which even those with Dyspraxia struggle to understand. Research into children with DCD has found that DCD is a socially isolating experience (Smyth & Anderson, 2000) and one that may be associated with social avoidance behaviours (Forde & Smyth, 2021). Ginny (PP-E) described how the experience of Dyspraxia for some people may be one of:

> They [people with dyspraxia] need a lot of support to be able to function in society. But also, a lot of the adults are a little bit quirky, and they don't understand the social rules so they find it really hard to make connections and to fit in and connection's such a big thing for everybody and, in my opinion, that's a big reason for depression, anxiety, mental health problems - the lack of connection that people have with themselves and others. So, I do see this as being a lot more challenging for people with dyspraxia.

Autistic people have been found to burnout from the pressure of constant attempts to pass as normal (Pearson & Rose, 2021). Similarly, people with Dyspraxia may also be at risk of burnout in response to the perceived need to pass as normal.

The need to belong, and be accepted, is an important aspect of social life and an area where people with Dyspraxia may experience difficulties with one professional observing: "The stats will show that long term social isolation is really harmful for our health and our mental wellbeing and actually shortens our length of life" (Anna PP-M+E). Penny (D/ED 20-30) illustrates her awareness of her own social vulnerability in relation to Dyspraxia and the experience of social exclusion when she said:

> New Zealand's got a lot of homeless, I mean I could have been one of those people who's gone off the rails if I wanted to, you know, I'm a loner, you know you hear on the news that serial killers and murderers are loners and I don't want people to say I was a loner…'cos I'm a loner and it's my choice because I'm weird…I'm a loner and I'm like no, I choose… you know I could get in contact with people but I got sick of being that person, I got over being that person that wanted to meet up all the time. I don't want to show how desperate I am…like one good friend, I did that, and I've Facebooked her three times and now it just looks desperate and I'm like no, I'm going to wait for her to get in contact with me 'cos I'm not going to run after you.

Similarly, symbolic stigma represented through cultural discourses and images, can have negative impacts on the moral-emotional life world in response to interactions with stigmatising social values (Yang et al., 2007), with a number of participants highlighting the negative implications of social media. Study results suggest that psycho-emotional difficulties may be, at least in part, socially constructed in response to interactions between people with Dyspraxia and their social worlds. Most Dyspraxic participant narratives describe experiences of social rejection and isolation, as well as insecurity about their ability to successfully make social connections.

Having explored interpersonal social interactions, the following section focuses specifically on the role of sport and physical ability in the Aotearoa New Zealand context as regards the development of social connections in the lives of Dyspraxic participants.

5.2.2 The effect of ability on the socialization process in Aotearoa New Zealand

This section looks at the unique role of sport in the socialization process of Dyspraxic participants. Predominantly professionals but also a few participants with Dyspraxia identified compulsory participation in sports as an aspect of Aotearoa New Zealand schooling that may pose difficulties for people with Dyspraxia. Sport plays a dominant role in Aotearoa New Zealand society and is an important sphere of social life (Pringle, 2004). Social participation has been found to be impaired as a result of DCD through two pathways, the first being an inability to engage in sporting activities, with the second being difficulty with social comprehension and executive functioning (Leonard, 2016). Another observation recounted by several professionals was the possibility of people with Dyspraxia withdrawing from socially promoted forms of social connection that may disadvantage them:

> Socially it is hard, especially for young boys, particularly with sports. I've got two boys and sports are such an important part of being a male. I know that's quite stereotypical and so if you don't fit into that then, and this is stereotypical as well, I see a lot of gaming happening. So, a lot of my guys will end up on screens and they avoid anything physical because it's actually, it's hard for them. But there's something for everyone, I don't care how dyspraxic you are, there's something there that you can enjoy". Anna (PP-E)

Some participants described their experience of school sport as being a mechanism for social exclusion with Elle (D/ SD 40-50) commenting: "you'd never get picked for teams". Effective provision of physical education, and that works positively for everyone, positively correlates with an increase in social ability for both students with neurodiverse conditions, for example, and their neurotypical peers (Grenier et al., 2014). Analysis of study findings suggests that the preoccupation in Aotearoa New Zealand, relative to some other countries, with sport has potentially significant: "It's hard to find those groups because what we're [people with dyspraxia] not good at is team sports and everybody in New Zealand goes through team sports" (Simon PP-E/D/ED 40-50). Many participant accounts indicate that physical ability can have a huge impact on whether social bonds are formed, with one participant

observing: “they [people with dyspraxia] do tend not to make friends with the sporty kids generally” (Cameron PP-M).

Childhood DCD studies have shown that social exclusion and reduced self-esteem are mostly attributed to challenges with participating in sport (Jarus et al., 2011). One professional participant described the experience of Dyspraxia in terms of social interactions in terms of:

> From what I’ve seen it’s harder for children to make friends because I think people don’t understand what dyspraxia is and they just think it’s a physical thing that you’re not able to do something but as you know yourself it’s a whole learning process and it affects everything. Children get stigmatised a bit and those psychosocial factors of the self-esteem, confidence, and all that, that affects social situations, so yeah, they probably would be a bit more isolated. They might not get chosen for the top team, all those kinds of things, society’s pressures on sport, especially in New Zealand. The other creative arts like drama, I guess it would be good if there was equal balance put on all of them because who says that sports are better than arts or drama. Emily (PP-E)

In conclusion, Dyspraxic participants forming positive social relationships depended on the degree to which they were socially accepted by their peers and the degree to which they had been able to develop social skills. The majority of Dyspraxic participants frequently identified their socializing preferences as being with individuals younger or older than themselves but frequently not with their similarly aged peers. An inability to build social relationships with similarly aged peers was a common theme that frequently occurred in conjunction with an increased awareness of difference relative to other people and a sense of social vulnerability. Socialising difficulties were frequently identified through comparison of the self with neurotypical individuals to whom Dyspraxic participants attributed a ‘normal’ social status. Analysis of the findings suggested that social inclusion in adulthood was found to be an ongoing difficulty with Dyspraxic participants frequently attributing a devalued social status to themselves relative to other people and often identifying social situations as stress inducing. The participation in sport in Aotearoa New Zealand education contexts in childhood and adolescence was found to present particularly significant difficulties for most Dyspraxic participants in terms of socialization and led to exclusion imposed by individuals or the decision to voluntarily exclude themselves from sporting contexts.

Preceding sections have looked at the role of social inclusion on the lived experience of Dyspraxia. The next section will present findings pertaining to the role of the education sector on the life outcomes of people with Dyspraxia.

5.3 The experience of Dyspraxia in social context

The role of Aotearoa New Zealand institutions on the life outcomes of Dyspraxic participants will be explored in this section, specifically the institution of education (with the health sector having been previously discussed in Chapter 3). There is a question of how, and to what degree, the health and education sectors should ameliorate any adverse social effects associated with Dyspraxia. An analysis of the role and responsibility of social institutions, for example government agencies (Clark, 2014), toward Dyspraxia populations has been omitted from DCD literature which typically has focused on the conceptualisation of Dyspraxia as a set of motor coordination difficulties along biomedical lines. Identification of systemically created social barriers that do not have their basis in an individual person's biology and which may be best addressed through systemic changes (Clark, 2014) may be obfuscated by the dominance of such biomedical social narratives. Further, conceptualising people as needing to have their impairments ameliorated, treated or cured minimizes, or even makes invisible, the positive aspects that stem from being (Guevara, 2021) Dyspraxic in relation to and independently of, their Dyspraxia:

> Society, in agreeing to assign medical meaning to disability, colludes to keep the issue within the purview of the medical establishment, to keep it a personal matter and "treat" the condition and the person with the condition rather than "treating" the social processes and policies that constrict disabled people's lives (Linton, 1998, p.11)

Adhering to the individual-medical model may mean that the medical diagnosis and not the needs of the individual person are prioritized (Haegele & Hodge, 2016). Policy measures then, will seek to ameliorate restricted activities, rather than targeting social barriers to participation (Trani et al., 2011).

The social and financial burden that Aotearoa New Zealand institutions may need to carry, such as the social justice sector, to support adults with Dyspraxia/ DCD and who have not received the necessary supports to ensure their wellbeing and life outcomes in childhood and adolescence, may be

considerable. Ginny (PP-E) describes the risks associated with the lived experiences of people with Dyspraxia in terms of:

> There's kids slipping through the gaps. Like anything, they need more money pumped into it [the education sector], more understanding about what's going on and these kids grow into adults and depending on how much support they've had as a child will depend on whether they need the [criminal justice] system later. So, if they've got a good wrap around service and they've been well supported then chances are they won't need to be in the system later on.

A high percentage of prison inmates have been identified as having learning difficulties with failure in the education sector associated with later difficulties in the health and justice sectors (Einat & Einat, 2008). Several professional participants observed that a lack of effective support, particularly in education institutions, may result in a disproportionate number of adults and young people with Dyspraxia, and likely other neurodiverse conditions, needing to access Aotearoa New Zealand's criminal justice system, with the following professional working in the not-for-profit space observing:

> We do get lots of calls from the other extreme, in corrections and prison where there's people who have ended up there through difficulty with what's going on with them with the dyspraxia. Ginny (PP-E)

The role of DCD on daily activities and education outcomes, and "social participation, physical health, and mental health concerns, combined with the high prevalence rate [of DCD], indicate that the social and economic burden is considerable" (Blank et al., 2019 p.252). It is important to consider whether government ministries and agencies are justified in leaving families to financially, and practically, support children with Dyspraxia/ DCD and what role Aotearoa New Zealand institutions have in the provision of adequate resourcing, and the adjustment of social arrangements.

According to Linton (1998), the result of framing a dis/ability as a biomedical issue and not acknowledging its social and politically situated nature, is that "adversity is not depicted as [a] lack of opportunity, discrimination, institutionalisation and ostracism: it is the personal burden of their own body". A psychiatrist illustrated in the following quote how greater social awareness of Dyspraxia may be achieved: "I think for professionals, I think it's just about getting people to be more aware, getting GPs to be more aware, people at schools to be more aware and I think what would be good would be a tiered approach to intervention" (Cameron PP-M). A tiered approach would include the initial

identification of Dyspraxia within institutional settings followed by the provision of an ever-increasing degree of support in response to an individual's needs. Depicting Dyspraxia as a pathology of the individual may inhibit a social response that might otherwise prioritise the removal of social barriers were Dyspraxia conceptualised as an aspect of human diversity and not a deviance.

Extensive waiting lists, poor social understandings about DCD and limited-service availability have been identified by parents as being social barriers to accessing support for their children in Aotearoa New Zealand (Hitchcock et al., 2020) Most professional narratives express concerns about the interactions people with Dyspraxia may have with Aotearoa New Zealand institutions and the resultant adverse repercussions for QoL: "We signed up to the United Nations Rights of the Child and we ain't doing it and we need to because every child has the right to reach their full potential with whatever supports they need". (Allegra PP-E). Houston (2001) states that the ability to promote capabilities that enable individuals cannot be achieved without understanding and addressing the social arrangements that either inhibit or allow people to achieve fulfilling lives. While the government ministries of the MoE and the MoH are, arguably, responsible for publicly funded service provision in childhood for Dyspraxia, there appears to be a lack of "nationally endorsed health guidelines and agreed pathways to coordinate health and education services to ...[meet] the needs of children and the families living in Aotearoa New Zealand" (Hitchcock et al., 2020, p. 23)

A key finding, and frequently articulated theme, was the significant role of the Aotearoa New Zealand education sector on the life outcomes of all Dyspraxic participants. Starr and Janah (2016) found that, despite it being compulsory for children and adolescents to attend Aotearoa New Zealand schools, current legislation is inadequate at providing protective procedures to ensure appropriate supports are delivered by schools or government institutions: "but parents of children need to know that the needs of children are being met, 100 percent because [parents] entrust their children to the MoE's care for 6 hours a day, five days a week for as many as 12 years" (Kristen PP-E). Aspects of education delivery that need improving have been identified by primary support networks as including a need for:

> more information about what support is available, and assistance with accessing the support. [The recognition that] schools are inconsistent and variable in their approach to supporting students with learning support needs. [Further] the capability and capacity of teachers, teacher aides, and other specialist support providers varies between schools (New Zealand Parliament: Report of the Education and Science Committee, 2016, p. 5).

By contrast, the Ministry of Education (2016) states that the necessary supports for neurodiverse conditions are already available in Aotearoa New Zealand schools, claiming that:

> significant additional funding and resources are available to schools, teachers, students, and parents to support students with dyslexia, dyspraxia, and ASD. Existing policy settings support all learners to achieve educational success, with a range of support available for students with additional support needs…Adapting the school curriculum for the needs of individual students or groups of students is a core capability that all teachers should have (p. 40).

While a small number of Dyspraxic participants identified clinical interventions such as occupational therapy as being helpful, most Dyspraxic participants had not accessed experts knowledgeable in DCD/ Dyspraxia: "A good teacher is a good year, they [clients with Dyspraxia] all said that. When we had a good teacher, it was easy when we had a teacher who didn't get us it was really hard. And our parents being there for us". Sarah (PP-M). Results suggest that of far more significance than therapy was the importance of having teachers who supported their neurodiverse learning needs. According to Alesch and Nayar (2021) teachers are essential in helping a child achieve a feeling of belonging and acceptance in the classroom. That the provision of the support that is available is inconsistent between schools was suggested by Mark (PP-E) when he stated: "My last school the RTLB [Resource Teacher of Learning and Behaviour] was absolutely, diabolically terrible, considering the level of experience they, in theory, have… they'd finally come up with a plan in term four! … Apparently the RTLB's really good for this school… and that's fantastic".

It has been claimed that education sector arrangements in Aotearoa New Zealand prioritize the augmenting of current education practices to accommodate neurodivergent learners (MacArthur, 2009). Inclusive education has been equated with a form of classroom intervention, the purpose of which is to assimilate students in relation to established normative expectations (Baglieri et al., 2011). Consequently, the institutional response presumes that it is the individual who needs to be adjusted to education structures, and not that education structures need to be reshaped to suit the needs of the individual (Reindal, 2008). One educator described the unique learning needs that may be associated with Dyspraxia as:

> In the first couple of years of school, especially kids with dyspraxia, need to be playing, experiencing. … Moving into their cognitive brain too early is actually detrimental to them. So that worries me about school in the younger years and then they also develop feelings that

> they're not OK and their self-esteem starts getting affected. At this really early age when their brain actually can't access that information just yet. (Ginny PP-E)

Many professional participants identified the importance of a diagnosis/ assessment (as discussed in chapter 3), in state education institutions, as being essential to accessing the supports that are available in Aotearoa New Zealand education settings, which is illustrated by Allegra (PP-E) when she observed:

> Maria: How does a diagnosis of dyspraxia help a child in the classroom?
> Allegra: You won't get, for example, for NCEA exams a reader or a writer or use of a computer if you do not have the diagnosis. So, you have to have the diagnosis. Teachers do not react, and funding is not available [for NCEA] in schools unless there's a diagnosis.

The MoE (2016) states that:

> ...a critical feature of education in Aotearoa New Zealand is that it is not diagnosis dependent. Apart from the questionable value of a diagnosis in an education context, the cost of diagnoses can be high and a financial burden for parents when they are not funded. This can impact disproportionately on those with the fewest resources... Some parents may choose to pay for a diagnosis or private assessment but the Ministry does not believe parents should have to fund assessments and interventions for students with additional learning needs, because of the issues around cost and the inequity that this creates (p. 24).

Applying Sen's (1999) CA to Dyspraxia, what is needed is to ensure that Dyspraxic people have equal access to social conditions that promote capabilities like adequate housing and nutrition, education, and employment opportunities, to ensure that they can access a greater array of possible choices. Some ethnic or different socio-economic groups will be more disadvantaged than others by the lived experience of Dyspraxia. Models of development based on capitalism frequently result in adverse implications that may disproportionately affect marginalised populations, such as Pasifika and Maori, due to unequal social arrangements (Hyslop, 2021).

Submitters to the Inquiry into the identification and support for students with the significant challenges of dyslexia, dyspraxia, and autism spectrum disorders in primary and secondary schools (New Zealand Parliament: Report of the Education and Science Committee, 2016) have disagreed with the MoE's

position, claiming that children's difficulties are not taken seriously until a diagnosis had been privately obtained. Some submitters identified being denied RTLB support and SACS until a diagnosis/ assessment was obtained (Ministry of Education, 2016).

A common theme was that the state education sector is not engaging with neurodiverse conceptualisations, as suggested by Allegra (PP-E) when she commented:

> They [the Ministry of Education often have blinkers on and they just, "This is how we do it". The brain is such a complex organism and there's such a lot of new research being published and going on at the moment, well over the last 12 years, and it's exploding. If you do not keep up with what's going on and see that there are also other ways to think about things, then you're in trouble.

To qualify for SACs at Aotearoa New Zealand state schools and additional learning supports at state tertiary institutions, participants repeatedly stated that a valid educational psychology assessment must be obtained: "It has to be a registered psychology assessment that we like to be no more than three years old" David (PP-E). Additionally, high decile schools have been found to have higher numbers of students with an assessment because higher decile schools can pay for assessment services (Ministry of Education, 2016). Equity issues have been raised in relation to the degree of family input required to access support and the implications for "cultural and socio-economic groups" who may not possess the same ability to advocate as other social groups (New Zealand Parliament: Report of the Education and Science Committee, 2016, p. 23). Liz's (PP-E/DP) quote below describes the role of the need to access privately funded support to address the needs of people with Dyspraxia when she said:

> There's very little money for resourcing the children with dyspraxia in schools so parents are paying for private OTs, private tutors, speech, and language [therapists], that sort of thing… And I do worry about the kids whose families aren't in a position to fund those extra things for them. So, if they're disruptive in the classroom they get extra funding but on the whole they just don't.

Professional and Dyspraxic participant narratives suggest, in keeping with Sen (1999), that the impairment of Dyspraxia may engender the need for a different degree of financial resources than for a person without an impairment, to achieve the same level of social participation and access to capabilities. As one education professional noted: "There are a lot of people who go: "I've got a

diagnosis of dyspraxia now what help is available?" and there's nothing. So, I'm often saying to people: "getting a [medical] diagnosis isn't going to get you any [state funded] help at school unless there's other more challenging behaviours on top of it". (Ginny PP-E). Findings from this study indicate that there appears to be a lack of incentive for the government and social institutions to engage meaningfully with the needs of the Dyspraxia minority, which is suggested by Cameron (PP-M) when he said:

> The hope of that [Select Inquiry] was that there would be teacher support, learning assistance for children with dyspraxia in the schools because they miss out. It's only the bottom … it's either 1% or 3%, who get funding. You have to have a lot of needs to get that funding, the OARS funding, the Ongoing and Resource Funding and cos children with dyspraxia don't have the cognitive difficulty. They're not as bad as that but I sometimes get annoyed with the funding because it's the children kind of in the middle who miss out on the funding that, maybe [the kids] have that really good potential.

Contrary to claims by the MoE that the resourcing exists for all neurodivergent learners, some professional participants commented that the degree of need must be pronounced, and socially visible (see section 5.2.1), to access limited state funded support. Further, one professional in the education sector commented: "I think high schools are failing when it comes to [assistive] technology… If it were introduced in high school, then that's going to give them the skills that will equip them better for tertiary" (Annabel PP-E).

Most Dyspraxic participants who had accessed the state sector education, suggested that they were frequently unable to effectively achieve the capability of education because they "lack the ability or knowledge" (Hart, 2019, p.591). Consequently, their experience of education is vastly different relative to neurotypical individuals (Hart, 2019). Simon (PP-M+E/D/D-E 40-50) described the interaction between current education practices and Dyspraxia in terms of:

> They're [Dyspraxic students] not at the bottom, they're not in the middle, they're not at the top end. They've got things that they're brilliant at, great at and then some often quite simple things that they can't get. And we've got an educational system that tends to want to put you at the beginning, middle or end of that and we don't necessarily fit.

To conclude, the significance of the education sector on the life outcomes of Dyspraxic participants represents a predominant theme in participant accounts. The implications for the Dyspraxia lived experience and social equality in response to current institutional arrangements will be studied in the next section.

5.3.1 Dyspraxia and social equality

Whether current institutional arrangements in Aotearoa New Zealand are equitable, will be explored in this section. A successful social response, one that would enable access to the capabilities that Dyspraxic people need is dependent on the ability of social institutions to provide the necessary opportunities. Most participant discourses suggest that current social structures may prevent a child from accessing help with several participants stating that institutions in Aotearoa New Zealand should err on the side of doing too much rather than too little to ensure that children get the early intervention they need: "If there's early intervention and there's nothing wrong with the kid well at least you'll be able to pick them up" (Penny D/ED). Study results identified current social arrangements as being perceived to be at least partly responsible for creating social barriers to QoL. One professional in the health sector illustrated this when they noted that a small amount of institutional support for people with Dyspraxia may lead to huge improvements in the life outcomes of people with Dyspraxia:

> I think it's an appalling waste of human potential, not to provide the relatively moderate supports that people who are functioning reasonably well, and I'm talking little people up to adults who can function with strategies that will help them participate, to learn and be part of communities. You know the communities they live in. Why do they fall between the cracks? I mean it's a no brainer. There are a lot of people, and dyspraxia's just one of them, but with a relatively small amount of support could go on to do most of the things they want to do. And what we do here in New Zealand is that we fund from the most severe to the least severe. And the money runs out long before it gets to the children who could profit most from a small amount of support and to me that's just crazy. Now I'm not saying you shouldn't support the child who's got severe cerebral palsy, who needs round the clock 24 hour care, is in a wheelchair etc., I mean clearly that person needs support but I get very cross about the failure to recognise just how much could be improved for the lives of people with dyspraxia by: putting money into improving the training of childhood teachers; providing supports [for groups] like the [names not-for-profit], funding it, giving them an opportunity to do professional development so they haven't got to go

> cap in hand to get Trust and Grant money. The government should be investing in helping every child realise their full potential, whatever that takes. Belinda (PP-E+M)

Despite most professional and participant accounts suggesting that individuals in Aotearoa New Zealand have limited knowledge of Dyspraxia/DCD the identification of Dyspraxia/DCD, if not done by a child's parent, is left to the discretion of teachers in Aotearoa New Zealand schools. The role of the school in identifying Dyspraxia is described by Laura (PP-E) when she stated:

> Unless a child arrives at the school with a known issue or a known disability or a known… [difficulty] and the parent is aware of it and has gone and done some work before they arrive at the school and comes with material saying we've had this diagnosed, it's up to the teacher to come and say: 'I'm a little concerned about …' and then we start the process of what the concern might be.

Study findings further indicate that there may be many children and adults who need institutional support to succeed and which they are not receiving: "I think it's very hard for them [people with dyspraxia] out in the world. I think very few of them ever have their potential met" (Allegra PP). The prioritizing of behaviour as a signifier that state funded support may be required, may undermine access to publicly funded support for those who may not "present with [the] levels of challenge in school sufficient to trigger the usual supports but who [may still] have significant problems accessing the curriculum" (Olivia PP-E), as suggested by the following account:

> People make judgments so easily. I don't know what it is about humans but we judge and [what is needed is] just helping people get the understanding. And I think on the whole teachers are pretty good if they are given the information and the help they need, not all, but on the whole most of them are. That's why they went into that profession but there are some pretty challenging kids out there. There's a little kid who's finding it hard to handwrite and is a little bit challenging in the playground [and] is not going to stand out as much as somebody who's full on, throwing chairs". Anna (PP-E).

Some professional participants in the education sector associated Dyspraxia with diminished QoL in adulthood in response to adverse experiences in Aotearoa New Zealand education institutions:

> I think a lot of kids come out of high school still having not had that mentoring, particularly the kids who have got some issues around learning. Because they're not engaged, they're not excited about the next stage of their life. Because they haven't been engaged in high school. And then there doesn't kind of seem to be… once you've left high school well, that's it, you're an adult, you're on your own and that's it. Liz (PP-E/DP)

A study by Chapman and Carel (2022) found that the causes of diminished wellbeing in Autistic populations are the disabling social barriers and the attribution of social stigma (Chapman & Carel, 2022). Further, Autism research that identified that social assumptions that assume Autism and wellbeing are incongruent are a form of prejudice (Chapman & Carel, 2022).

Successful inclusion is the ability of an education environment to educate neurodivergent people with their neurotypical peers and to provide the support necessary for all students to succeed (Block & Obrusnikova, 2007). Students with SpLDs may be unrecognized in the classroom, not accessing support and resulting in students attempting to compensate with "limited ways of coping with their learning difference in a classroom context" (Ministry of Education, 2016, p. 28) A significant difference between state and private educators appears to be that private schools educate Dyspraxic students how to learn, providing effective learning strategies through target specialist support, which is described by Edward (D/ED 20-30) when he said:

> I got special support through their literacy department and that involved helping with my writing and maths… They did certainly help, and I did learn lots of skills that I probably wouldn't have got in the public system. That's one of the reasons that my parents invested a lot of money in the private sort of stuff, a lot of money went into that. At [private primary school] they taught me how to do things and at [private high school] they helped me develop the skills that I lacked.

Findings further suggest that the motivation of parent participants to access private tutors and/ or private schools, was to address limitations of education provision identified in the state education sector, which is described in the accounts of three participants below:

> Jane: There's no resources. And I found too that the teachers [in the public sector] aren't trained. But the teachers weren't trained in anything outside the square like dyspraxia. I don't think your teacher even knew what dyspraxia was [this said to her son who is between about 12]. In this day and age, that's not good enough

> Bianca: And she wasn't an old teacher, she was a young teacher.
> Jane: She was 32. Well, all the teacher's at [Name of private school], they're all trained about everything, and they could see a child with dyslexia or dyspraxia and that teacher would 'click' onto it straight away and they could see the difficulties in a particular area.
> Eric: It was more like them saying: 'There's an issue here. What do we think the issue is?' And they've got the tools to work it out.
> Jane: But when we put him into [Name of public school] it was just a disaster, and they just weren't interested. I don't think they knew [about Dyspraxia]. Jane (DP)/ Eric (DP)/ Bianca (D/ED 20-30)

The private education sector was further identified by several participants as having the capacity to successfully address the Dyspraxia lived experience in relation to education: "We took Bianca out of the state system in Year 4 or 5, and we put her into [names private school] and that just transformed her. You wouldn't be where you are today but for that school" (Jane DP). Another common theme in Dyspraxic, and professional, participant narratives was that of the positive life outcomes and success associated with social practices aligned to universal design, and its ability to effectively support Dyspraxic participants, particularly in the state tertiary sector:

> So universal design is where you design your programme and courses and your teaching style so that it appeals to all students, so you're an inclusive teacher… and lecturers have their doc cams. So, their slides are sitting on the laptop and it comes up on the big screen. So that helps people who have vision impairments, we've got echo recordings so students who have specific learning difficulties can go back and listen to the recordings again. Universal design appeals to all students. All students benefit from different ways of teaching… It's a basic thing to do for all students (Freda PP- E)

Results of this study suggested that UD, in the state tertiary sector, represented a structural arrangement that benefited Dyspraxic participants, in contrast to primary and secondary education sector arrangements. This finding implies that the key theme identified by all Dyspraxic participants, to varying degrees, of the state education sector representing a significant barrier to the accessing of capabilities.

UD has been identified as being a means to promote social inclusion and equality (Iwarsson & Stahl, 2003), involving careful consideration of what constitutes inclusion and not merely augmenting current

mainstream practices (Berghs et al., 2016) to accommodate disabled individuals. The purpose of UD is inclusion and the reduction of exposure to inequalities (Berghs et al., 2016). Kattari (2018) recommended the adoption of UD, enabling dis/abled people to avoid the discrimination sometimes associated with 'out[ing]' themselves. The promise of meeting the individual needs of minority student populations such as those with neurodiversity who struggle to succeed in mainstream education and access the curriculum, lends relevance to the ability of UD to support all students rather than some students, (Rose & Strangman, 2007) such as the neurotypical population. UD has the potential to contribute to a: "re-imagining [of] a different schooling system, in terms of policy, curricula and pedagogy" and that, further, "while the principled framework for educational capability equality should inform and underpin policy design, curricula and pedagogies need to be reconsidered in the light of children's wellbeing and agency too" (Terzi, 2014, p.491).

Further individuals with expertise in neurodiversity, were suggested by results to mitigate exposure to social stigma, which is illustrated by Zoe (PP-E) when she commented:

> I love children finally seeing that they can achieve, and the lightbulb goes on and they go: 'I can do it!' And they start to believe in themselves and they're gutsy and courageous to do it. I love that. I feel very proud and privileged to be in this position, to help people who feel like they're failing, and they can't explain it and for me to be able to point things out and for them to trust me enough and for them to finally click and take on strategies.

Education professionals with expertise in Dyspraxia suggested that social relationships based on trust could enable the children and adolescents they worked with to attempt success, through risking failure. Self-efficacy in the face of failure must be sufficiently positive so that an individual can improve and attempt again tasks they have previously failed at (Alkire, 2005). According to Alkire (2005), self-efficacy refers to either internal or external empowerment relative to the degree of agency a person perceives they possess.

This section has explored the role of the private, and state tertiary, education sectors in removing social barriers for Dyspraxic participants and further, the benefits of structural arrangements such as universal design. Having investigated equality in relation to Dyspraxia, the following section will explore alternative social arrangements, and social responses to Dyspraxia, and their role on the life outcomes of Dyspraxic participants.

5.4 Dyspraxia and employment

The section below describes the role of employment on the social Dyspraxia experience. On the question of employment in relation to Dyspraxia this section will look at the degree of institutional support for employment and normative social expectations around employment. Participants with Dyspraxia described varying degrees of challenge associated with employment. Some difficulties, expressed by participants, were significant and suggestive of either a reduced ability to earn the same income as a neurotypical adult and/ or greater costs associated with their disability as the two primary types of material disadvantage common to many people with dis-abilities (Mitra, 2006; Robeyns, 2006). Lucy's (D/ED 20-30) quote below described the lack of access she experiences to capabilities, in keeping with Sen (1999), that would enable her to access the valued functioning of independence:

> The thing is to get away from my Mum, I really want to be independent and that's my biggest challenge and since there are no jobs and in the Hawkes Bay the rents are ridiculous. I'm not sure if I'll ever move out. I want to move out, I have to but how? How do I go about it?

An individual's economic environment affects their employment opportunities and ability to be self-sufficient and understanding additional economic burdens associated with an impairment is central to understanding the experience of disability (Mitra, 2006). The experience of Dyspraxia can pose motor coordination challenges for people in the workplace, with the majority of Dyspraxic participants mentioning employment related challenges that they associated with their Dyspraxia. Claire (D/MD 50-60) described her difficulties in the workplace in the following quote:

> I worked in soils, but I was really bad. I liked the idea before I left school of working in a laboratory but turns out I'm really bad at it, like diabolically bad. I was the person who when you're trying to do stuff with acid, I was the person who ended up with acid in my mouth or on my clothes (laughs). Or I would smash the glassware and be the person who accidentally stood in it and then I'd have to go to the doctor who would literally have to cut bits of glass out from my foot… But then we did things like we had to spray trees to mark where we'd measured them, and I was the person who would end up getting the spray paint in my face and we'd have to take the rest of the day off, but I did still enjoy it. Or collecting beetles, which is kind of fun where you have this little sucker thing and again, I was the person who would end up with a mouthful of insect excrement… Everybody hated me, like all the other lab people, who were all women, hated me.

A common difficulty identified by Dyspraxic participants in the workplace was in relation to the acquisition of new skills and the learning of new tasks, which is illustrated by Fred (D/ED 20-30) in the quote below:

> And I had a job at one point in a small office and I had it for about a month and then I got fired because I just couldn't, even after I had learnt the processes, I just couldn't do it all quickly enough. And to be fair to the lady, she's got to pay staff expenses, but she could get a bit grumpy that I wasn't as fast as the previous person.

The adverse implications of DCD for adults and adolescents, indicated by an "emerging but limited body" of literature identifies difficulties with "independent living, employment, work performance, leisure and physical activities, and QoL satisfaction" (Blank et al., 2019 p.277). One of the most common themes articulated by most participants with Dyspraxia, and most professionals, is how, despite the concomitant social challenges associated with Dyspraxia, there is limited provision of institutional support in Aotearoa New Zealand. Many participants describe social barriers to accessing support at all ages. Martin (DP) discusses a challenging situation he encountered accessing support for his son, with a professional at the Ministry of Social Development, in the following discourse:

> Even when we went to social welfare and asked for some help 'cos he only had dyspraxia it wasn't enough to get help. They said: 'What else has he got?' 'I mean, what else do you want him to have, I mean this is hard'. So, he's got this contract through the Ministry of Social Development 'cos I eventually went in and said: 'Look, I need help. I can't keep doing this on my own'. I went there and said: 'Is there any way we can get some help?' And the lady says: 'We actually can't, he hasn't been on the dole long enough and he's not a problem. I said: 'So what, do we wait around until he's a problem?'. And she goes: 'Look, come here' (in a whisper) So we went into a room, and she gave me four or five phone numbers to ring. And I got a hold of the guy who liaisons, he's another Ministry of Social Development guy and he said: 'Funnily enough, we've got a programme coming up, would you like to be involved'. And I said: 'Yes please'. So, you've got to actually push without being grumpy. Like I was frustrated but I never showed it cos I thought, if I get grumpy, they're just going to push me aside which means that Jonathan gets pushed further away.

In keeping with Thomas's (2021) study, most Dyspraxic, and many professional, participants in this research also identified ineffectual communication and stigmatizing interactions within health, welfare and education settings (see Chapter 5. Liz (PP-E/DP) described in the quote below how current institutional support may be inadequate in terms of meeting the needs of people with Dyspraxia:

> I think money isn't necessarily the answer. I just think that particularly for people who aren't working and who go to Work and Income, it's very much a shoe box: 'This is what you do' and everyone's kind of treated the same. I don't think there's a lot of: 'What needs to be done to get this person into work'. One of our young guys who has left High School and they've basically just said: 'You just need to look for a job' And you know, he's got some issues. And they may not be significant issues for the person who works at 'Work and Income' but for him, they're a barrier for him getting a job. I understand why you've got a one size- fits all situation because you've got this many people and you need to be able to deal with them in a certain way and perhaps that person at Work and Income was just box ticking whereas if he'd seen somebody else, they might have said I know somebody else like Workbridge or actually we can send you to a career advisor. Let's nut out where your strengths are.

Most participant accounts identified restrictions in the workplace that they associated with their Dyspraxia, with one participant observing that, in terms of social supports: "there is nothing in New Zealand about supporting people with dyspraxia in the workplace and yet we're quite an obvious group in the workplace" (Simon PP-E/D/ED 40-50). Having looked at the degree of institutional support available to Dyspraxic participants, I will now move on to discuss how participants perceive, and experience, normative assumptions in employment settings.

5.4.1 The role of normative social expectations on employment

The implications of normative social in relation to Dyspraxia and employment will be addressed in this section. Jack (D/ED 20-30) describes the complexity of social relationships on his identity and his interactions with significant social actors in his life when he says: My aversion to writing is why I didn't come to Uni straight away like in terms of physically writing. So that definitely had an impact on me deciding to work instead". Most participant accounts of people with Dyspraxia describe how the experience of motor coordination challenges, and associated cognitive difficulties, can disadvantage them affecting both the life choices they make and adversely impacting on their life outcomes. Andrew

(D/MD 20-30) discussed in the account below how he is disadvantaged by an employment assessment due to his Dyspraxia and which did not reflect his actual abilities:

> I struggled a lot with the logic-based puzzles. Read the story, now tell me what happens? And yeah, even today, I actually tried to apply for a graduate job with the Bank of New Zealand and one of the things that they asked you to do is to fill out a one-hour online test. To give you a benchmark to determine how good at performing you are, and they were basic, very very basic tests such as read this story, now tell me what happened and see this picture, look how many triangles are in this picture. All these logic-based things. Fact is I was the lowest, I got the lowest, I was really really bad, really bad and that actually affected my application, the whole idea of auditing and benchmarks. Normality again. I mean I haven't paid much attention to my difficulties but sometimes when you get these sorts of tests the problems are still there (laughs).

The preceding quote is an example of how, if a participant does not have access to a given opportunity, in this instance the ability to present their strengths in a way that does not disadvantage them, then participants do not have that opportunity. Sen (1999) describes capabilities as being opportunities. Having a dis/ability like Dyspraxia can represent a limitation in capabilities and therefore opportunities. Terzi (2005) argues that the experience of disability in relation to dominant social arrangements can be seen as limiting the ability to access capabilities and thereby restrict the future functionings that a person may hope to attain. One way that capabilities may be impaired is the inability to produce acceptable written evidence of knowledge due to difficulties with handwriting. Not possessing the conversion factor of adequate handwriting is illustrated by Simon (PP-M+E/D/ED 40-50) when he commented:

> And I think the other thing is explaining that the quality of work that is produced by a student may not have a direct relationship with their academic or cognitive strength. I always say to people if you ask me a question, I'm brilliant. If you put a pen in my hand, I'm a lot less clever.

Forde and Smythe's (2021) study of avoidance behaviours in adulthood further found that people with DCD actively avoid social situations in both education and employment contexts. The implications of not being able to produce work of the same calibre, or in the same manner, in employment settings represented a common theme. Further comparisons with individuals perceived as possessing neurotypical characteristics were common although, as Martin (DP) a parent of a Dyspraxic young adult said:

> He wasn't at the same level of maturity but then there were some guys with lots of maturity who were dicks. One of the dads does the hedges around and he was saying to me one day: "Where's James?". And I'm like: "He's working". And he's got a boy, cos he and Jonathan went to school together. And he said: "I wish I could get my son. I have to drag him out of bed and by about Wednesday he gets up and he'll do a couple of days with me and then sleep on the Friday". And he said: "How did you do it?". And I said: "Got him out of bed!". So, his kid was very talented at everything and all he does is lie in bed all day whereas Jonathan wasn't, and he's at work. There's no guarantee [if your child is typically developing], you know what I mean?

Another common theme was that of comparison with individuals perceived by Dyspraxic participants as possessing socially accepted normative traits, that they themselves may lack. Penny (D/ED 20-30) illustrated the role of comparison with other social actors on a Dyspraxic participants' identity when she stated:

> I've got to stop comparing myself with people I went to school with and remember that people achieve different things and I've got to remember that it's my life and I want a career and if I don't get that well…at least I'm going to try but I'm really nervous about the big outside world that I put myself in and I know the harshness of the world because I've already experienced it and I already know that in the workforce, I'm scared you know if you muck up an appointment.

Self-effacement in response to Dyspraxia was a common finding and due to perceived neurotypical behaviours, was found in several participants with Dyspraxia. Further, Dyspraxic participants frequently articulated accounts suggestive of a heightened awareness of the potential for adverse life outcomes through participating in social life: "what I'm really scared of is getting my first big proper job and finding it too overwhelming" (Penny D/ED 20-30). Results suggest that the ability of people with Dyspraxia/ DCD to achieve at the same employment level as people they perceive as being 'normal' may be in doubt, raising questions about how much the experience of DCD/ Dyspraxia may adversely affect the employment aspirations and outcomes of this population, relative to the general population. The preceding quote is an example of how, if a participant does not have access to a given opportunity, in this instance the ability to present their strengths in a way that does not disadvantage them then, in keeping with Sen's (1999) CA, participants do not have that capability.

Several participants observed that society values the contribution of innovative thinkers who perceive information differently to what is considered neurotypical:

> I think mental differences are pretty important, to create different thinking. 'Cos you hear that Leonardo (Da Vinci) had something, or Einstein was dyslexic? But had differences and created some really different thinking and I'm really good at Art and I'm wondering would I have that if I wasn't dyspraxic, I wouldn't be myself if I wasn't dyspraxic and I quite like myself (laughs) and also, I'm not sure if you actually tested everybody, I don't think anybody would be completely normal on every scale. They might not be diagnosable but yeah, I think there needs to be a bit more acceptance. Amber (D/ED 20-30)

The promotion of a strengths-based conceptualization (Nicolaidis et al., 2011) of neurodiversity in the workplace may enable the attribution of the respect and dignity that should be afforded to people with Dyspraxia/ DCD. Findings suggest a dichotomy in society - valuing the contribution of unique thinkers like Einstein and DaVinci and not -valuing other embodied experiences of difference (such as neurodiverse individuals who engage with the social world in cognitively and physically alternate ways). Dyspraxic participant narratives, such as Elle's (D/ED/DP 40-50) account below, illustrated the importance of social validation, inclusion and acceptance:

> There are lots of heroes in the dyslexic thing but not many in dyspraxia. I don't think there's been enough research been done, how dyspraxia … the advantages … or perhaps dyspraxia's hard slog and that's just the way it is (laughs).

Simon (PP-M+E/D/ED 40-50) described how being able to think systemically, rather than linearly has benefitted him in his working life:

> I think dyspraxics are really good at taking the structure and form in one area and seeing whether it fits in another… They might say that social science is not environmental science don't confuse the two because that'll make it all grey but the successes, I've had in my life are when I've gone, well that works over there I wonder if part of it will work over here and that's dyspraxia at its best".

In conclusion, this section has presented study findings suggest that it is difficult to obtain support for Dyspraxia/ DCD from Aotearoa New Zealand social institutions, such as social assistance with

obtaining employment. The next section will look at stigma in relation to the lived experience of Dyspraxia.

5.5 Dyspraxia/ DCD and the experience of stigma in Aotearoa New Zealand

This section will investigate the role of internally and externally attributed stigma, psycho-emotional difficulties and the role of institutions in relation to Dyspraxia, as described by the participants in this study. According to Goodley (2013, p.640) "ableist processes create a corporeal standard, which presumes able-bodiedness, inaugurates the norm and purifies the ableist ideal". Society reflects back at the disabled/impaired social actor, ableist ideals and assumptions that they will then perceive themselves in relation to, likely perceiving their own identity as lacking (Goodley, 2011, as cited in Goodley, 2013) which is suggested by study findings. Further, how connected an individual feels to their social world is contingent on their ability to perceive that they belong and share a common social identity with others (Coates & Vickerman, 2016). Several Dyspraxic participants, however, identified their experience of Dyspraxia with an overtly negative life trajectory, rather than a more nuanced experience comprising positive and negative aspects. Results of this study suggest that Dyspraxic participants may internalize stigma and discriminate against themselves in response to interpersonal social interactions and social arrangements resulting in psycho-emotional difficulties which will be explored below.

5.5.1 Psycho-emotional difficulties

This section looks at the key theme of psycho-emotional difficulties associated with Dyspraxia, one that current DCD research delineates as being separate from the DCD etiology but a co-occurring aspect of the DCD experience (Blank et al., 2019). The internalizing of difficulties as a result of having DCD, has been found to occur in response to challenges in the environment (Cairney et al., 2013). According to Harris et. al. (2021), DCD researchers attribute increased anxiety to the presence of motor skills deficits as well as the socially situated nature of the DCD experience. Further, Zwicker et al. (2018) note that motor coordination difficulties may be compounded by secondary psychological as well as socialising difficulties.

Researchers and medical professionals frequently assume that reduced QoL is due to the presence of an impairment (Kothari, 2004, as cited in Hammell, 2015). That most previous DCD studies have

employed the ICF (Blank et al., 2019) is suggestive of the likelihood that many DCD researchers understand DCD to be the primary causal factor of the psycho-emotional difficulties associated with DCD. Such approaches, however, may fail to investigate and identify appropriate measures to address the likely socially constructed aspects of psycho-emotional difficulties in relation to the DCD experience.

Previous studies have found that the adverse consequences of DCD may be psycho-social, behavioural, and/ or academic in nature (Cantell et al., 1994; Hill et al., 2011; Smyth & Anderson, 2000; Tal-Saban et al., 2014). The results of this study suggest that the psychological difficulties associated with Dyspraxia are significant, with one participant observing: "We do see a lot of kids who come through and who do develop a lot of anxiety and depression. And that's not a part of dyspraxia but it's a consequence of their difficulties with dyspraxia" (Ginny PP-E). Similarly, DCD research has found that children with DCD likely experience a higher degree of risk from psychosocial difficulties (Hill & Brown, 2013; Rasmussen & Gillberg, 2000).

Several education professional accounts commented that there is a point where children become aware that they can't move as well as their similarly aged peers, which Mark (PP-E) described in the following quote:

> That seems to be the age when there is awareness, not when they're younger, but as they get older, they can see that: 'well they can run and jump all over that, but I can't really do that'.

Several professional participant discourses suggest that children with Dyspraxia/ DD may experience social vulnerability and be unable to conceptualise their experience of social difference in positive ways, such as regarding DCD/ Dyspraxia as an alternate way to learn, beyond a certain age. Zoe (PP-E) describes this when she said:

> You have to be really vulnerable don't you, to be able to open yourself to not being able to do something? And if you've built up that it's hard and I'm not going to learn, I can't learn. And look it's really obvious, every time I sit a test, and the teacher doesn't have the time, but all the kid feels is failure, failure, failure, it's horrible right? So, picking them up is really important so that they're still really happy and they start to know that they learn differently. They're just different learners and that's fine, everyone learns differently. I actually think we're all on the spectrum.

Previous studies have found that the experience of motor coordination difficulties in childhood has been correlated with diminished emotional and social outcomes (Lingam et al., 2012) but there have been few studies of adults and the possible negative implications for mental health over the life course (Rigoli et al., 2017). More is now known about adults with a diagnosis of DCD, or who would qualify for a diagnosis as an adult, but there is limited knowledge about their QoL. Diminished self-worth and self-esteem are associated with DCD (Piek et al., 2000) with DCD children found to be socially anxious relative to children without DCD (Harris et al., 2021; Schoemaker & Kalverboer, 1994), and exhibiting lower academic achievement (Cantell et al., 1994). Study findings suggest that experiences in relation to Dyspraxia may lead to a diminished self-concept with one professional participant stating: "Often that they have had negative experiences and it's a lack of self-esteem sometimes… you know parents can be quite negative about their disability" Renate (PP-E).

Wide variations in self-concept existed within the Dyspraxic participant sample. One Dyspraxic participant observed: "self-esteem is one thing I've always had plenty of" (Edward D/ ED 20-30). However, most Dyspraxic participants suggested that social relationships, to varying degrees, had significant impacts on the adoption or attribution by other individuals of a devalued social identity. Penny (D/ED 20-30) illustrates this when she comments:

> When I was 8 years old, I couldn't talk properly … and getting called 'munted face' and all those types of things, they do stick with you. And when you finally get diagnosed with what you've got, you're a little bit too far along in the system for anybody to do anything really and then when you get to high school, I knew I was different and that played on mind.

It is a commonly held view that that 50-70% of adolescents and adults diagnosed with DCD in childhood retain challenges with DCD (American Psychiatric Association, 2013) with studies indicating that individuals with self-identified DCD, ages 18-27, report reduced satisfaction on QoL measures in relation to neurotypical peers (Hill et al., 2011). Previous DCD studies have found that difficulties in adulthood include challenges with reduced attention, depression, anxiety, low self-esteem, and low executive functioning (Blank et al., 2019). Anxiety may arise in response to disabling social structures, in keeping with the social model. Hill and Brown (2013) state that high anxiety rates may continue from childhood into adulthood.

Further, it has been claimed that co-occurring difficulties like ASD, dyslexia and ADHD may compound secondary impacts including anxiety and depression in response to both social and environmental

factors (Blank et al., 2019). Lucy (D/ED 20-30) described how the lived experience of Dyspraxia may be a complex physical and cognitive functional experience and also a complex socially embedded experience:

> It sucks because it's common with dyspraxia to have other learning conditions like autism, dyslexia, depression, anxiety. It's not really a stand-alone condition, it coexists with other conditions, disorders. But without the right support it can progress into depression and anxiety. That's what I've got. It's frustrating and really hard. I just feel lonely and misunderstood.

According to Reeve (2002), people who experience a disability, like that of Dyspraxia, may be psychologically harmed through exposure to negative perceptions and attitudes that people hold:

> Internalised oppression is not the cause of our mistreatment; it is the result of our mistreatment. It would not exist without the real external oppression that forms the social climate in which we exist. Once oppression has been internalised, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day or our lives (Mason, 1992 in Reeve, 2002, p. 27)

The above comment pertains to all people who have experienced any form of oppression not just those who have Dyspraxia and is a point that can be generally applied to the experience of Dyspraxia. Doyle (2020) found that mental health challenges in relation to neurodiversity are often caused by a lack of societal support experienced by neurodiverse individuals, whose social experiences are typified by exclusion, frustration and limited agency, resulting in anxiety. A theme that occurred in some interviews with some Dyspraxic participants was that of a heightened awareness about their social vulnerability in terms of their ability to achieve positive life outcomes. Penny (D/ED 20-30) illustrated this vulnerability when she says:

> I got really nervous because I don't know what my life's going to be like so I decided to get a degree at least that's one thing that no one can take away from me. Say I lose a job or if New Zealand had a high unemployment rate, I'm not going to be one of those statistics, I'm not going to be one of those people who are struggling.

A perceived social vulnerability in response to the embodied experience of Dyspraxia may be a capability deprivation. How capable study participants perceived themselves to be had repercussions for their "sense of agency, future ambitions, coping abilities and sense of identity" (Payne & Ward, 2020, p.250). Andrew (D/MD 20-30) illustrates the awareness, articulated by several Dyspraxic participants, of an increased risk of social vulnerability associated with the social experience of Dyspraxia when he described his social circumstances relative to another Dyspraxic person he identifies as experiencing social vulnerability due to his Dyspraxia:

> I mean he's currently working full time at a supermarket, and he doesn't like his job, but he's terrified about what would happen if he left and got something that made him, that was even more challenging and to think that that could have been me or at least may have been me. I know somebody who's dyspraxic and dyslexic and they have big, big challenges and it saddens me really, it saddens me.

The experience of adversity has been found to increase the risk of psycho-emotional difficulties, chronic illness, diminished education, and employment outcomes relative to peers who have not experienced adversity (McLaughlin et al., 2012). References to suicidal ideation by Penny (D/ED 20-30) in the quote below are indicative of the degree of distress experienced by some study participants and which may be compounded by the experience of Dyspraxia/ DCD.

> When I think about it now, but people are committing suicide…not me…but people are committing suicide and it's no wonder when they're being treated so badly, and I know there's a whole lot of other things but it's no wonder we've got such high rates in New Zealand of suicide. And I never did that because I care too much about people even though it crossed my mind.

The experience of personal failure has been equated with suicidal thinking (Tanner, 2009). The inability to achieve employment and professional qualifications or knowledge may serve as a constant reminder of the experience of cumulative failure (Tanner, 2009). Failure can also be a positive experience depending on the degree of resilience and motivation an individual possesses (Tanner, 2009). According to Harris et al. (2021) reduced levels of resilience correlated with higher anxiety in the DCD population. Resilience has been defined as being able to adapt in response to difficult circumstances (Southwick et al., 2014). Adults with DCD have been found to hold negative perceptions of themselves, heightened anxiety and, relative to neurotypical people, and are less likely to attribute their successes to their own internal resources (Harris et al., 2021)

The previous section has shown that psycho-emotional cognitive difficulties are also associated with the experience of Dyspraxia in the life world of adulthood, representing a key theme. Psycho-emotional difficulties were also attributed by several Dyspraxic participants to an awareness that they perceive themselves to be cognitively, and/ or physically different, relative to other, normatively perceived, individuals. This section has demonstrated that psycho-emotional and cognitive difficulties were identified as being significant in adulthood.

5.5.2 Internally and externally attributed stigma

This section will look at the role of internally and externally attributed stigma on the lived experience of Dyspraxic participants at the interpersonal level. Stigma has been described as a learnt cultural behaviour, historically situated and attributed to individuals who are excluded for failing to conform (Grinker, 2020) Stigma results in the social devaluation of an individual in response to a perceived form of social difference (Bogart & Dunn, 2019) and may lead other individuals to adopt a position of superiority (Parker & Aggleton, 2007) in an effort to exploit certain individuals or social groups, enforce social norms and/ or to avoid disease (Phelan et al., 2008). Awareness of and familiarity with Dyspraxia has been found to lead to the reduced attribution of social stigma (Gillespie-Lynch et al., 2015) but findings suggest that Dyspraxia is poorly understood by Aotearoa New Zealand institutions and individuals, which may contribute to the attribution of stigma described in participant accounts. The following discourse by Kristen (PP-E) illustrates the importance of social awareness for people with Dyspraxia, particularly in relation to a person with Dyspraxias ability to adopt a positive self-concept:

> I think some children like to know that they have that, so they know that it's OK. That it's not actually anything wrong with them … And I think also for everyone around them as well in our society, which we live in, it's a better understanding for them and if we do use the words dyspraxia, dyslexia, autism it will become easier for people to talk about, to understand, to get an understanding of and not to alienate anybody who has these learning differences … I just want society to understand that it exists, and that adults and children have to deal with this on a daily basis and so, they're already dealing with this themselves, they don't need any sort of prejudice from society but a better understanding.

Children and adolescents with motor coordination challenges have been found to experience a higher degree of victimization from their similarly aged peers (Campbell et al., 2012). Several Dyspraxic

participant narratives, such as Katherine's (D/SD 30-40) below, suggested that their exposure to stigma and discrimination started as early as 5-years-old, indicating that diagnosing at five may be too late to prevent the internalisation of stigma in response to current social arrangements:

> So going back to kindergarten, that's the first education I guess, and I was really happy and excited to be alive and was like: "Yeah world I'm here, what can I do, where can I go?" ...I remember that feeling, I remember being really excited about life and then from the age of 5, that all just crumbled away and vanished and ... it's a very strong memory I have, that 5-year-old or 6-year-old hunched over [in the primary school classroom] not wanting to be seen. That's pretty clear, even as I talk about it, I can feel emotion around it, and sadness and grief that that was my experience... School for me I label it my 13 years of failure and talking about it with you tonight I can feel the emotional trauma and scar inside me that I'm only just starting to scratch the surface of as an adult and I didn't feel supported by my family, I didn't feel supported by school... I started school and started discovering how I couldn't do what everyone else could do ... and I would hunch my shoulders forward and lower my head and hide behind people so I wouldn't be asked questions. And I would do that all the time and every now and again she'd [her teacher] pick me out because she'd see me hiding and... I was so panicked about not knowing the answer... I grew up feeling like I was a failure and now as an adult I feel like I'm a victim to the emotional trauma this caused inside me and I can only imagine that many others will feel the same way... I know if I was little and I was at school now I would be getting substantially more support than I ever got.

The above quote highlights many issues, such as strategies, the experience of failure, fear in social settings and the ongoing implications of self-blame. While the early identification of DCD has been recommended (Cairney et al., 2007; Schoemaker et al., 2006), EACD experts state that a formal diagnosis should not be given before the age of five, unless there is a significant impairment, to take into account the wide variability of normal motor development before this age (Blank et al., 2019). If support for Dyspraxia/ DCD is not provided to a child and/or adolescent then support may not be able to be sought until a person has achieved a degree of independence in adulthood.

Subjectification occurs from below when people ascribe truths to themselves, for example the act of identifying as dis-abled in response to communication with other individuals (Shakespeare, 1996). That the experience of difference in social settings may lead to a devalued social status was a common theme of this study. As noted by Shakespeare (1996), the investment of a person in their

impairment may become a means of rationalizing their experiences of failure. Results of this study suggest that Dyspraxic participants may experience capability deprivation (Wolff & de-Shalit, 2007) when they adopt, or are attributed, a diminished place in the social order and without an awareness (Parker & Aggleton, 2007; Shildrick, 2019) that they are accepting a devalued state and internalizing stigma (Corrigan & Watson, 2006).

Stigma research has shown that stigmatized groups who experience stereotyping, social discrimination and prejudice internalize stigma (Earnshaw & Quinn, 2012) as a result of interactions with other individuals. People with dis-abilities are exposed to social barriers and discriminatory practices that develop in response to social ignorance and prejudice (Barnes & Mercer, 2010). Simon (PP-M+E/D/ED 40-50) described in the quote below how social assumptions and arrangements may harm a child with Dyspraxia:

> If you get, and I have in my own teaching career, get people who say: 'well he just has to try harder' then that's an OK response for an ordinary kid but it's pretty damning for a kid who's trying at 180% but only producing at 50%.

Regarding themselves as deficient in relation to normative ableism will likely contribute to the internalising of stigma and possibly cause permanent psychological damage and often at a young age (Goodley, 2011, as cited in Goodley, 2013) A common theme articulated by Dyspraxic participants was that the effects of the exposure to stigma in Aotearoa New Zealand social settings, in varying degrees, may last well into adulthood. Failure to acknowledge the actual needs of minorities can significantly contribute to anxiety arousal, with studies linking the degree of control a person feels they have over possible threats in their environment (Bandura 1988) to an increased risk of adverse psychological effects.

Externally attributed, and internalized, stigma may be instrumental in creating the conditions to engender the secondary psychological pathologies frequently associated with Dyspraxia, as suggested by Kate (PP-E) in the quote below:

> I worked at [names school] and she had special assessment conditions. The other students in the class were incredibly horrible to her. They thought that she was cheating and that there was nothing wrong with her and that she didn't need any extra time. She didn't have any friends in the class but fortunately she had a lot of friends through part of a dyspraxia group … and that was

her saving grace I think because honestly, the girls were foul to her. If she wasn't in the room and was out doing an assessment with a reader/writer, the other girls would be moaning and complaining that 'there's nothing wrong with her'. It was quite interesting how negative they were towards her. That's probably my main experience where I've noticed dyspraxia being an object of discrimination. She didn't have a broken leg or anything, they couldn't see anything. Just like a lot of mental illnesses so they assumed that there was nothing wrong with her.

Most Dyspraxic participants recounted experiences of stigma in relation to Dyspraxia, with several participants still visibly emotionally traumatised in the interview setting. Elle (D/SD 40-50) illustrates her emotional distress from articulating past traumas when she commented:

> Elle: I got bullied at school and it was subtle being girls. It was teasing. (is crying at this point and cries frequently for the rest of the interview)
> Maria: If you don't want to talk about it, I completely understand!
> Elle: I don't know what started it but not reading social cues… I just remember running away into the girl's concrete toilets one time cos these kids were teasing, bullying me and I locked myself in the loo and they were trying to get to me below and above. And I don't know why but the teacher was trying to enforce some discipline but the whole thing got blown into this whole big thing, so she lined us up into the front of the classroom … because I wasn't supposed to be where I was and that was quite shattering".

The adoption of stigmatising careers in the form of bullying was one significant mechanism of causing internalized stigma, identified by most Dyspraxic participant accounts. "Unequal power relations, social inequality and exclusion" (Parker & Aggleton, 2007, p.22) may be responsible for the stigma, stigmatization and ableist discrimination experienced by people with Dyspraxia. Further, other societal actors who identify as able will also embody the superior identity of normal and attribute the identity of 'other' (Goodley, 2013) to neurodiverse individuals.

To conclude, the external attribution, and subsequent internalization, of stigma and attending psychological difficulties, was a key finding of this study, representing a fundamental aspect of the Dyspraxia/ DCD social experience. According to Brittain (2020) disabled individuals may attempt to emulate the norms dictated by ableist society attempting to appear, as close to normative expectations as possible. Ableist social expectations are imposed on an individual, consequently impacting their ability to access (Brittain et al., 2020) capabilities with potential implications for

wellbeing and life outcomes. The next section considers the role of institutional stigma on the lived experiences of Dyspraxic participants.

5.5.3 Institutional stigma and the education sector

Study findings suggest that stigma may occur in response to attitudinal barriers and enculturated practices in Aotearoa New Zealand institutions. As previously stated, individuals may adopt stigmatising careers or be stigmatised (Yang et al., 2007) in response to current social attitudes about ability. That current education practices in Aotearoa New Zealand may disadvantage learners with Dyspraxia and create social environments that lead to stigma and discrimination, was a major theme of both professional and Dyspraxic participant accounts, articulated by Belinda (PP-M+E) when she observed:

> How many go undiagnosed, and they just struggle and end up jumping through the hoops, and they just do the bare minimum, thinking they're really bad at things… And computers can help, typing especially and that's where learning how you learn is so important and how is a nine-year-old supposed to know that?

Education practices create social environments that lead to stigma through not having institutionalized practices that recognize, and/ or diagnose, Dyspraxia and resource distribution. Social perceptions and assumptions about the abilities of people with Dyspraxia, in conjunction with limited social knowledge, may have significant implications for the cumulative exposure to stigma in the education environments, as suggested by Liz (PP-E/DP) who stated:

> I remember one year when the kids made a colour wheel and put them up on the wall. His was the only one that wasn't finished because he hadn't finished it in the timeframe that the teacher had given and she still put it on the wall. His was the only unfinished one and I said to her, you could have sent that home and we could have finished it. But she said, that's what he'd done in the time that they had and she couldn't see how that would impact on him being the only one that was unfinished. So, she wasn't willing to make many accommodations for him but then other teachers tend to dumb things down, which does a disservice to the child because they're not dumb. They don't need to be working at a lower level they just need to do it slightly differently to achieve the same results and then there's other teachers who have expectations but who have realistic expectations. So, my son has had all three".

The above quote demonstrates that some teachers stigmatise while others don't. Further, interpersonal incidents of stigma may be supported by institutionalised stigmatising processes. According to Jackson (2017) neurotypical individuals have been found to frequently possess patronizing attitudes with regards to neurodiverse populations. A key theme in the results of this study was that of the role of the education sector as being significant for Dyspraxic participants in relation to stigma with Matt (D/ED 20-30) illustrating this when he said:

> Matt: So, I left school in seventh form, even though the teachers wanted me to leave I stayed. I was the first person in my family to stay to seventh form. I left and went to the New Zealand army for 6 and a half years.
> Maria: What did you mean the teacher's wanted you to leave?
> Matt: Oh, basically in Intermediate I was told I'd amount to nothing, and another teacher told me my dreams were stupid and one other teacher told me that I would end up working at The Warehouse. At intermediate… At high school I got told to leave, I said no.
> Maria: Who told you to leave?
> Matt: My dean, so the top teacher who does the whole form and she said, 'you should leave and do an apprentice[ship]' and I said 'I'll just finish high school. None of my family members had so I thought I'll stick it out. So, from 15, 16, 17 I got told you should leave and go work at the supermarket, go work at Burger King.

The preceding quote is a rich account of how social actors may discriminate against Dyspraxic participants and alludes to inter-generational difficulties, possibly with neurodiversity and/or socio-economic circumstances. The ability to discriminate against another individual or social group is reliant on a degree of power, whether social, political or economic (Link & Phelan, 2001). All Dyspraxic participants spoke of experiencing exclusion and/ or stigmatization, to varying degrees, and in different contexts and times, recounting instances of discrimination in social environments such as education and/ or employment settings. Parent participant accounts suggest that social rejection and exclusion can be experienced by children with Dyspraxia as well as their parents: "Some of the parents back in the day people didn't understand, so they thought it [Dyspraxia] was catching. At 5 he was invited to all the parties, at 6 he was invited to about half of them, by 7 it was one or two, by 8 it was none (Martin DP). That families may also be exposed to stigma in response to a limited social awareness of Dyspraxia was a common theme that is illustrated by Jane's (DP) discourse below:

> Jane: "So they sent us to [early intervention provider] where we saw [names professional] and they did an assessment as well
> Maria: An OT assessment?
> Jane: She was an educational psychologist I think but she couldn't find anything … and she said: "The child's clearly dysfunctional and maybe the parents need to sort it out" I mean, "sort it out?" Anyway, after that the school got so pissed off because they weren't getting what they wanted to hear that they called in [names RTLB] from the RTLB [service]. And so, then he came around to our house and spent 8 hours with us. It was a very long time. And he said: "Hmmm" at the end of it all and he said: "I'll be back". So, to cut a long story short, he came back the next week and said: "Well I've put all this stuff together and she's actually gifted" And we went: "Oh, what's that then?" And he explained what giftedness was and that just made so much more sense. So, we went back to the school, and they said: "Oh Rubbish! She's at the bottom of the school". And we were like: "That's right but that can happen with giftedness as well".

The experience of an invisible disability, like Dyspraxia, represents a different experience of ableism to that experienced by individuals with visible disabilities. The experience of ableist social attitudes that people with invisible disabilities, for example Dyspraxia, may encounter are unique to the invisible disabled experience:

> including frequently having their bodies policed by those around them, struggling with when to engage in dialogue about ableism, desiring to change to create a more just society for disabled people, and even internalising ableism in multiple ways (Kattari et al., 2018, p.489).

Discrimination differs from stigma in that the former refers to exclusion inflicted by individuals who exhibit discriminating behaviours, whereas the latter refers to those who are subjected to discriminating behaviour (Sayce, 1998). The policing of dis-abled people by individuals who consider themselves to be able bodied may lead to experiences discrimination for disabled individuals who may be unable to adapt to achieve social acceptance (Kattari et al., 2018). Kattari et al (2018, p.486) observe that part of "policing" the disabled individual by other people may be to erroneously assume that they are "lazy or overexaggerating their condition(s)".

According to Hart (2019) just because a person has access to the capability of education does not necessarily translate to successful life outcomes. Life success is dependent on how well the education sector can meet their needs and in conjunction with other environmental and social factors,

for example, whether they have access to teachers trained (Hart, 2019) in neurodiversity. However, as Simon, who has Dyspraxia and is also an education and medical professional stated: "Teachers are supposed to find the kids who are finding difficulties and find ways to help them but if you know nothing about dyspraxia how are you supposed to help a kid who's got dyspraxia? Simon (PP-M+E/E/ED 40-50). Applying Navarro's (2009) argument to Dyspraxia/ DCD, it is arguably not power differentials existing between social classes, resource scarcity or inequality that may limit the life outcomes for Dyspraxic participants but rather individuals and institutions which may be responsible for a reduced QoL.

Social individuals who are taught in a manner that addresses and supports their education and social needs will succeed whereas those who experience alienation and fail to successfully assimilate into the cultural norms perpetuated by education institutions may experience discrimination (Hart, 2019). Katherine (D/SD 30-40) in the quote below describes how institutional processes like SPELD reports can have stigmatizing consequences and a role in the process of stigmatization:

> All I can really remember is reading SPELD reports which would say things like; Katherine is, I was 13 years old and I had the reading ability of a 9-year-old and the maths ability of an 8-year-old and it always made me feel, it proved how stupid I was, reading those things.

The quote above describes an institutional process (having a SPELD report) that seems to have a role in stigmatisation, representing an institutional process with stigmatising consequences. Yang et al. (2007) argue that at certain times over the life course stigmatisers or stigmatised individuals will internalise dominant, socially accepted power arrangements in the social environment.

Navigating Aotearoa New Zealand institutions in terms of accessing support elicited a variety of responses from Dyspraxic participants. Penny's (D/ED 20-30) account below shows how interventions can evoke conflicting responses of gratitude in response to the provision of institutional support in conjunction with embarrassment, which is indicative of the disabling power of institutions:

> I remember I had to trot off to the learning help centre, well I was the only one that did that so that was quite embarrassing… I did just completely get a reader/ writer for year 10,11,12 exams but it just makes you feel so weird because you're different. No one else is going and you're the one not going into the hall (with everyone else). But I'm glad I did it because I got quite good marks, and I thought I was going to completely fail but I did alright.

The above quote is an example of an institutional practice that can stigmatise. According to (Ferri et al., 2001) having a difficulty identified was a prerequisite for obtaining support but identification was also potentially stigmatizing. To achieve the socially provided accommodations necessary for a person to flourish necessitates a focus on their disability, when the person themselves may be doing their best to approximate a social presentation that is normal to minimize feeling 'othered' (Goffman, 2009).

Several Dyspraxic participants also described instances where targeted intervention accommodated neurodiverse needs successfully in institutional settings and in a manner that did not evoke any stigma, of self or by others, with Penny (D/ED 20-30) illustrating this when she said:

> It was quite good in Year 11 because I got extra English tutoring and she was amazing and if I didn't have her, I probably would have failed all my English exams at NCEA because she really helped by doing intense tutoring with a whole group of us. There was a whole group of us and that was really good because you didn't feel like you were different, whereas if only one of you is going, well, everyone's going to know I'm different.

The account below by Amber (D/ED 20-30) shows how Dyspraxic people may need to respond to socially agreed upon social discourses that are socially enacted by non-disabled individuals (Runswick-Cole, 2014) and which enable social interactions that may be demeaning, invasive and inappropriate (Goodley et al., 2018):

> The thing with the teacher was I wasn't a problem child therefore I couldn't have a disability. So, there's this link between disability and problem. I was doing well, and I was well behaved so I couldn't have anything wrong with me. There are those kids, and they need help, but there are other kids, and they also need help. And they [teachers] have [been given] an official piece of paper [assessment] and they think "Oh no that couldn't be true", but "Are you a specialist? No". And they [teachers] called it only child syndrome and [said] that my Mum was overreacting even though my Mum had given them the paper [assessment]".

Some Dyspraxic participants criticized the response of the education sector in relation to their experience of neurodiversity. Tom (D/ED 20-30) described his negative emotional response as an adult to his experiences in education sector in the following narrative:

> I'm kind of pissed off at the whole education system thing that I was't diagnosed…this is exactly why I wanted to do the interview [for this study] because I don't want other people to be in the same spot because it really sucked. You know, thinking you're stupid when you actually have a proper condition. Yeah so, I'm actually quite pissed off at the education system and I'm sure there are hundreds of other people who had the same thing. I feel very strongly that the education system failed.

Analysis of the results suggests that most Dyspraxic participants possessed varying degrees of anger and disillusionment in response to their experiences in the state education sector, which is indicated by Penny (D/ED 20-30) in the following quote:

> I feel angry because now in this era when technology's brilliant there should be a lot more with learning disabilities in the education system and I'm sure high school hasn't changed in the five years since I left but NCEA you've got to get a tutor and I wish I'd got one because it's hard but there's got to be a place where children can go.

Both Tom and Penny are rejecting aspects of the education experience and discursively resisting the idea that they may be the cause of the difficulties experienced in Aotearoa New Zealand education institutions. The irritation, and even anger, exhibited by Dyspraxic participants at the internalised narratives they had, appeared to lead to improved agency, in keeping with the CA, and the development of individualised and successful counter narratives (McKenzie-Mohr & Lafrance, 2017). This is illustrated in Tom's quote above when he describes his anger and perception of a lack of intelligence as being due to his experiences in the state education sector.

In conclusion, findings indicate that attaining social acceptance and a positive self-concept is contingent on the ability to access social functionings and capabilities within current social arrangements. The primary difficulty experienced by many people with dis/abilities does not stem from their bodies but rather from how society responds to them, excluding and disparaging them through negative social attitudes, normative assumptions and structural processes (Goering, 2015). The identification of social barriers may be made difficult due to biomedical framings making the Dyspraxia experience a pathologized condition of the individual body and not about potential social barriers. The predominance of biomedical conceptualisations may obfuscate the social causes of, for example, the stigma identified as being experienced by most Dyspraxic participants in response to interactions with individuals who may possess a limited understanding of Dyspraxia.

5.6 Conclusion

This chapter has explored the implications of the embodied Dyspraxia experience in relation to the social world inhabited by Dyspraxic participants. Study findings suggest that the ability to navigate Aotearoa New Zealand institutions in adulthood is significantly influenced by the degree of financial, social, emotional and/ or academic support provided by families. A lack of support highlighted the need to manage difficulties with Dyspraxia alone, leading to a higher risk of psycho-emotional implications. The ability to provide an education to Aotearoa New Zealand children and young adults, and one that can be accessed by all, is a human right and a prerequisite for ensuring people with differences can achieve "meaningful, productive and successful lives" (MacArthur, 2009, p. 7). The greater costs associated with Dyspraxia, for example, relative to their neurotypical peers such as in the Aotearoa New Zealand education sector may represent a human rights issue for Aotearoa New Zealand, possibly amounting to discrimination against, particularly, lower income earners. In response to inadequate resources in the state education sector, families were found to access private support.

Further, impairments have been found to limit an individual's earning capacity and constrain individual spending (Mitra, 2006), with study findings indicating that Dyspraxia has the potential to create a significant economic burden for some Dyspraxic adults. A key theme of this study was the need to negotiate employment situations through engaging in a process of responding to normative perceptions of oneself as a Dyspraxic person, and the normative expectations of other individuals. Terzi (2005) argues that dis/ability in relation to dominant social arrangements can be seen as limiting the accessing of a person's capabilities and thereby restricting future opportunities, with study findings strongly indicating that the decision to disclose Dyspraxia in the workplace may either dis- or en-able a person depending on the response of individuals.

The socially invisible nature of Dyspraxia is compounded by a lack of social investment in Dyspraxia due to the perception of Dyspraxia as mild relative to other neurodivergent difficulties. There have been very few studies investigating the experience of invisible dis/abilities in relation to daily life situations, for example employment (Norstedt, 2019), however, capabilities such as education and the ability to achieve gainful employment may be impacted if Dyspraxia is socially invisible. A common finding of this study was how the seeming invisibility of Dyspraxia, as perceived by influential neurotypical individuals and institutions, may invalidate the social Dyspraxia/ DCD experience contributing to social exclusion, social intolerance. A consequence of a lack of social validity being attributed to the

Dyspraxia/ DCD experience was found to be limited access to social interventions in early childhood due to a lack of social recognition and knowledge by professionals and institutions. Early identification is a key tenet of the UN CRPD (2006a) which calls for:

> b) provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate and services designed to minimise and prevent further disabilities, including among children and older persons.

That social barriers, preventing neurodiverse populations from achieving QoL exist, need to be removed by society (Chown et al., 2017) also occurs in conjunction with challenges associated with neurodiverse experiences in social environments (Kapp, 2013). Scambler (2018) identifies the causal role of social arrangements in the attribution of stigma, which prioritises the accumulation of capital over just societal arrangements.

The attribution of stigma in some social contexts, and presented in this chapter, may be due to Dyspraxia/ DCD being an emergent phenomenon that is socially conceptualised almost entirely along biomedical lines. Biomedical framings of Dyspraxia or DCD may contribute to wellbeing through, for example, the provision of effective social interventions or engendering social recognition. Nevertheless, a successful institutional response, and one that can celebrate neurodiversity, can be achieved while still acknowledging the need for social assistance with impairments (Kapp, 2020, as cited in Bottema-Beutel et al., 2021).

Biological essentialism promotes social discourses that regard humans who possess impairments as having a devalued embodied experience relative to a normatively construed majority (Feely, 2016). For populations unable to meet the standardized social ideal of an individual as the primary unit of social production, the social experience can be one of exclusion and objectification (Link & Phelan, 2001). Study results revealed that a devalued social status, isolation, loneliness, discrimination, rejection by others and rejection of the devalued self is experienced, in varying degrees, by most Dyspraxic participants, to varying degrees, in relation to the experience of Dyspraxia. Accounts of participants with Dyspraxia suggest, in keeping with Campbell (2009), that they may lack the embodied experience of feeling safe and accepted in their interactions with social institutions and actors, an experience which likely has its origins in societal responses to, and perceptions of, difference. In addition, study results suggest that Dyspraxic participants attribute significant psycho-emotional difficulties to the possessing of a Dyspraxic, embodied social identity in response to inter-personal social interactions.

Findings suggest that Dyspraxic people need to manage how they are perceived by others and to attempt to approximate normative behaviours, to avoid being attributed an 'othered' status. The 'othering' of people with dis/abilities, by the general public and in response to human variation, permeates, not only social consciousness but also the consciousness of the people who have disabilities (Marks, 1999). Ubiquitous social norms that permeate all aspects of the life world are promoted by dominant groups whose social identity and cultural representations are both universally accepted and socially unremarkable (Young, 2004). Conversely, individuals who are attributed a differentiated status may be simultaneously identified as different and remarkable, relative to a normatively perceived population (Young, 2004).

This chapter has looked at the role of social interactions on the lived experiences of Dyspraxic participants. A lack of social understanding and access to information about Dyspraxia/DCD may impair how people with motor coordination difficulties understand themselves and how wider society responds to them with implications for social inclusion and wellbeing. An evolving social response that celebrates diversity may contribute to a greater valuing of human variation and the diminished attribution of social stigma.

Chapter 6: Discussion

The argument to be presented in this chapter is that the experience of Dyspraxia is not adequately understood by the medical or social models of disability. These models contribute to partial understandings of the Dyspraxia lived experience and each capture aspects of the emergent phenomenon of Dyspraxia as described by study participants. However, the medical and social models are unable to conceptualise Dyspraxia holistically or adequately explain the capability Dyspraxic participants have, to achieve the life outcomes they want. This chapter argues that the capabilities approach (CA) can be used to understand the lived experience of dyspraxia more fully and incorporate the main features of that experience identified in this study. In addition, it provides a framework to understand the effects of stigma, inequitable economic factors, and social structures (Hammell, 2022) described in Dyspraxic participant narratives. Through highlighting the sociopolitical context and processes within which Dyspraxia is constructed and lived, the CA can better understand the social mechanisms that may generate exclusion and oppression (Dubois & Trani, 2009). In contrast to other models, I argue that the CA has the capacity to encapsulate many aspects of the lived experiences of Dyspraxic participants rather than focusing exclusively, as other models do, and as Dubois and Trani (2009) note, on the difficulties, whether cognitive and physical difficulties, or in response to interactions with social institutions, associated with an impairment. The CA also has the explanatory power to analyse Dyspraxic participant discourses in relation to the ability of participants to experience agency, freedom, access to capabilities, and be fully functioning across multiple domains of life. The CA has previously been applied to disability (Baylies, 2002; Burchardt, 2004; Mitra, 2006) but it has also been noted that it has yet to be applied in a way that would significantly influence social progress in the disability sector (Berghs et al., 2016).

In exploring the Dyspraxia lived experience through the concepts of functionings, capabilities, the overall capability set and agency (Sen, 1999) the CA provides an improved understanding of the lived experiences of the DCD/ Dyspraxia phenomenon. It does this through its focus on the developmental trajectory as a product of the interactions between people and their environments. Fundamentally, the CA is focussed on the freedom and agency of people to be able to achieve the capability to do the things in life they value and choose. Sen (1999) calls these capabilities the successful 'beings' and doings' of life such as being educated, getting married, going travelling and being well nourished. When a person has the resources and power to achieve these capabilities, they are fully functioning capabilities (Sen (1999) calls these 'functionings). A person therefore uses the resources at their

disposal (Sen (1999) calls these conversion factors) to support their achieving of capabilities to be able to do the activities and be the person they want to become in a fully functioning way. In this way the CA allows us to interrogate the lived experiences of Dyspraxia through the lens of having the fully functioning capabilities a person has reason to value in life (Sen, 1999). For example, many participants in this research report that the capability to be educated (capability) is hampered by a lack of knowledge about Dyspraxia in the teaching staff (conversion factor). Most importantly, use of the CA as a 'lens' through which to view the lived experience of Dyspraxia provides a more comprehensive understanding of the considerable inter-individual variations that exist between the experiences that people with Dyspraxia have. Further, how the lived experience of disability changes over the lifespan can be explored using the CA because, as originally developed, its focus has been specifically on the interplay between individuals and their particular social and economic environments to achieve their valued lives (i.e., on 'human development, in the embedded sense).

Three key insights emerging from the results are presented in this discussion in relation to the medical and social models, and the CA. Firstly, the response of institutions in Aotearoa New Zealand are explored, specifically the education and health sectors, and their role in promoting the life outcomes of Dyspraxic participants and further how Dyspraxic participants may respond to institutional arrangements. Secondly, the implications of possessing an embodied state that is not socially 'visible' are studied, focusing on current discursive practices and the effect of visibility on wellbeing over the lifespan. The role of cognition and normative social arrangements will also be studied. Finally, this chapter will investigate how Dyspraxic participants perceive their lived experiences of Dyspraxia in terms of their identity, by looking at the role of adaptation and the perceived need to identify the benefits associated with Dyspraxia. In response to these insights, this discussion makes use of the CA as one theoretical model which may improve the conceptualization of the lived experience of Dyspraxia.

6.1 The institutional response to Dyspraxia/ DCD

This research has identified gaps in the current literature by exploring the experience of Dyspraxia from a sociological and lived viewpoint rather than a medical one. There has been little research to date that seeks to understand the lived experience of people with Dyspraxia, or that prioritises their discourses rather than the perspectives of medical professionals who speak for them. Dyspraxic participant narratives identify many instances where- in the concepts made available by the CA - they are unable

to convert capabilities into functionings. Significant capabilities that were impacted by the lived experiences of Dyspraxic participants were, and to varying degrees, those of access to an effective education, employment, and socialization. Opportunities identified by some professional participants that were deemed to be lacking concern difficulties accessing, or inconsistent access to, publicly funded interventions in the health and education sectors. Conversely, a conversion factor that facilitated success was access to private sector support.

Results suggest that most Dyspraxic participants may be limited by aspects of their Dyspraxia that inhibit their ability to access certain capabilities, resulting in the need to frequently, as Rose (1998, p.297) states, 'embrace, or submit to,' established social discourses and practices that are enacted by authoritative individuals and institutions. The relatively recent 'discovery', or recognition of DCD by medical professions may be one reason for the current lack of social engagement. Further, the fact that Dyspraxia is not perceived as being as debilitating as other neurodiverse conditions is suggested by the lack of funding available, relative to other medical conditions such as ASD and ADHD. The lack of social adjustments implemented for people with Dyspraxia may be exacerbated by a 'narrow' definition of Dyspraxia as 'only' being DCD. The experiences of participants showed that the narrower definition of DCD, as an exclusively physical functional deficit prevents the social recognition of cognitive difficulties. Constructive power is a privilege possessed by certain societal groups which may disempower other social minorities leading to diminished decision-making power in relation to access to the social resources and structures that affect them (Wardrope, 2015). DCD researchers possess constructive power which can influence what aspects of the Dyspraxia/ DCD phenomenon are deemed relevant and what aspects constitute a diagnosis. The choice of medical researchers to use the term DCD is representative of what Bottema-Beutal et al. (2021) calls a linguistic choice that represents dominant social discourses and power arrangements which are representative of ideological social positions that are not neutral and devoid of judgement.

Aotearoa New Zealand society could address Dyspraxia/ DCD in a needs-based manner, in keeping with the CA and to promote access to capabilities, rather than in response to social perceptions about a medical label:

> From a capabilities perspective then, assessments, outcome measures and research tools focused on appraising abilities are inadequate unless capabilities are also evaluated to determine whether the conditions are available to allow people the real opportunities, or alternatives to choose to do and be the things they value doing and being (Hammell, 2022, p. 7).

In line with predictions of the social model, data suggest the ways in which institutions in Aotearoa New Zealand address and respond to the needs of participants with Dyspraxia can be disabling. A common theme of many Dyspraxic–and professional–participant narratives was that of frustration at the limited resources available in Aotearoa New Zealand for Dyspraxia and the inadequate response of social institutions. Wolff and De-Shalit (2007) observe that societal resource limitations require that democratic decisions need to be made about resource allocation to ensure social justice. Decisions about resource allocation require deciding how important certain social functionings are for wellbeing which often requires weighing up their significance in relation to wider society (Wolff & de-Shalit, 2007). The critiques by professional participants of the government response to Dyspraxia/ DCD suggest that Dyspraxia/ DCD may not be perceived as being socially significant enough to warrant either social investment or the altering of current institutional arrangements.

The conceptualisation of Dyspraxia using the medical model was suggested by study results to be a limited way of framing the lived experience of Dyspraxia. Perceiving Dyspraxia as a medical pathology was indicated by findings to contribute to education institutions regarding it as needing to be addressed through medical institutions, thereby potentially obfuscating the cognitive difficulties that are associated with Dyspraxia across the lifespan. The state allocates often limited resources to help people address the functionings that they may lack (Wolff & de-Shalit, 2007). Many professional participants suggest that the limited provision of social support may not be due to the availability of public funds but in response to social arrangements. The limited access to health sector support, identified in several Dyspraxic participant, and many professional accounts, is suggestive of Dyspraxia/ DCD being a partially medicalised phenomenon that is in the process of being institutionalised. Whilst the process of medicalisation and institutionalisation is problematic and can lead to pathologizing the phenomena, it does at least give people access to health sector support. DCD has been extensively researched internationally and effective intervention processes exist to ameliorate functional difficulties. However, findings suggest that intervention processes based on the medical model are yet to be operationalised in Aotearoa New Zealand. A number of professional participant discourses indicate that there is a lack of access to institutionalized diagnostic pathways, publicly funded interventions and professional expertise suggesting that the role of the health sector may have a limited role in enhancing the functionings of people with Dyspraxia.

A common theme was that DCD was frequently not recognized by medical professionals, with only the most significant difficulties identified and supported by the public health sector as discussed in

chapter 3. One medical professional commented that intervention providers do not publicise their services in response to limited social resources, with implications for social justice for this population. Dyspraxic participants seemingly fall below the social threshold in terms of access to public support, which is suggestive of, in keeping with Nussbaum (2006), a failure of social justice. The importance of access to clinical and therapeutic settings to ameliorate motor coordination deficits, particularly in childhood was indicated by many professional participant narratives. A common theme of many education and health professionals, with expertise in neurodiversity, was the need to advise parents to access private support rather than attempting to attain state funded support. A medical model narrative about DCD/Dyspraxia has the potential to assist, and/or inhibit, access to the capabilities by providing access to interventions to address cognitive and physical functional difficulties.

Sen (1999) states that equitable access to capabilities is reliant on the implementing of social arrangements that ensure equality. If a person with a dis/ability has the same access to commodities as another non-dis/abled person then they will not have the wellbeing or QoL that the non-dis/abled person can access (Sen, 1999). The ability of a person to use an income and advantages to generate wellbeing is dependent on "personal heterogeneities, environmental diversities, variations in social climate, differences in relational perspectives and distribution within the family" (Sen, 1999, p. 70). People with the same or similar degree of impairment due to Dyspraxia may or may not experience dis/ability through their interactions with social arrangements depending on other factors that are unique to them. Prior studies have noted that people with the same impairment may experience a disability differently and that their experiences may change over time, even if the impairment remains the same (Begon, 2021). For some participants the experience of Dyspraxia/ DCD resulted in additional financial costs relative to the neurotypical population, to ensure the same social outcomes as neurotypical actors, such as the need to privately access an educational psychology assessment process to access supports in the education sector as described in chapter 5.

In keeping with Rose (1998), Dyspraxic people are not devoid of social agency, nor are their social identities passively created through social forces. Rather, agency arises in, and through, the interactions between the Dyspraxic participant and society. Sen (1999) defines agency as being both the ability of a person to be agentic in their social environment and able to act and enact change in terms of their own values and goals. Access to an education is an example of a social institution that must promote equality and provide people with the agency to identify the functionings that matter to them as well as the agency to attain those functionings they value. A social model conceptualization of education would require structural changes to state education practices, to promote inclusivity and in

conjunction with a willingness to change the system, rather than changing Dyspraxic individuals. Even if these structural changes occurred and society moved to a social model of disability, this would still not be a complete solution; it would only be half the journey towards a successful system. The social model would remove society's obstructions but a further step would be needed to truly help people move beyond the obstructions and to access and build their capabilities. This second step could be encompassed in utilising a capabilities approach.

Central to Sen's (1999) understanding of social development is the ability of people to access the freedom that can enable them to support themselves and have agency in their social world (Sen, 1999). Access to a state education that supports neurodiversity and to a health sector that addresses motor coordination difficulties in childhood could contribute to economic development in the form of reduced dependency on support by neurodiverse people. Understanding that perceptions of agency change over time is important to consider when analysing whether the policies and subsequent interventions can create new opportunities for people through possibly changing social arrangements that are part of their capability set (Sen, 1999). Chapman (2020) observes that the value in the term 'neurodiversity' is in its ability to epistemically generate new ways of understanding and perceiving the social world from its current constructions. It may be, however, that both deficits, if such a term must be attributed, and differences are valid to conceptualise the lived experience of Dyspraxia.

Most Dyspraxic participant narratives, and most professional participants in the education sector, described the requirement of Dyspraxic individuals to navigate social structures that are not designed to address their neurodivergent needs. One Dyspraxic participant described the agency in relation to Dyspraxia as not being in 'bottom, middle, or end' in terms of ability but rather existing in all three, with the education sector wanting individuals to possess agency in a more uniform neurotypical range as discussed in chapter 5. Neurodivergence, however, may preclude this desired uniform behaviour in both ability and agency. It is important to note that ability and agency are not the same phenomena and don't present equally for each person or each ability. That is that neurodiverse persons can be seen to be divergent in both ability and agency and these cannot be conflated. Several education professionals interviewed believed that the education sector is best designed to respond to the learning needs of neurotypical students and not to the needs of those students who they describe as learning differently. Whether the education sector is structured in a manner that can address neurodivergent learning needs could be better understood through the CA and its focus on development.

Contemporary state education practices that prioritise discourses grounded in academic output and academic achievement reinforce ableist values ignoring barriers to learning created by structural arrangements for learners (Barnes & Mercer, 2010) including those with Dyspraxia. If a child is unable to learn they are frequently perceived as having a pathological deficit (Deacon et al., 2022) If the education system was structured in a manner that fully acknowledged neurodivergence–through, for example, undertaking such measures as training teachers about neurodiversity–then such a structure would allow every student to access the capability of education.

Agency may be constrained through an impaired lack of access to capabilities, such as those of an education or health, and access to support in the addressing of cognitive and physical functional deficits. However, within current social arrangements it was found that it is the agency on the part of parents, and sometimes adolescents and/or students at the state tertiary level, that enables people with Dyspraxia to access, at least to some degree, the capability of education. Most Dyspraxic participants, and education professionals commented that any state education assistance was predominantly instigated by parents with available support and knowledge inconsistent between teachers and schools. Families, then, are a significant conversion factor enabling people with Dyspraxia to access their capabilities. Similarly, while teachers and schools with the appropriate knowledge of Dyspraxia may act as conversion factors, an absence of knowledge of Dyspraxia was claimed by some Dyspraxic and professional participants to result in what amounts to capability deprivation. An inability to access social support is suggestive of a lack of access to the capabilities as described in Vizard and Burchardt's (2007) human capabilities list based on the UN Declaration of Human Rights, such as the right to be healthy and knowledgeable. Many participants stated that they had navigated the state education sector without support, which represents a key finding of this study and one that application of the CA helps to highlight.

The CA is useful in exploring the equality of current social arrangements. Inequality can be assessed by comparing how capability sets are distributed among people (Burchardt, 2004). The CA can contribute to understandings of how socially entrenched perceptions of dis/ability may affect the response of institutions as well as both neurotypical and neurodivergent individuals. In line with the CA's emphasis on freedom, data suggest that ableist social discourses may interfere with the opportunities of Dyspraxic people to achieve the lives they value. Equality from the perspective of the CA is the ability to provide people with equitable opportunities for wellbeing and an inability to do so can be deemed a capability deprivation (Wolff & de-Shalit, 2007). Some Dyspraxic participants in this study described not being able to achieve equality through current institutional arrangements and which limited the

degree of agency they could exercise. Social, physical or economic restraints prevent equality in the achievement of capabilities (Burchardt, 2004) with data suggesting that persons with Dyspraxia can experience adverse outcomes in social, physical, or economic ways. The result may be to create inequitable opportunities to attain wellbeing, relative to the general population.

Data showed that many Dyspraxic participants were able to exercise individual agency (or their parents did) to access necessary conversion factors to ensure they were able to achieve an adequate threshold of capabilities. However, others were unable to access individual agency such as those who were unable to achieve independence from their parents through living away or having a job and being respected by their families. The CA then, can be used to examine both social structures and the agency people with Dyspraxia possess in relation to those structures.
Changes to the structure of the education sector would enable access to the capability of education in contrast to current arrangements which are dependent on the attaining of access through individual agency. The CA can reveal the social resources that support or constrain the life outcomes of Dyspraxic participants through the identification of the presence or absence of capabilities from the perspectives of people with Dyspraxia. People with Dyspraxia may lack the opportunity of inclusion within current state education structures for example. Successful inclusion would be the teaching of neurodivergent people as effectively as neurotypical people and removal of all social barriers to learning (Block & Obrusnikova, 2007) and structural changes to provide more variation in the provision of support structures to enable individual agency to access the capability of education.

The ability to achieve human dignity is based on inclusivity because the CA is grounded in the idea that the dignity of every individual must be upheld (Nussbaum, 2006). The ability of participants with Dyspraxia to achieve capabilities in childhood has significant repercussions in adulthood and whether they can attain human dignity as individuals, which is central to the CA (Nussbaum, 2006). Human dignity, which, in the CA, all individuals are morally entitled to, is assured when all individuals can achieve an adequate threshold of capabilities (Nussbaum, 2003). Knowledge of neurodiversity by teachers and greater access to effective interventions were cited as being the main differences between the state and private education sectors suggesting that this is how teachers can be successful conversion factors for those with Dyspraxia. Many professional accounts gathered in this study suggest that where individuals and institutions have expertise in relation to Dyspraxia, such as in the private sector, the response to Dyspraxia is more in line with the social model of disability, actively engaging in removing social barriers to learning. Further, the CA can complement, rather than completely replace, the social model.

One example of a conversion factor beyond those suggested by the medical and social models of disability, that could aid access to desired and needed capabilities such as education, is UD. UD may be one way to reimagine and restructure the state education sector. As Rose and Strangman (2007) note, practices like UD are adopted to ensure that the widest array of individuals are accommodated and that social structures and institutions are accessible. UD is a broader conceptualization of learning that prioritises many mediums for accessing information for as many learners as possible. The ability to learn in a multi-sensory manner, which is facilitated by UD, at the state tertiary level was identified by some Dyspraxic participants as providing a more accessible way to learn than their experiences at primary and high school. However, data also suggested that several Dyspraxic participants still struggled with aspects of learning at state universities with a number describing varying degrees of success in implementing self-identified strategies to support their learning. Nevertheless, the adoption of UD may be one way to enhance the ability of Dyspraxic people to both gain the capability of access to rewarding and effective employment in adulthood and education settings that promote their capability of wellbeing. Applying UD in employment settings would contribute toward the goal of development, as per the CA, which is to enable Dyspraxic people to fulfil their potentials and attain wellbeing.

The CA can identify capability deprivations that may exist in a person's social environment. Capability deprivations of Dyspraxic participants may be created, compounded, or ameliorated by current social arrangements, such as in employment settings and interactions with state institutions, with sometimes adverse implications for wellbeing. Whether social development has been successfully enacted and a person's freedom enhanced can be ascertained if a particular deprivation is removed. For example, Dyspraxic participants describe adulthood as being an important conversion factor. Adulthood was found to enable the accessing of employment (capability) because most Dyspraxic participants had a greater knowledge of the strategies (conversion factors) they needed, to support their Dyspraxia. An understanding of strategies was found to help Dyspraxic participants to learn effectively and succeed in employment settings. Further, most Dyspraxic participants describe the ability to mask cognitive and physical functional challenges as an acquired conversion factor that creates the appearance of having the necessary ability to obtain employment. However, the workplace is also an institution that can assume levels of cognitive and physical functioning that several Dyspraxic participants did not possess and so could not access the capability of successful employment.

For Dyspraxic people to achieve healthy, happy lives through their participation in the workplace, what is needed is consideration of more than merely the accumulation of wealth or income. In keeping with the CA, people need to be placed at the centre of economic and social concerns through a focus on capabilities rather than the evaluation of functionings (Deneulin & McGregor, 2010). Further, current workplace arrangements may not prioritise the security, as defined by Sen (1999) of Dyspraxic people in employment settings. Security in this context refers to protections that provide a social safety network that would prevent the exposure of (Sen, 1999) people with Dyspraxia to adversity, such as the inability to attain or retain the employment they choose. Instead, however, of prioritising security what may be prioritised is the enhancement of an individual's human capital and, hence, their ability to effectively engage in commodity production rather than their individual wellbeing. The CA can incorporate the role of human capital as one capability that an individual needs to attain the life they value and the successful attainment of an income that can enhance the ability of Dyspraxic people to achieve the opportunities necessary to attain the lives they value. But it can incorporate human capital in this way without sacrificing the priority of individual wellbeing. Findings suggest that adjustments are not being made–or, at least, are not being perceived–in many workplace settings for Dyspraxic participants meaning that this is a conversion factor that they do not have access to and which may impact their ability to attain the capability of successful employment.

The CA can be applied to Dyspraxia to identify the ability a person has and then compare that to the ability they could have in an ideal social environment that is free of social, physical, and economic barriers (Trani et al., 2011). A common theme was that of individuals having the ability to match identified strengths with available career options to attain the chosen functioning of successful employment. Dyspraxia was found to have implications for the freedom Dyspraxic participants had to choose the career they wanted (as described in Chapter 4). There is a strong ethical component inherent in the CA's focus on positive freedoms for people to be who they want and do what they desire rather than adoption of a negative conception of freedom seen as a simple, even simplistic, removal of barriers. The Stanford Encyclopaedia (Robeyns & Byskov, 2023) explains the CA understandings of freedom as:

> Real freedom in this sense means one has all the required means necessary to achieve that doing and being if one wishes to. That is not merely the formal freedom to do or be something but the substantive opportunity to achieve it.

Several Dyspraxic participants recounted adopting the assumption that they could not pursue a chosen career due to their Dyspraxia only to reframe this assumption later. One participant described this process as reframing their understanding of Dyspraxia to subsequently attain the career they had initially chosen but then forsaken. In contrast, several Dyspraxic participants described wanting to attain modest capabilities such as independence from their families and the ability to attain a job as functionings that they were aware they lacked.

Being unable to convert the resources and limitations that a person possesses into the life outcomes they choose (Trani et al., 2011) is the point at which an impairment becomes dis/abling (Mitra, 2006). Identifying the right career because of having Dyspraxia, for example, was identified as posing difficulties for some Dyspraxic participants. This was because they perceived themselves to have some abilities that were useful to them and other abilities that made finding a career that worked for them difficult. The ability to identify a career direction that a participant wanted, or had a capability set that would support such a career choice, were conversion factors that were a common theme in participant accounts. The experiences of Dyspraxic participants suggested that to experience success in employment settings the conversion factor of knowledge of an individual's functional strengths and weaknesses was important. Further an absence of knowledge about an individual's strengths was found to lead to many changes in career.

This section has examined the complex experience of Dyspraxic participants in relation to institutions. The following section will look at how social awareness impacts the lived experience of Dyspraxia.

6.2 The social invisibility of Dyspraxia

Current social understandings of Dyspraxia may be inadequate. A common theme articulated in many professional participant accounts was that of Dyspraxia being unknown in Aotearoa New Zealand resulting in children being undiagnosed by parents and teachers. A lack of, or limited, awareness in institutions of the capabilities necessary to promote the wellbeing of Dyspraxic people was found to obfuscate other opportunities that would enable them to flourish. For example, findings suggest that the ability to access funding in the state sector was contingent on cognitive and/or motor coordination difficulties being apparent to individuals who act as gatekeepers to social support. Basing publicly funded interventions on a medical diagnosis of Dyspraxia, which, perhaps inevitably, prioritises the visible severity of symptoms, was found to obfuscate the actual degree of difficulty experienced in the social world (as discussed in Chapter 3). Anti-social behaviour was found to be almost a necessary

precursor for people with Dyspraxia to access support. That is, people who are not disruptive may not be identified despite also experiencing difficulties engaging with the curriculum. If Dyspraxia/ DCD is not visible to social institutions and actors then it leaves many Dyspraxic individuals in the situation of having to navigate normative social expectations and assumptions while possessing an invisible, social disadvantage and experiencing social isolation in response to their Dyspraxia, frequently from a young age.

Sen (1999, p. 36) describes the 'expansion of freedoms' in terms of the freedoms that improve life and are comprised of capabilities such as the meeting of basic human needs such as the need to be socially accepted and be literate. Successful development is the ability to expand these freedoms. Whether social development is successful for the Dyspraxic population can be assessed in relation to whether these freedoms are achieved. The promotion of a greater social awareness of Dyspraxia by state institutions can promote the freedom of people with Dyspraxia to achieve the doings and being that would enable them to attain the lives they value but:

> The social commitment to individual freedom need not, of course, operate only through the state, but must also involve other institutions: political and social organisations, community-based arrangements, non-governmental agencies of various kinds, the media and other means of public understanding and communication, and the institutions that allow the functioning of markets and contractual relations (Sen, 1999, p. 284).

Applying Sen's ideas to Dyspraxia, a person with Dyspraxia may not have financial resources and lack the freedom to socialize successfully because there is a lack of social understanding about Dyspraxia and social acceptance of difference. Substantive freedoms are interconnected and complement each other (Sen, 1999). For example, social opportunities that support neurodiverse people such as access to a society informed about Dyspraxia is a freedom that may contribute to improvements in the education and health sectors and greater access to these capabilities.

Social invisibility was found to contribute to a limited social awareness of Dyspraxia which has repercussions for whether Dyspraxia is identified, addressed and/ or well received by society at large. Difficulties meeting normative social expectations and limited social awareness of Dyspraxia, were found to contribute to the social intolerance of Dyspraxia differences and the attribution of stigma, such as in employment settings. A further capability deprivation described by several Dyspraxic participants was associating Dyspraxia with diminished intelligence to varying degrees and relative to individuals perceived as 'normal', resulting in internalised stigma. For example, several professional participants stated that people with Dyspraxia may not ask for support so that they do not appear

‘stupid’ (as described in Chapter 5) to manage the social perceptions of other individuals. It may be that the decision of whether to disclose or conceal Dyspraxia is about self-protection and evaluating the risks and benefits of potential exposure to discrimination.

Discriminatory societal attitudes to difference and an ineffective response to the Dyspraxia embodied experience by institutions was found to result in exposure to stigma. Socially attributed stigma has been found to lead to the subsequent development of psycho-emotional difficulties (Grue, 2011). The lack of acknowledgment of Dyspraxia in institutional settings–perhaps based on medical and social model framings–can result in a sense of vulnerability, a lack of ‘voice’ and, ultimately, experiences of failure. Sen (1999) highlighted this lack of a ‘social voice’ as an impediment to the attainment of capabilities. Feeling different from other individuals was indicated by findings to compound anxiety and lead to depression (as discussed in Chapter 5). Experiences of failure were recounted by many Dyspraxic participants, in response to interactions with social institutions. Approaches to Dyspraxia that reduce the risk of socially attributed stigma, are suggested by study findings to exist in the private education and tertiary sectors and the not-for-profit space.

One significant capability deprivation was the need to conceal difficulties with Dyspraxia in social environments to be perceived as normal (and, thus, adding to the social invisibility). The concealment of Dyspraxia in social environments was often perceived as a conversion factor that was employed in response to internalized stigma and/ or to avoid anticipated stigma. The ability of Dyspraxic participants to conceal their difficulties was suggested to contribute to the social perception that Dyspraxia is not as serious as other neurodivergent conditions, such as Autism and/ or Dyslexia and potentially contributes to capability deprivation in the form of a lack of social investment. By contrast, it may be more difficult for Dyslexic and Autistic individuals to conceal their difficulties in institutional settings leading to greater social support. That Dyspraxia is not as recognizable as other neurodivergent conditions may be due to the huge variation in how Dyspraxia may present between individuals. The next section will look at the lived experience of Dyspraxia from the perspective of Dyspraxic people.

6.3 The Lived experience of Dyspraxia/ DCD

The capabilities a person has access to, can change over time. The CA can conceptualise these changes which is a strength of the CA relative to the medical and social models. Experiences of Dyspraxic participants suggested the complexity of their lived experiences by describing how different

conversion factors can be accessed at different times over the life course. Adulthood was associated with the ability to access more conversion factors, such as the reframing of the Dyspraxia experience from a negative one to a positive one. In childhood access to conversion factors was helped or hindered by a dependency on parents and/or teachers. Adulthood, conversely, was a conversion factor that was found in most Dyspraxic accounts to engender greater agency to access support in ways they were unable to in childhood, such as knowledge of what strategies would facilitate access to capabilities for example in the state tertiary education sector and in employment settings. As adults, several Dyspraxic participants described being able to reframe their experiences of Dyspraxia into a positive aspect of their identity and attribute positive and neutral aspects to their embodied experience of Dyspraxia meaning that in adulthood they were able to access these capabilities. Dyspraxic participants further possessed the agency in adulthood to address their Dyspraxia difficulties, with varying degrees of success, which was particularly significant if they had received limited childhood support. This leads to two conclusions; firstly, that children and youth need external support to access conversion factors and while this is very dependent on the inherent capabilities of family and educational settings, it is possible to deliberately enhance these opportunities through training of teachers and education of parents about the inputs for success for Dyspraxic children and youth. Secondly, that Dyspraxic adults can act for themselves and access conversion factors on their own, but this is not universally experienced. This research suggests successful access to conversion factors by Dyspraxic adults depends on their ability to reframe their experience and their personal agency to act and advocate for themselves.

The majority of Dyspraxic participant discourses suggested that they had internalized, to varying degrees, Dyspraxia as a significant aspect of their identity, responding to current social conceptualisations of Dyspraxia, based on the medical and social models, as they understood them (as discussed in Chapter 4). The social model, for example, stipulates that 'people first' language be used but Dyspraxic participants chose to identify as Dyspraxic, much like many members of the Autism community in Aotearoa New Zealand choose to identify as Autistic. A reason for perceiving Dyspraxia as being interconnected with other aspects of the self is suggested by results as being in response to the iterative nature of identity construction in relation to the embodied social experience. According to Feely (2016), the body is situated in a specific time and place and the capacities a person has access to are contingent on contextual and relational circumstances. Every person has a different body and all bodies are in a constant process of change over time (Feely, 2016). The CA can conceptualise how Dyspraxic participants perceive their self-concept relative to the motor coordination, cognitive, and socially situated nature of the Dyspraxia lived experience over the lifespan.

The CA can incorporate how Dyspraxic participants see themselves without having to adhere to current normative social assumptions about dis/abilities or impairments enabling a broader conceptualisation of the lived experience of Dyspraxia. The CA can explore the complexity of the Dyspraxia embodied experience across the life course rather than just focusing on the disadvantages associated with an impairment (Dubois & Trani, 2009) experienced by an individual (the medical model) or in relation to institutional arrangements (the social model). For example, several professional, and Dyspraxic, participants described Dyspraxia as a 'global' experience and one that can affect all aspects of a person's life which is a broader interpretation than either the medical or social models are able to accommodate.

In the same way that society, and individuals, may reject what is undesirable about the Dyspraxia embodied experience, Dyspraxic participants may also reject their own embodied Dyspraxia experience. People with Dyspraxia will have diverse personal heterogeneities, as Sen (1999) calls them, or, more simply, diverse physical and cognitive abilities in relation to their Dyspraxia. Further, such personal heterogeneities will have different implications in different social environments for each individual. Personal heterogeneities, or the characteristics of a person, whether cognitive or physical, were indicated by the data to affect what capabilities they can access and whether Dyspraxic participants can attain the lives they value. In terms of socialization for example, several Dyspraxic participants possessed the personal hetereogeneities that enabled them to socialize successfully. Some Dyspraxic participants described personal heterogeneities that they perceived rendered them socially different and which they found to be at odds with some of the social conditions they inhabited. As Hart (2019) observes, a person may have a high degree of education, wealth and be culturally knowledgeable but may nevertheless lack the important social functioning of being well-liked.

Finding ways to compensate for identified deficits was suggested by most Dyspraxic participant accounts to be an ongoing process of attempting to access capabilities to promote life success. The ability to access a given capability is determined by firstly, whether an individual can access the capability and, secondly, what they are able to do with their resources, with Wolff and de-Shalit (2007) commenting that:

> The interaction of your internal resources and your external resources with the social and material structure within which you find yourself determines your genuine opportunities. Social structures provide the parameters within which a person can use the resources they possess (p. 173).

External resources, identified by Dyspraxic participants, include financial security, in the form of success in employment environments. Adaptation is an example of an internal resource and one described by all Dyspraxic participants. Most Dyspraxic participants described engaging in a lifelong process of adaptation and strategy formulation to varying degrees in response to cognitive and physical challenges associated with Dyspraxia. The ability to create coping mechanisms represents a key difference between childhood and adulthood–for example the ability of Dyspraxic participants to identify how they learn best in education settings–and represents an important conversion factor (as described in Chapter 4). Strategy creation was not always straightforward nor always achievable but such conversion factors may be necessary to mitigate deprivations in an individual's social environment.

The difference in capability sets between Dyspraxic and neurotypical people could be termed what Sen (1999) calls interindividual variation within a culture. The need to create strategies to manage characteristics associated with Dyspraxia represents an additional capability required of Dyspraxic participants that may not be necessary for the general population. In effect, not only are some capabilities that are relatively easily acquired by most neurotypical people made difficult by current social arrangements for Dyspraxic people to achieve, but also an additional capability, such as strategy creation, (not needed by others) must be gained and often without any support. The neurotypical population, for example, may not need the same strategies to access the state education sector as the neurodivergent minority, a potentiality that is not recognized by current education structures.

Adaptation was described as undertaken in isolation and without support by most Dyspraxic participants. It was therefore carried out in an experimental manner and through a process that evolved over time (as described in Chapter 4). Several adults with Dyspraxia described struggling with executive functioning challenges because they had not created the coping strategies and compensatory abilities needed to manage their motor challenges by adulthood. However, current DCD research has not addressed how children with DCD identify, acquire, and implement the strategies they require in social settings and, further, what role societal arrangements may play in supporting strategy acquisition.

How successfully a person can use these resources depends on social structures including power relations, be they formal or informal, and social norms (Wolff & de-Shalit, 2007). The possession of a social status that deviates from social norms reinforces how important and beneficial it is to belong to a dominant social group (Berezin, 2014) and explains the great lengths most Dyspraxic participants

described going to, to approximate, or adopt, social preferences and behaviors deemed by themselves, and others, as acceptable. Most Dyspraxic participants stated that they are frequently unable to meet normative social expectations, to varying degrees, in different contexts and times. Stereotypes that may be enacted on the lifeworld of minority populations are universal and so unremarkable as to be incontestable (Young, 2004). A key theme was the awareness of a need to achieve normality and deviate as little as possible from normative social perceptions (as discussed in Chapter 4). Several Dyspraxic participants stated that they constantly attempted to achieve the overall capability of normality to attain desired life outcomes. According to Kearney, Brittain and Kipnis (2019):

> While normalcy is existent in the background and is unobtrusive in everyday life for people meeting the established criteria of 'normal', for those perceived to deviate from the 'norm' it often exists in the foreground of their realities and is more prevalent in their perceptions of lived experiences within the social order (p. 7).

Dyspraxic participants identified a need to attain the appearance of a normal degree of functioning as a desirable capability that having Dyspraxia made difficult, rendering Dyspraxia in this social circumstance a capability deprivation.

Some Dyspraxic participant narratives, however, suggested resistance to social perceptions that they did not possess a normatively acceptable status and attributed benefits to their Dyspraxia experiences. The identification of strengths occurred despite social arrangements for most Dyspraxic participants rather than because of them. Another significant finding was the need to identify strengths and avoid institutional situations that disadvantaged identified areas of cognitive or motor coordination weakness (as discussed in Chapter 4). That some Dyspraxic participants associate strengths with their experience of Dyspraxia represents a key finding of this study. Dyspraxic participants identify strengths that they associate with their Dyspraxia, strengths that are not discursively acknowledged in formal social structures such as the DSM-5 (American Psychiatric Association, 2013). Strengths associated with Dyspraxia were found to promote access to the capabilities of wellbeing, education, employment and to facilitate the attainment of desired functionings. Benefits associated with Dyspraxia by some Dyspraxic participants included: 'outside of the box' or systemic thinking, an intense focus and a heightened ability to think critically, the ability to think in a broad and slow manner, the need for an in-depth comprehensive understanding of a topic, and non-linear thinking as described in chapter 4. In terms of wellbeing, attributing strengths to the lived experience of Dyspraxia enabled the reframing of

the experience from dominant deficit-based conceptualisations to one of an aspect of the identity that some Dyspraxic participants perceived as possessing both positive and negative aspects.

One paradoxical outcome of the social arrangements and social attitudes toward normality and difference in relation to how a dis/ability like Dyspraxia is socially perceived, may be that the *strengths* identified by Dyspraxic participants can be made socially invisible in terms of both the medical and social models. A subsequent capability deprivation experienced by Dyspraxic people may be exposure to universal social perceptions that ascribe negativity to their lived experiences and the negation of positive aspects of Dyspraxia. Deficit based framings with limited explanatory power in relation to Dyspraxia, and their influence on the social response to Dyspraxia have the potential to adversely affect the ability of Dyspraxic people to access capabilities. Accounts of some Dyspraxic participants indicated that the social invisibility of Dyspraxia adversely impacts–and therefore compounds–their ability to identify their strengths and weaknesses in institutional settings.

The association of benefits with Dyspraxia contrasts with ableist social discourses and represents a conversion factor that enabled some Dyspraxic participants to reframe the negative social ascriptions of current social discourses to Dyspraxia. The social experience of Dyspraxia has the capacity to be a capability that may contribute to the attainment of certain functionings, for example, an ability to identify as possessing a learning *difference* rather than possessing a motor coordination or cognitive *deficit*. Further, several Dyspraxic participants articulated a preference to retain their Dyspraxia difference, if given a choice, rather than have their Dyspraxia remediated to better assimilate into dominant neurotypical culture. Many Dyspraxic participant accounts show that there is more to Dyspraxia than the potentially disabling aspects associated with the experience. A strength of CA is that it can readily frame the lived experience of Dyspraxia as an aspect of human diversity and one that may have aspects to celebrate rather than one solely ascribed negative social value in relation to normative assumptions about human development. A comprehensive understanding of strengths and weaknesses was identified as a conversion factor that was necessary to ensure the life outcomes Dyspraxic participants valued.

The CA can conceptually account for benefits associated with Dyspraxia in the form of capabilities that the embodied experience of Dyspraxia may make available for some people with Dyspraxia. This is especially the case for those who have had access to the conversion factors necessary to identify Dyspraxia benefits. Such conversion factors would include a degree of support from family and access to private support. Benefits associated with the lived experience of Dyspraxia are an aspect of the capabilities available to some Dyspraxic participants who have the agency (and, perhaps, the hard-

won capabilities) to conceptualise their understandings and experience of Dyspraxia, enabling them to identify positive aspects, despite predominant social framings of Dyspraxia. The lived experience of Dyspraxia changes over the life course and is an evolving and shifting experience in relation to motor and cognitive challenges that changes over time. This section has looked at the lived experience of Dyspraxia in relation to the creation of strategies, ideas of normality and benefits associated with Dyspraxia.

Chapter 7: Conclusion

In conclusion, the lived experience of Dyspraxia is more complex than current conceptualisations, such as the medical and social models, allow for. Dyspraxia was found to change between adulthood and childhood. Another key theme was that of Dyspraxia affecting every aspect of a person's life, sometimes leading to the need to adapt behaviours to emulate neurotypical actors. The agency to engage in adaptation was a key difference between childhood and adulthood. Cognitive difficulties were found to be more prominent in adulthood than motor coordination difficulties. What the CA may be able to contribute to understand the lived experience of Dyspraxia is the ability to incorporate developmental processes across the lifespan in relation to the socially situated experience of Dyspraxia and contribute to a better understanding of how people attain capabilities to achieve what they want in life. The CA is one possible way of understanding Dyspraxia that can incorporate (and therefore complement) both medical understandings of physical disability and disabling factors created by society, in keeping with the social model. That is, the CA be used in conjunction with the medical and social models, recognising that both have the capacity to contribute to an improved QoL of people with Dyspraxia, while also identifying the potential limitations of both the social and medical discourses on the life outcomes of Dyspraxic participants.

Aotearoa New Zealand has been found to have a perceived socially ubiquitous lack of awareness of DCD/ Dyspraxia highlighting a need to improve social understandings as discussed in chapter 3. The limitations of the current social response to Dyspraxia/ DCD may not be due to the degree of provision of state funding necessarily but due to a dominant social ontology based on normative assumptions being enacted in social institutions such as the education and health sectors. For example, the idea that dis/ability must be visible to incur social support, and that if, as in the case of Dyspraxia, difficulties are not visible then Dyspraxia may be assumed to be not a serious enough challenge to warrant state funded support. This belief may be compounded by a limited understanding of the adult experiences of Dyspraxia (and the extent to which it occurs in the adult population).

Current societal discourses were found to affect Dyspraxic participants in relation to self-concept, exposure to stigma, the socialisation process, and the response of social institutions. Nussbaum (2006) argues that society should strive to ensure that people with impairments are able to access the same level of capabilities as other members of society and achieve a minimum threshold of capabilities. Capability thresholds, based on Burchard and Vizard's (2007) list, that Dyspraxic participant narratives indicate may not be achieved due to Dyspraxia include not experiencing security,

lacking a voice and influence, not feeling protected and not enjoying a full and reinforcing social life. Dyspraxia was found to be part of the self-concept of Dyspraxic participants and indistinguishable from their identity as described in chapter 4. A general lack of social awareness about Dyspraxia was found to lead to an inadequate social understanding of Dyspraxia resulting in negative implications for the identity of most Dyspraxic participants and their ability to attain the capability of a positive self-concept.

Contemporary social responses to Dyspraxia, as argued in this chapter, in the state sector and by the general population frequently render Dyspraxia a capability deprivation due to people with Dyspraxia having needs that are additional to the needs of the general public. For example, to successfully access the capability of a state education, a conversion factor in the form of access to educators knowledgeable in teaching neurodiverse students may enable greater access to functionings. Dyspraxia as a way of 'doing' and 'being', in keeping with Sen (1999), would benefit from social arrangements that have, embedded in their structure, knowledge and an awareness of neurodiversity. An example of this is the ability of the private education sector to teach strategies and promote access to functionings for Dyspraxic people as noted by many professional participants in the education sector and several Dyspraxic participants.

Wellbeing, as promoted by the CA, is assessed in relation to the opportunities that are available to the individual, or the capability set they possess, and which allow them to do, or be, a range of different things. Dyspraxic participant discourses suggest many of the capabilities outlined by Vizard and Burchardt (2007) may not be achieved, or may be harder to achieve, in adulthood through a failure to attain a *threshold of capabilities* in keeping with the general population. Currently life success for most Dyspraxic participants was dependent on factors external to state institutions, such as family support and access to the private sector.

The medical model frames the experience of Dyspraxia as a deficit. Social structures based on the medical model may defend the academic superiority, and socially embedded nature, of the biomedical approach over the relevance of the lived experiences of Dyspraxic people as discussed in chapter 3. However, current social conceptualisations of DCD/ Dyspraxia are contested, and the definitional and etiological conflict associated with Dyspraxia suggests this. Separating DCD from Dyspraxia reflects medical conceptualisations of the phenomenon but is not representative of the lived experiences of people with Dyspraxia/ DCD and invalidates the contribution that every person with Dyspraxia in this study made. Qualitative studies, such as the current study, can more readily identify oppressive social practices and inequality.

Applying the CA to Dyspraxia enables not only a more comprehensive understanding of how Dyspraxia/ DCD is socially responded to currently but also how it could be better responded to in the future. Dyspraxic participants described having to cope with how they were treated in society in terms of their Dyspraxia and that their Dyspraxia consists of not only coordination difficulties, cognitive challenges but also experiences that they identify as beneficial. It is significant that strengths were attributed to Dyspraxia by many Dyspraxic participants, who exist within a social environment that attributes conceptualisations of universal deficit to their embodied life experiences. Study results suggest that the social experience of Dyspraxia has the potential to be reframed, for example through use of the CA, to better represent the experiences over the lifespan of Dyspraxic people. The contribution of this study is an improved understanding of how the institutionalisation of Dyspraxia/ DCD is occurring in Aotearoa New Zealand in relation to an inadequate framing of the lived experience of Dyspraxia/ DCD. Study results further suggest that the institutionalisation process in relation to Dyspraxia is inadequate and/or inappropriate and does not reflect the life experiences, or social requirements, of the Dyspraxia social minority in Aotearoa New Zealand.

In summary, the findings presented in this study suggest that biomedical conceptualisations based on enculturated ableist, normative assumptions about the embodied state may underpin social framings of an embodied experience of difference, such as Dyspraxia. It is possible therefore that the possession of a subjective and normatively evaluated able and/ or dis/abled social identity, relative to other individuals, may result in the external attribution of, or internalizing of, either a valued or devalued social status, with the attribution of either being themselves contextually and/ or temporally and culturally dependent.

This study has applied sociological inquiry to explore the, heretofore reductively understood, and regarded as disparate aspects, of the Dyspraxia/ DCD experience to understand how factors both internal and external to the embodied Dyspraxic/ DCD experience interrelate. Further, the present study raises the possibility that the lived experience Dyspraxia is a largely invisible and emergent social phenomenon which is in the process of being institutionalized in Aotearoa New Zealand. These findings support the idea that Dyspraxia/ DCD is not well understood in the Aotearoa New Zealand context which may have significant implications for the wellbeing and life outcomes of this population. Overall, results suggest that more systemic framings, for example neurodiverse conceptualisations of Dyspraxia/ DCD and the CA, may incorporate the many facets of the lived experience of Dyspraxia/ DCD, possibly helping to mitigate the implications, whether social, academic, financial, or psycho-emotional, of social responses grounded in medical model conceptualisations of dis/ability. This study addresses the lack of sociological studies about the embodied Dyspraxia/ DCD experience across the

lifespan by utilising a methodological approach that fore fronted the perspectives of people with Dyspraxia/ DCD, undertaken reflexively by an insider researcher who has Dyspraxia.

As with all studies, this study was limited by its scope and access to participants. - Access to participants was very challenging because of the emerging nature of Dyspraxia and the lack of diagnosis. While participants were found through state universities and not for profit sectors, it is not known if the sample of participants accessed in this study is representative of the Dyspraxic population. In fact, in various ways, the sample of participants may be likely to have accessed relatively 'successful' Dyspraxic people. For example, the sample of Dyspraxic participants was possibly biased towards those Dyspraxic people who had been aware of their Dyspraxia and successful in the achievement of at least some valued capabilities. However, there is a further population of people with Dyspraxia who may not be aware of their Dyspraxia and successful because of receiving adequate familial support that were also not well represented in this study sample. This study took place in one part of Aotearoa New Zealand and so further research in other parts of the world with different medical and educational arrangements would be of value. For example, in the UK where understanding of Dyspraxia appears to have a longer history, or in the US where access to medical support is primarily privatised. Given the impact of the medical and educational sectors described by participants, studies undertaken in places with different systems would be of value.

A third of Dyspraxic participants were engaged in current university studies, indicating that investigation in other social contexts is likely required. Three quarters of Dyspraxic participants were well-educated or engaged in current tertiary study. It is likely that both the socioeconomic position of participants and the level of education leads to an awareness of Dyspraxia as a condition and access to financial resources to obtain professional assessments. All Dyspraxic participants appeared to be highly motivated to take part in the study. Future qualitative studies could explore different life stages and look at different contexts, for example employment and unemployment in relation to DCD/ Dyspraxia.

7.1 Future Research

A conclusion of this research is that there is a need for considerably more research to better understand the socially situated phenomenon of Dyspraxia in Aotearoa New Zealand. Results from this study suggest that what is lacking from the academic and social response is an exploration of the social origin of many of the disabling experiences that impact on people with Dyspraxia/DCD. There is

significant scope for further progress in determining the role of social structures on an emergent and invisible social phenomenon like Dyspraxia/ DCD.

7.1.1 Methodological approaches

In keeping with Yang et. al. (2007), future studies need to adopt an array of methodologies and perspectives to ensure that successful intervention measures can be created, enacted and evaluated in social settings. In focusing on the CA and other similarly inclusive and process-oriented frameworks, a different account of the Dyspraxia social phenomenon may be understood. For example, if the CA were applied to institutional arrangements in relation to Dyspraxia, then the socially invisible nature of the Dyspraxia lived experience may be highlighted and addressed. Further, research based on a CA methodology has the capacity to be interdisciplinary, allowing for the use of both ethnographic methods and quantitative techniques to explore the experience of Dyspraxia/DCD in Aotearoa New Zealand, and internationally, to better understand QoL outcomes and exposure to social inequality (Robeyns, 2006). Future research into Dyspraxia, adopting frameworks like the CA which already contribute to social science knowledge and policy development, could explore how individuals with Dyspraxia can be placed at the centre of relevant policy creation, prioritising the human dignity of this population and the exploration of their social decision making power (Deneulin & McGregor, 2010). The application of the CA to the lived experience of Dyspraxia as an a priori framework and in a detailed and specific way is likely to yield fruitful and interesting insights, which in turn, could indicate specific ways that Aotearoa New Zealand society could better respond to people with Dyspraxia and to the wider neurodiverse community. The CA in future research may have the scope to create, for the Aotearoa New Zealand context, quantifiable indices (analogous to the Human Development Index) that can be ethically applied to better understand how people with Dyspraxia are supported or adversely impacted by current institutional arrangements.

7.1.2 Inclusive research

Further research is needed to evaluate the impacts of biomedical social discourses and their significance for the lived experience of Dyspraxia/ DCD. Employing a systemic approach to dis/ability can integrate both the physical sciences and the embodied disabled experience in a more inclusive manner than poststructuralist epistemologies to “engage productively, rather than critically, with the material sciences” (Feely, 2016, p.871). Inclusivity, in relation to Dyspraxia, would require people with

Dyspraxia to be included in the research process. Autism research is currently being undertaken by either proponents of the social model, including insider researchers (Guevara, 2021), or professionals who adhere to more biomedical framings (Leveto, 2018). Research into Dyspraxia/ DCD is not being similarly contested in the literature outside of biomedical settings, but rather is dominated heavily by inquiry based on biomedical assumptions. At present, expert knowledge of DCD is predominantly derived from medical practitioners, with DCD research based on deficit-based approaches to diagnosis and interventions that locate DCD symptoms within people with Dyspraxia (American Psychiatric Association, 2013). The recent use of the ICF by DCD researchers represents a step in the right direction, as does the recognition that there is a need for participation of adolescents and adults to inform future clinical responses to DCD (Blank et al., 2019). Where the contribution of disabled stakeholders are taken into account in the public health sector, critics have argued that inclusion is usually along lines of top-down engagement and decidedly tokenistic in terms of public involvement (Berghs et al., 2016).

In future research, it might be possible to use different methodologies to engage with emergent populations, like those of Dyspraxia/ DCD, more productively ensuring they play a primary role in the research process and not merely as the subjects of the research. The neurodiversity movement has much to offer people with Dyspraxia/ DCD, in terms of helping to create a collective identity and a social movement with the potential to advocate for change. Along these lines, autistic self-advocacy groups have called for the need for alignment between the Autistic community and the priorities of researchers which tend to generate research that is framed in deficit based language and that perpetuates social stigma and dehumanizing stereotypes (Nicolaidis et al., 2011). To engage appropriately with the Dyspraxia community, neurotypical researchers need to ensure that people with Dyspraxia remain at the center of all stages of the research process. The Community-Based Participatory Research (CBPR) model, promoted by AASPIRE is the best practice for conducting research that impacts disabled populations (Nicolaidis et al., 2019; Nicolaidis et al., 2011). This model is designed to promote the inclusion of the communities for whom researchers claim to be working on behalf of in all stages of the research process from its conception to its application (Kingsbury et al., 2020). In keeping with Nicolaidis (2011), what is needed is research that promotes inclusion of Dyspraxic people in issues that affect them, as equal partners, employing research questions that are relevant to the Dyspraxic population, to promote positive changes in society for the Dyspraxic community. While there are issues associated with promoting participation in research settings (Fletcher-Watson et al., 2019), respectful engagement with Dyspraxic people can ensure that the production of knowledge, about them, has maximum integrity and the potential to improve people's

lives in both identity affirming and practical ways, for example, to better inform appropriate intervention measures and policy development.

7.1.3 The societal response to Dyspraxia

This study explores possible institutional dis/ablism at a specific period of time which will undoubtedly change in response to how disablism manifests through institutional structures (Came, 2014). Future studies could examine how a society potentially dominated by ableist assumptions could be altered to better incorporate the complexity of differentiated embodied states, like Dyspraxia/ DCD. This research represents a step toward a dialogue that is somewhat dialectical in nature to "transform ignorance and misapprehensions (accepting historically mediated structures as immutable) into more informed consciousness (seeing how the structures might be changed and comprehending the actions required to effect change)" (Guba & Lincoln, 1994, p. 110). Further work also is required to determine the efficacy of educational institutional arrangements in meeting the needs of neurodiverse populations like Dyspraxia. This is especially important given the current study's findings that identify varied and dynamic developmental trajectories for participants that are strongly influenced by their experiences in their school years.

A further possible area for future studies, for the Dyspraxia population in Aotearoa New Zealand, is researching the potential for economic vulnerability relative to the general population, based on measures including: their rate of employment as adults, household income and access to financial capital (Whelan et al., 2015). A further related area for further research in Aotearoa New Zealand would be to investigate the financial costs associated with Dyspraxia, as well as the spending required to meet the needs of the dis/ability (Mitra, 2006) and to ensure social justice and equality (Sen 1999). Additionally, research is needed into interventions for Māori and Pacifika with Dyspraxia and the ability of these populations to access public information about Dyspraxia, and the types of support that may be available.

7.1.4 The lived experience of Dyspraxia

The implications of changes over the lifespan was significant for people with Dyspraxia, indicating the importance of including the lived experiences of adults in future research (Berghs et al., 2016).

An important finding, for example, was that strengths associated with Dyspraxia by Dyspraxic participants promoted access to capabilities and the attainment of valued functionings. A further study with more focus on positive aspects identified by Dyspraxic participants is therefore suggested. That each person is unique and deserving of having their capabilities met (Nussbaum, 2006) is a freedom that study findings suggest may be denied Dyspraxic participants, whose socialization process may not include the discovery of personal strengths in relation to their Dyspraxia through social processes. Relatedly, additional work is needed to understand how the life world of the Dyspraxia/ DCD population is impacted by stigma processes. Many social researchers who investigate stigma are not themselves stigmatized but rather explore stigma theoretically and lack an understanding of the lived experience of the populations under study (Kleinman et al., 1995) such as those with Dyspraxia. Ideally, this research would be undertaken by insider researchers with lived experience of Dyspraxia.

7.2 Recommendations

7.2.1 The effective representation of Dyspraxia

Study findings suggest that despite significant efforts on the part of families, the not-for-profit sector and neurodiversity professionals, there is a lack of representation of Dyspraxia in terms of involvement and consultation on policy creation in Aotearoa New Zealand. Effective representation of the Dyspraxia lived experience would ideally be undertaken by people with Dyspraxia themselves to better reflect the variability and complexity of the Dyspraxia lived experience. Parsloe's (2015) study of Autism has implications for explaining the needs of people with Dyspraxia. In keeping with Parsloe's (2015) ideas, there is arguably a need for people with Dyspraxia/DCD to take ownership of their life experiences, challenge biomedical narratives and advocate for changes in public policy. Similarly, advocacy groups working to support individuals with Dyspraxia need to have representation of Dyspraxic/ DCD people at all organisational levels and promote the experience of Dyspraxia/DCD as one with both positive and negative aspects. Employing means such as national media campaigns to promote social awareness in the Aotearoa New Zealand context.

Where Dyslexic and Autistic populations in Aotearoa New Zealand and internationally are becoming increasingly more vocal in their self-advocacy, people with Dyspraxia are only just beginning to contribute to narratives about their life experience. Dyslexia and Autism communities have advocates

who identify as neurodivergent and who are motivated to challenge deficit framings of their experiences. Conversely, people with Dyspraxia in Aotearoa New Zealand have not self-mobilised and currently lack the social networks and financial capital to represent themselves independently and affirmatively. The reasons for this are multidimensional and may include the fact that most people who have been assessed as having Dyspraxia are in their twenties, and therefore are a young population, with older generations that may possess more agency, frequently less informed about their own experiences with motor coordination challenges.

7.2.2 Social identity and Dyspraxia

Many people with Dyspraxia have likely internalised aspects of normative values in terms of how they perceive their abilities in relation to neurotypical people and may have accepted the deficit framing of their experiences. In response to harmful normative ideals and exposure to oppressive and discriminatory social assumptions, social minorities may embrace the identity of 'Other' in an act of resistance, thereby enabling society to evolve to be more tolerant (Reeve, 2002). Further, identifying as neurodiverse, or Dyspraxic, represents an alternative, systemic conceptualisation and evolving relationship between an individual and their social lived experience with the neurodiversity movement actively resisting normative social assumptions of deviance. Adopting what Castells (1997) calls a project identity, or engaging in the construction of a new social identity for example by identifying as Dyspraxic, can enable the resisting of normative ideologies on social groups attributed a devalued social status helping to create what Castells (1997) calls a 'resistant identity'. Neurodiversity can help to promote a social response to differences, whether physical or cognitive, in terms of human flourishing and in keeping with the CA which celebrates human variation rather than alienating individuals ascribed a differentiated social status. Further, questions of validity over temporal scales, for example whether gene sequencing will one day lead to the identification and rejection of neurodiverse human fetuses can be explored and challenged through a collective neurodiverse, or Dyspraxic, identity. The collective adoption by people of a neurodiverse, or Dyspraxic identity, may promote the conceptualisation that populations currently perceived as 'disordered', possess desirable human traits with much to offer the existential human experience.

The Dyspraxia community in Aotearoa New Zealand has much to gain from aligning itself with other neurodiverse movements, which can contribute to positive framings of Dyspraxia at the level of the collective group and the individual. Collective capabilities result from "a process of collective action" (Ibrahim, 2006, p. 398) and have the potential to be beneficial for all members of the Dyspraxia/ DCD

community (Trani et al., 2011). Having the opportunity to tell their life story was important for many of the participants in this study because they represent a population whose voices have been mostly silenced with well-intentioned parents and medical professionals frequently speaking on their behalf (Atkinson, 2010).

7.2.3 Effective interventions for Dyspraxia

Some practical recommendations mentioned in participant discourses included educators possessing basic knowledge, and experience, of Dyspraxia so that professional development can then use specific programs such as 'Zones of Regulation' and the 'Alert program'. Further use of specific professional development programs that target executive functioning, social interaction skills, handwriting and physical education, were recommended in response to identified areas of difficulty for Dyspraxic students. Improved access to teacher aids and RTLB services was recommended, as was the use of perceptual motor programs to identify new entrant Dyspraxic students. Implementing measures like the Partnering for Change (P4C) model which was developed in Canada in response to extensive wait lists for DCD assessments, was further recommended (Missiuna et al., 2012). The P4C involves a partnership between clinicians, parents, and teachers, the goal of which is to facilitate the collaboration between teachers and OTs within the classroom to enhance teacher confidence and their ability to identify and respond to the needs of a children with Dyspraxia (Missiuna et al., 2012). Greater access to occupational therapists was recommended. Whether modern learning environments or smaller, single celled classrooms were used should be based on the needs of individual Dyspraxic students who may thrive in either. That children should be screened for cognitive processing difficulties in their first year of school and taught in a manner that engaged all the senses rather than relying on verbal cues, was also suggested.

Time to process verbal instructions and the repeated modelling of tasks in an education environment to enable Dyspraxic students to execute an activity and having the opportunity to explain rather than write their work was recommended. Awareness of strategies that would enable a child to transition between tasks, visual prompts, and having spaces that are less stimulating to integrate and process their learning were interventions identified as possibly being useful for neurodiverse learners. Parents were suggested to help familiarize their children with their individual education plan, and/ or educational psychology report, if they had one. In the tertiary sector the use of study plans and comprehensive lecture notes, as well as proficient use of assistive technology programs like 'Grammarly' were also deemed effective for learning.

This study has argued that while the medical and social models can help to explain some aspects of the lived experience of Dyspraxia and, consequently, positively contribute to the lives of Dyspraxic people, new explanatory approaches are required if a more complete account of the phenomenon is to be achieved. For several reasons, the CA has been presented as one way that previous models can be expanded upon because it can incorporate the complexity of the Dyspraxia experience over the lifespan. The CA can incorporate the changing nature of Dyspraxia between childhood and adulthood identified by Dyspraxic participants and highlight the implications of Dyspraxia on wellbeing over the life course. Second, the CA can better explain how Dyspraxic participants frame their own experiences of Dyspraxia as they navigate towards lives that they value. That is, the CA can provide a more flexible conceptualization, such as allowing for the identification of both benefits and weaknesses associated with the Dyspraxia experience. Third, the CA can also conceptualise Dyspraxia as being both a socially situated and embodied phenomenon, one that, for example, requires ongoing adaptation in response to social arrangements, such as through the creation of strategies to achieve the life outcomes that participants value. Finally, the CA has the potential to examine ablest social assumptions and their implications for the Dyspraxia lived experience with an aim to improve social responses to Dyspraxia in Aotearoa New Zealand in the future.

Appendices

Appendix A: Research information sheet

Lincoln University

Environment, Society and Design Faculty

Research Information Sheet

I would like to invite you to participate in a project entitled "Examining the lived experience of people with dyspraxia/ DCD". My name is Maria McAllum and this research is for my PhD at Lincoln University. The aim of this project is to examine the lived experiences of adults with dyspraxia and also to better understand dyspraxia in relation to the wider world. To that end your opinion about dyspraxia in a social context is invaluable to this study.

Your participation in this project will involve a 45-60-minute interview. With your consent the interview will be recorded for transcription purposes.

Your participation in this research is voluntary and you may decline to answer any question. You may withdraw from the project, including withdrawing any information you have provided, up to December 31st, 2018, by contacting me (Maria McAllum) or my supervisors (Kevin Moore and Roslyn Kerr) through the contact details below. A copy of the transcribed interview will be provided for you to review and make any changes to, should you wish to.

The results of the project will be written up and published as part of my PhD thesis. The results of the completed project may be submitted for publication in academic journals and may be presented. However, you may be assured of your anonymity in this investigation: the identity of any participants will not be made public or made known to any person other than the Lincoln University Human Ethics Committee in the event of an audit. To ensure anonymity, individual interview data will be seen only by me and will be stored in an electronic form with password protection. Only aggregated data will be presented in any publications and no information will be reported in a way that might identify individuals.

This project has been reviewed and approved by the Lincoln University Human Ethics Committee. If you have any queries or concerns about your participation in the project, please contact me or my supervisors; we would be happy to discuss any concern you have about participation in the project.

Appendix B: Participant consent form

The lived experience of people with dyspraxia

Consent Form

I have read and understood the description of the above-named project. On this basis I agree to participate in the project, and I consent to publication of the results of the project with the understanding that anonymity will be preserved. I understand also that I may withdraw from the project, including withdrawal of any information I have provided, up to December 31st, 2018.

I consent to having an audio recording made of my interview Yes ( ) No ( )

Name: _____

Signed: _____ Date: _____

Appendix C.1 Interview Questions - Professionals

- Let's start with a story. Can you describe any occasion that stands out for you in relation to your work with people living with dyspraxia?
- How do you work with people with dyspraxia?
- What do you find most difficult about your work with people with dyspraxia?
- What's one of the strategies that works best for you in this work?
- What do you think about diagnostic labels like dyspraxia and dyslexia that are used to describe children? What do you think about current diagnostic categories?
- What is your opinion about the idea that everyone has a unique neurodiversity profile?
- What new resources, in your view, are needed?
- What are, and what is your opinion of the intervention strategies that are implemented to assist children and adults with dyspraxia?
- In your experience, is the help that's available to people with dyspraxia useful to them?
- In your opinion, do teachers in schools have a good understanding of dyspraxia?
- Do you think that teachers have different expectations of children with dyspraxia?
- How does cognitive profiling work? Do you think it is helpful or unhelpful?
- How do you think provisions for children or adolescents with dyspraxia in the education sector could be improved?
- If there could be an ideal educational setting for children with dyspraxia, what would it look like?
- What do you think could be done by the government to help people with dyspraxia?
- How do you think people with dyspraxia fare in their social world?
- What are you most passionate about in your work with people with dyspraxia?

Follow up questions

- Why do you think so?
- What are some of your reasons?
- Are there any other reasons?
- Why do you think people who take the opposite view would do so?
- Do any examples come to mind to illustrate your point?
- Tell me more....

Sub-questions

- Have you worked with many people with dyspraxia? Children or adults? How many adults?
- What is your opinion about how dyspraxia is diagnosed?
- What is your opinion about basing diagnostic criteria on predominantly motor coordination issues?
- In your opinion are there any attributes common to people who have dyspraxia?
- What do you think are the best ways to help people with dyspraxia?
- Can you describe the symptoms of dyspraxia in adults and children?

Demographic questions

- Gender
- Occupation
- Education background in relation to dyspraxia/ DCD
- Years working with dyspraxia/ DCD

Appendix C.2 Interview questions – Participants with Dyspraxia

- Let's start with a story. Can you describe any occasion that stands out for you in relation to living with dyspraxia?
- What do you find most difficult about your dyspraxia?
- What's one of the strategies that works best for you to help with your dyspraxia?
- What is your opinion about the idea that everyone has a unique neurodiversity profile?
- What are, and what is your opinion of the intervention strategies that are implemented to help with dyspraxia?
- In your experience, is the help that's available for dyspraxia useful?
- In your opinion, do teachers in schools have a good understanding of dyspraxia?
- How do you think provisions for dyspraxia in the education sector could be improved?
- If there could be an ideal educational setting for you, what would it look like?
- What do you think could be done by the government to help people with dyspraxia?
- How do you fare in your social world?
- What are you most passionate about with regards to dyspraxia?

Follow up questions

- Why do you think so?
- What are some of your reasons?
- Are there any other reasons?
- Why do you think people who take the opposite view would do so?
- Do any examples come to mind illustrating your point?
- Tell me more....

Demographic questions

- Gender
- Occupation
- Age
- How diagnosed with dyspraxia
- Education background

Appendix D: ADC checklist

Adult Developmental Coordination Disorders/Dyspraxia Checklist (ADC)

As a child did you:				
	Never	Sometimes	Frequently	Always
Have difficulties with self-care tasks, such as tying shoelaces, fastening buttons and sips?				
Have difficulty eating without getting dirty?				
Have difficulties with playing team games, such as football, volleyball, catching or throwing balls accurately				
Have difficulty writing neatly (so others could read it?)				
Have difficulty writing as fast as your peers?				
Bump into objects or people, trip over things more than others?				
Have difficulty playing a musical instrument? (e.g. recorder, violin)				
Have difficulties with organizing/ finding your things in your room?				
Have others comment about your lack of co-ordination or call yourself clumsy?				

Currently: Do you have difficulties currently with the following 10 items:				
	Never	Sometimes	Frequently	Always
Self-care tasks, such as shaving or make-up?				
Eating with knife and fork/ spoon?				
Hobbies that require good co-ordination?				
Writing neatly when having to write fast?				
Writing as fast as your peers?				
Reading your own writing?				
Copy8ing things down without mistakes?				
Organising/ finding your things in your room?				

Finding your way around new buildings or places?				
Have others called you disorganized?				

Please mark the suitable option. Currently.				
	Never	Sometimes	Frequently	Always
Do you have difficulties with sitting still or appearing fidgety?				
Do you lose or leave behind possessions?				
Are you slower than others getting up in the morning and getting to work or college?				
Did it take you longer than others to learn to drive?				
Do others find it difficult to read your writing?				
Do you avoid hobbies that require good co-ordination?				
Do you choose to spend leisure time more on your own than with others?				
Do you avoid team games/ sports?				
If you do a sport, is it more likely to be on your own, e.g. going to a gym, than with other?				
Did you tend in your teens/ twenties or currently to avoid going to clubs/ dancing?				
If you are a driver, do you have difficulty parking a car?				
Do you have difficulty preparing a meal from scratch?				
Do you have difficulty parking a suitcase to go away?				
Do you have difficulty folding clothes and putting them away neatly?				
Do you have difficulty managing money?				

Do you have difficulties with performing two things at the same time (e.g. driving and listening)?				
Do you have difficulties with distance estimation (e.g. with regard to parking, passing through objects)?				
Do you have difficulty planning ahead?				
Do you feel like you are losing attention in certain situations?				

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