LABELS, STIGMA, THERAPEUTIC CULTURE AND DCD

LABELS, STIGMA AND SICK ROLES IN A THERAPEUTIC CULTURE: THE CASE OF DEVELOPMENTAL COORDINATION DISORDER

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Abstract

Labelling Theory stipulates that once an individual exhibits deviant behaviour, such as acting outside of the norm, the public and even close relatives will react to this behaviour by labelling it. Some of these labels result in social and psychological consequences for the individual, and Labelling theorists argue that, at the very extreme, they culminate in a self-fulfilling prophecy wherein the labelled individual fulfills the expectations others have placed upon him/her. Labelling Theory has been questioned for its lack of consistent supporting empirical evidence and still faces much scrutiny by leaving many unanswered questions, particularly within educational contexts. Several societal changes have created a profoundly different climate for labelling in the domains of mental health and education and beg the re-evaluation of labelling theory's original arguments.

This dissertation empirically tests the main tenets of Labelling Theory within an educational setting by exploring the experiences of children identified as having symptoms of Developmental Coordination Disorder in a Northern Ontario city. This study finds that children who are yet undiagnosed with DCD are often stigmatized not only by their peers, but also by educators, public, and even close relatives. However, those children who were formally labelled were granted more opportunities and were often more accommodated within the educational context. It also finds that formally labelled children often had varying degrees of self-confidence; conversely, those who were not labelled or awaiting diagnosis were often more critical of their abilities and were frequently socially isolated. Finally, this study found that parents played an active role in

acquiring formal labels and services for their children throughout the diagnostic process and afterwards. These findings have implications for educational and health care related policies and future research for Labelling Theory.

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List of All Abbreviations and Symbols

ADHD- Attention Deficit/ Hyperactivity Disorder

ASD- Autism Spectrum Disorder

DCD- Developmental Coordination Disorder

DSM- Diagnostic Statistical Manual

IEP- Individual Education Plan

IPRC- Individual Planning and Review Committee

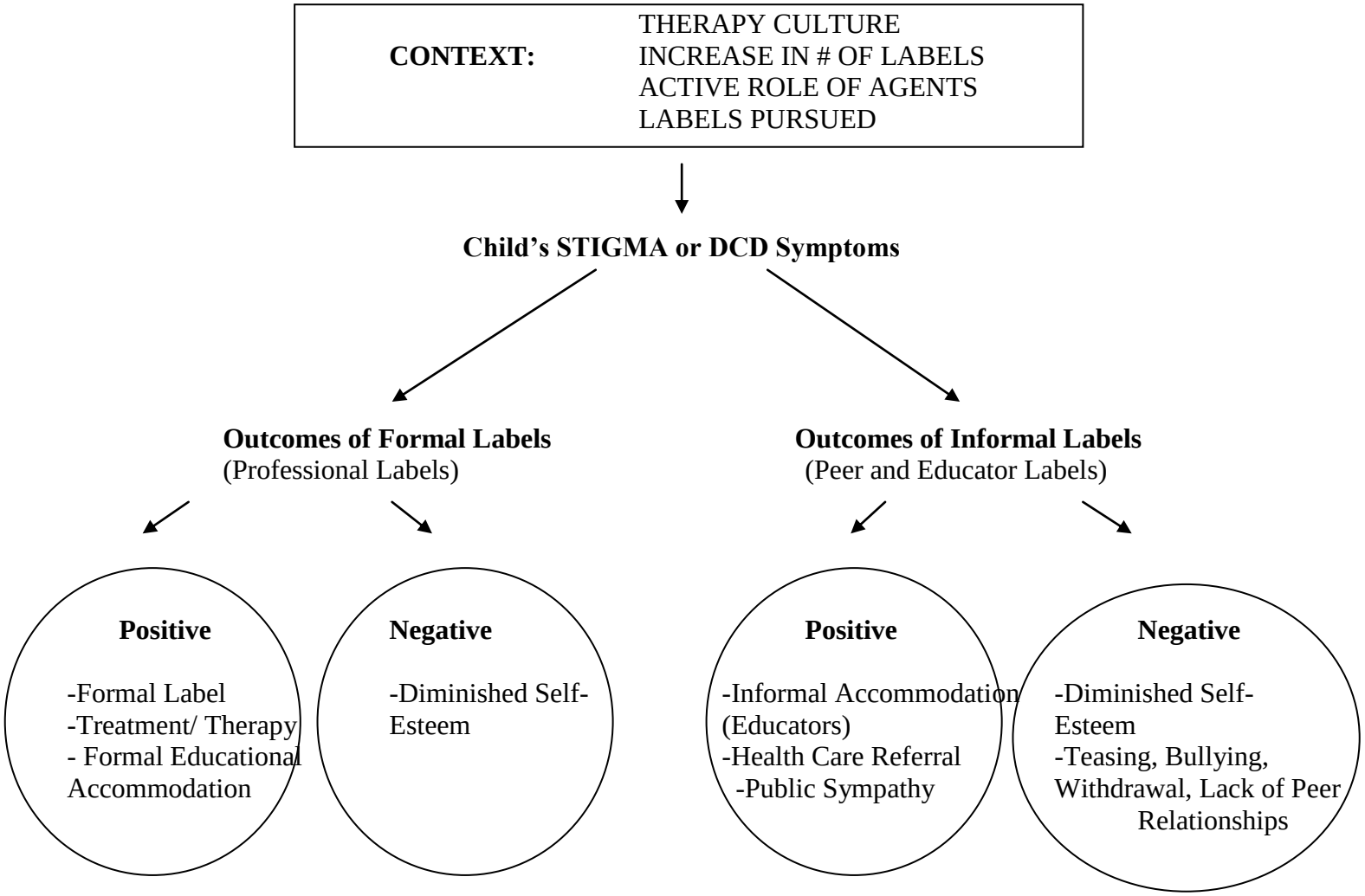
LD- Learning Disability

LT- Labelling Theory

MLA- Modified Labelling Approach

SFP- Self-Fulfilling Prophecy

Diagram 1: Social Reactions to DCD and Plausible Outcomes



Chapter 1: Introduction

For several decades, sociological theorists have believed that the labelling of individuals will have negative consequences such as lowered self-esteem and self-perception. Lemert (1951) laid the foundation for what has been deemed "Labelling Theory" (LT) when he noted that stuttering children increased those behaviours in the aftermath of social reactions to their marked differences. Elaborating on this, Becker (1973) observed that behaviours that deviated from the norm were labelled by those who held more social power, whether by being a professional authority or "moral entrepreneurs," a term Becker (1973) coined for those who were largely designated by society as being responsible for labelling and grouping deviants, such as the police. This concept of labelling was furthered by Goffman's work *Stigma* (1963), which outlined the negative social reactions to various kinds of visible and non-visible conditions among a range of individuals. Grouping visible and non-visible conditions, Goffman stated that individuals could be largely discredited or discreditable on how well they hid this condition; he asserted that individuals would go to great pains to hide their stigma from the general public for fear that they would be rejected.

Building on this work, theorists in the 1970s viewed labelling as a form of social control that comes in two forms: formal labels that are given by professionals such as psychiatrists, pediatricians, and psychometrists; and informal labels that are given by peers, family members, and even educators. Both are seen to trigger three kinds of "secondary effects": individuals may experience social stigma from the label; labels could be used to block various social opportunities such as peer interaction and employment

opportunities, and individuals may internalize negative labels. All three combined may lead to a self-fulfilling prophecy in which the labelled person's deviance is seen to worsen over time and eventually fulfill the expectations assigned to such a label. For example, an individual who has been labelled a criminal may be blocked from various employment opportunities because of the stigma attached to the criminal label; as a result, they suffer lowered self-esteem and continue using criminal tactics as it is expected of them by society. Over the past forty years, LT has been applied to the study of crime, mental health/ illness, and education.

In relation to the context of this study, Rist (1970) applied Labelling Theory to education, arguing that teachers label students in various ways leading to a host of negative consequences, such as limiting educational opportunities by streaming students into lower tracks, stigmatizing them as intellectually inferior, and causing students to internalize that stigma. Most educational Labelling theorists have since argued that labels that are imposed on children by teachers and other classroom aides may be intended to provide children with support, but may ultimately lead to fewer educational opportunities (usually through lowered expectations, ability grouping, and/or downward streaming), stigma, and, along with lowered self-concepts, can contribute to a self-fulfilling prophecy.

However, since the time of Goffman (1963), Becker (1970) and Rist's (1970) initial work of labelling, social conditions and contexts have changed substantially. In general, professional labels have proliferated in the areas of education and mental health. For example, conditions that were once only labelled informally are now given more medicalized terms, such as depression, anxiety, schizophrenia, dyslexia, learning

disability, and, as further discussed below, Developmental Coordination Disorder (DCD). Much of this present day labelling is done by professionals, such as pediatricians and psychiatrists. Consequently, there has been a marked expansion of the fields of special education and childhood disorders, in which special educators and other professionals readily apply formal labels to children's abilities and capacities within the classroom environment. Furthermore, a "therapeutic culture," has emerged, in which a semi-professional and medicalized understanding of children's (and adults') psychological and emotional functioning has entered popular discourse (Furedi 2009). The use of terms, such as self-esteem, self-perception, academic disability, and learning disability, has become common in popular culture to the point of being normalized. Lastly, there is far more awareness about stigma; for example, in the areas of mental health and education, and this awareness has centred on bringing new accommodations and treatments to labelled individuals and has led to the rise of anti-stigma campaigns (Stuart 2012) . Together, these three trends— the increasing number of labels, the rise of therapeutic discourse, and the rise of anti-stigma awareness —may serve not only to increase the odds of children receiving formal labels for a variety of primary conditions, but also to alter social reactions to those labels and ensuing consequences.

Whereas Labelling Theory has always purported that formal labels stigmatize individuals and lead to a self-fulfilling prophecy, new societal conditions may serve to vary the effects of labelling; this highlights an alternative to the sociological tradition, that of the "sick role," a tradition that has been largely ignored in labelling discussions. Parsons' (1951) notion of the "sick role" identifies how those labelled as "sick" may be

excused from normal social expectations and provided with accommodations and treatments for their conditions, thus suggesting that labelling can have more positive benefits. To illustrate, those individuals who are considered ill could be excused from formal duty in the military instead of being labelled as a "traitor" or "slacker." Today, it is possible that in some conditions providing a label may encourage opportunities, not limit them, and may create more positive attributions for deviant behaviour. Shilling (2002) also acknowledged that what is consistently lacking in Parsons' original conception of the "sick role" is how culture contributed to the consequences of this label; in fact, he posited that Parsons was contending with the budding modern health consumer and the societal change towards body consciousness and awareness.

Today, it can be argued that educational labels may perform a similar role; that is, educational labels can exempt children from learning in a "normal" fashion and provide them with varying opportunities to do so. For example, a child who displays certain symptoms that might once have been informally labelled as simply "lazy," "stupid," and "disruptive" may now be formally labelled as "uncoordinated," "dyslexic," or "hyperactive" by educators and healthcare professionals such as pediatricians and psychometrists. And rather than blocking opportunities, stigmatizing them as "failures," and/or lowering their self-esteem, some of these relatively new labels may bring therapeutic regimens and educational accommodations, thereby counteracting the negative effects of informal labels. Thus, while sociologists have persistently focused on the negative consequences of labelling, in this new context, the effect of informal labels may be mitigated by formal ones.

These new possibilities raise questions about the role of formal labels in generating social reactions to non-criminal deviance in the form of physical symptoms. There is a need to examine the ensuing consequences of new labels, to distinguish formal from informal labelling processes, and to examine the conditions under which families actively seek out labels. Some formal labels may be highly sought after by family members and educators if they provide alternative learning opportunities and strategies and alleviate normal learning expectations for children. In contrast, more informal, peer-generated labels, can still stigmatize and lead to a self-fulfilling prophecy, and even negate the intended positive effects of formal labels.

To investigate these possibilities, I examine the effects on children formally labelled with the condition "Developmental Coordination Disorder." DCD provides a test case as a relatively new label that is largely unknown among the general public and health professionals (Missiuna et al. 2006). It has clearly visible physical symptoms, but often goes unrecognized, and thus untreated, by medical professionals. Therefore, even when formal labels and treatments are absent these children are still likely to be labelled informally by their peers. By comparing youth who have been formally diagnosed with DCD with those who have been referred to specialists but not yet formally labelled, I was able to observe the impact of both formal and informal labels.

In this study, I worked with a children's treatment centre and four school boards in Northern Ontario analyzing two groups of children with similar physical symptoms. One group was currently in the process of being diagnosed, while the other had already been given a formal label of DCD and was receiving treatment. Various methods were used to

examine the effects of labels on children's social opportunities, social stigma, and self-conception. I interviewed three sets of actors: children, parents and teachers. Each interview source connected to one or more of the four research questions. Firstly, to elicit how children viewed themselves before and after receiving the DCD label, I interviewed children using the Perceived Efficacy and Goal Setting System (PEGS: Missiuna, Pollock & Law, 2004) instrument or with an interview instrument based on this assessment and suggestions from the literature. Secondly, parents were interviewed to address how they viewed children's experiences in the diagnostic process. Thirdly, to explore the possible effects of labelling for children at the school and among peers, I interviewed teachers to elicit their perceptions of how students fared in their classroom interactions, the child's self-worth and behaviours, and their own attitudes of integrating children into their classrooms. Current and previous teachers of children were interviewed to gain a retrospective account of their perceptions of the child. This retrospective bias can occur in any three of the interview sets as recalling experiences can often elicit feelings that are skewed more positively or negatively for any individual; this is somewhat compensated with the comparative components of each set. Lastly, to complement each of these components, all of the children were observed for a period of five days in the school and home environments for social reactions and peer relationships. Comparing the interviews of undiagnosed and diagnosed children, teachers and parents, as well as observational notes, I obtained a rich set of data on understanding peer relations and the effects of labelling in various contexts.

Prior to the discussion of findings, a narrative is provided on each child, their family life and settings. These narratives are meant to contextualize the discussion of my findings for the reader. The narrative chapter also includes a table to which the reader can refer. These findings are organized according to the relevant research questions posed in this study; within each of these research questions exist sub themes which are highlighted in relation to previous literature and the theoretical paradigm guiding this project. The implications of these findings are discussed in the final chapter which focuses on three major areas of discussion: 1) Implications for Labelling Theory; 2) Implications for future research on both DCD and labelling; and 3) Implications for educational and health policies.

Chapter 2: Theoretical Framework and Literature Review

Much of a person's identity and self-concept is derived from the beliefs and reactions of their peers and families. Early microsociologists, such as Mead and Cooley, noted the importance of general society's perceptions of an individual, as well as the individual's interpretation of these perceptions, in forming an individual's self (Wellford and Triplett 1990, Adams et al. 2008). Some of these researchers, such as Lemert (1951), Goffman (1963), and Becker (1973), were especially intrigued by how deviant behaviours triggered public reactions and were among the first to study societal reactions to an individual's non-normative behaviours and characteristics. However, their core understanding of these reactions centred on the notion of stigma provided by Link and Phelan (1999a). Goffman (1963) believed stigma derived from any blemish of physical feature, character, or personality, or of race or ethnicity; thus, stigma is "any attribute that is deeply discrediting" (Goffman, 1963: 3). Stigma has two components: (1) a physical or non-physical attribute, which ultimately leads to (2) a reaction to such attributes from members of society.

Labelling of these various primary attributes—such as behaviour, skin tone, and physical features—occurs when they are seen to deviate from social norms (Becker 1973, Scheff 1984, Link and Phelan 1999a). As Becker (1973: 9) stated, "social groups create deviance by making the rules whose infraction constitutes deviance and by applying those rules to particular people and labelling them as outsiders. There are marked differences between labelling deviant behaviour and stigmatizing physical attributes." Becker (1973) believed that "normal" individuals are able to reflect on their deviant impulses and

behaviours and adjust them to suit the needs of others and society in general while Goffman (1963) emphasized the physical attributes as being stigmatizing. As a result, Labelling Theory was born from both Goffman and Becker's work. Others, such as Wellford (1975) and Gove (1970), have also contributed greatly to its propositions and ultimately its popularity.

This popularity has led to applications in three mains areas: criminal justice, mental health/illness, and education. For example, Scheff (1974, 1984) developed Labelling Theory within the mental health area and applied its tenets to the mentally ill. Scheff postulated that labels themselves prompted secondary and dire consequences. Scheff (1974), and those in his camp, believed that once a label was ascribed, it became a master status thus dictating residual rule-breaking, or continual involvement in deviant behaviours (Scheff 1974, 1984). For Scheff, these labels were ascribed by various institutions for means of social control and manners of efficiency; labelling was part of a degradation ceremony which exposed individuals to various societal reactions. This meant that individuals were stripped of their previous identity and given a new one, for example stripping of outside clothes, personal belongings and instead being made to wear a uniform and shave their heads. For Scheff (1974), the field of mental illness was seen as a social institution that had its own rules and imposed these rules in a number of ways including rewarding normative behaviour and punishing non-normative behaviour. In his formulation of Labelling Theory, Scheff (1984) outlined a total of nine propositions concerning the theory of being mentally ill; propositions one through five are concerned with the understanding of how interactions and reactions take place for those with mental

illnesses while propositions six through nine involve the labelling of mental illness. These are summarized as follows: labelled individuals are highly vulnerable to suggestion and may therefore be rewarded for playing the part or punished if they revert back to their previous actions. As a result of these propositions, labelling is considered the "single most important cause of careers of residual deviance" (Scheff 1974: 93).

Motivations, a component that has been overlooked by early LT, were of the utmost importance to Scheff (1974). Scheff (1963) argued that these motivations need to be located within a broader social context; namely, the interaction between human action, and this social context provides for a rich understanding and application of human behaviour and LT. But despite its popularity in all three areas, Labelling Theory has been fraught with controversy over the lack of empirical evidence for any of these original tenets.

Gove (1975), a critic of LT, believed that any secondary effects were derivative of the primary condition, rather than from the labels themselves. He maintained that there was no empirical evidence to support LT; thus, LT was unfounded. Ultimately, he was more interested in why some individuals are labelled and why others are not and suggested that conditions such as socioeconomic status (SES), educational attainment, community tolerance, and degree of stigma visibility could be contributing factors (Gove 1975). More importantly, Gove was an avid opponent of Scheff's (1984) premise that individuals are labelled for purposes other than being actually mentally ill. Gove (1970) argued that individuals are labelled as mentally ill simply because they were mentally ill. More telling is the fact that LT is empirically weak and not reliably tested (Gove 1980).

In short, he contended that it ignores such criticisms and simply proclaims that labels are the single most powerful predictor of subsequent criminal behaviour, rather than familial context, peer relations, and school experiences, which have been empirically verified (Cullen and Agnew 2006). However, through the empirical research conducted by Scheff and his followers, three prominent themes of LT emerged: societal reactions to stigma, social and psychological consequences of labelling (altered self-conceptions), and limited/restricted opportunities (Davies and Tanner 2003), which ultimately all lead to a self-fulfilling prophecy (SFP). Thus, for traditional LT, labels have an independent causal power that eventually creates a self-fulfilling prophecy. For critics such as Gove, ongoing deviance is simply the continuation of the primary conditions, with labels having no additional or independent causal effect. In the next section, I discuss the major themes within LT and the SFP and review empirical research which may or may not support each tenet.

2.1- MAJOR THEMES WITHIN LABELLING THEORY

Societal Reactions and Stigma

Labelling Theory first explored the reactions of the general public and the integral role these reactions played in shaping the experiences of labelled individuals—against whom many are directly discriminated. For example, Link (1987) noted that individuals labelled with mental disorders are often excluded and rejected from social settings; the severity of these social reactions, which often defame a labelled individual's character (Lemert 1951), largely depend on the nature of the stigma or primary condition (Link and Phelan 1999b).

These general reactions of peers and social groups are important to both the individual's interpretation of the label and to the formation of individuals' own reactions to such (Gove 2004). Link (1987) found that societal reactions to labels are important in determining how the individual themselves would react and proceed: he posited that mental health patients who have been labelled with various mental disorders expect to be socially rejected, and that this expectation informs their future actions. Furthermore, Jones (1977) asserted that mentally ill patients often suffer more from societal expectations and reactions than do other types of individuals. Even professionals are guilty of reacting negatively to labels; label-based prejudice is common among health professionals (Stuber, Meyer, and Link 2008), admissions staff, and police, who often exhibit grossly exaggerated reactions to incoming psychiatric patients (Scheff 1984). However, more recent research has shown that professionals view mental illness more sympathetically and positively (Chambers et al. 2010), but this varies with their exposure to and experience with mental illness. Reactions to any attribute can be exaggerated or exacerbated (Lemert 1951), particularly if the stigma is threatening, but the intensity of these reactions is mitigated by the degree of visibility of the stigma (Goffman 1963, Katz 1981). In this capacity, stigma can vary in intensity by other actors' familiarity and view of the primary condition. For example, relatives and immediate family who have firsthand experience with a mental illness may accept an individual more than someone in the lay public who has no knowledge of the illness or person.

The general public reacts to stigma by assigning both formal and informal labels. Professionals, such as physicians, psychiatrists, and judiciaries give formal labels, while

informal labels can be given by all individuals. Examples of formal labels include criminal, mentally ill, depressed, or learning disabled. Much of the literature on Labelling Theory has focused on formal labels, based on the claim that these labels lead to negative outcomes. There has been little attention paid to the differentiation between effects of informal and formal labels. While both sources of labelling can easily set an individual apart from the norm of their peer group, each provides for vastly different experiences and outcomes. For example, Whalen et al. (1983) found that children's judgments of peers are a powerful predictor of performance and that both children and teachers are both active agents of informal labelling; because of these educator-provided informal labels, children can often be limited in their opportunities to learn or be pigeon-holed as not being able to learn above a certain level. In addition, when presented with specific labels, both educators and children have reacted more negatively to children with attention deficit, hyperactivity disorder than those with mild learning delays (Bell et al. 2010), which shows that even formal labels can have negative connotations attached to them. The most deviant of children for these two groups is the antisocial child, or those informally labelled based on their non-normative social behaviours. These judgments made by teachers and peers have direct consequences for those being labelled (Whalen et al. 1983; Gill and Maynard 1995), such as limiting the learning potential of these children. Even formal labelling agents often proceed with caution believing that labels can lead to differential treatment (Gill and Maynard 1995).

Peer directed informal labels can be given differentially by boys and girls (Bakker et al. 2007). For example, girls are more likely to be socially rejected if peers perceive their

academic ability to be low versus girls who are perceived as high achievers and popular as a result (Bakker et al. 2007). At the same time, these informal labels and reactions can be negotiated by age level (Bakker et al. 2007, Dijkstra et al. 2008). Bell et al. (2010) discovered that even with predominantly negative educator attitudes and reactions to such labels as ADHD, sympathy can be garnered with increased knowledge and awareness. Labelling Theory has ignored this idea and largely discounted the role of context in labelling individuals. Its main concern has centred on this idea of societal reaction to individual deviant behaviour, as reactions constitute the first step to more prominent consequences of informal and formal labelling (Bernberg, Krohn and Rivera 2009).

Limited/ Restricted Opportunities

Another key consequence highlighted by Labelling Theory is the limited or restricted opportunities that labelled individuals experience (Anthony 1993, Bernburg 2009). This was first elaborated upon within criminological research claiming that those who are labelled criminals often experience hindered employment opportunities because of routine criminal background checks (Bernburg 2009). The reduction of employment opportunities is both a result of the label itself and also the restricted educational attainment that labelled individuals experience (Bernburg and Krohn 2003). More specifically, Bernburg and Krohn (2003) stated that once labelled as troublemakers or deviants, school officials are more likely to limit these individuals from educational opportunities. This is also echoed in Hjalmarsson (2008), who cited that the incidence of incarceration has a negative effect on high school completion. In this case, Hjalmarsson (2008) speculated that reduced educational opportunities have much to do with the stigma

of being incarcerated. Furthermore, Tanner, Davies and O'Grady (1999:20) reasoned that "delinquency in adolescence yielded a negative dividend and reduced educational and occupational attainments in young adulthood, especially among males." Similarly, Davies and Tanner (2003) observed that more severe forms of labelling resulting from sentencing and incarceration have more profound effects on long-term educational and occupational outcomes. More recently, Kirk and Sampson (2013), who discovered that peer stigma and rejection, educational stigma, and individual attachment do not explain higher dropout rates, speculated that dropout rates could be due to institutional factors such as the recent implementation of "zero-tolerance" policies. Consequently, there is an increased need to acknowledge how stigma at both the individual and structural level could contribute to decreased educational opportunities (Kirk and Sampson 2013).

Conducting a study of criminal offenders, Pager (2012) learned that the mark of incarceration leads to decreased employment opportunities overall despite variables such as race. In another study, Rasmusen (1996) elaborated that employers and fellow employees are less likely to interact with heavily stigmatized labelled criminals once their identities are revealed. Employers justify their behaviour by stating that criminal activity is a mark of overall reduced productivity; however, this criminal stigma is dependent upon how much information is included on the criminal record. As time fades so too does the stigmatizing effect of the criminal record (Rasmusen 1996).

And just as labelled criminals are discriminated against, those with mental illnesses could also encounter restricted opportunities. For all fifty states, Burton (1990) analyzed the legal codes for those with a mental illness and who had been criminally

charged. He found that those labelled mentally incompetent and ill were and still are denied rights to hold office, serve jury duty, be a parent, and even marry. He concluded that the "mentally ill, incompetents, and ex-felons lose numerous civil rights" (Burton 1990: 274). Moreover, those with mental illnesses or incompetence were more restricted in their civil rights and opportunities than those with criminal offences (Burton 1990:274). This is echoed in Link's (1987) discussion of the mentally ill in which he reasoned that those with mental illness are often excluded from social interactions and groupings. However, as Burton (1990) concluded, future research should focus on how these restrictions have changed with time and social context and differ from regional to state variations.

Social- Psychological Consequences and Internalization of Labels

One of the other major concerns for Labelling theorists is how this stigma and restricted opportunities can prompt social and psychological consequences, such as "the weakening of social bonds and the accompanying feeling of shame and guilt" (Scheff 1984: 171) and lead to internalization of the label. Jones (1977) noted that reactions to formal labels shape individual behaviours and self-feelings (Scheff 1963). These social psychological consequences and behaviours (Davies and Tanner 2003) often manifest in the forms of further delinquency (Becker 1973, Scheff 1984), a more negative self-perception (Lemert 1951, Katz 1981), lowered mental health (Link et al. 1989, Shea and Wiener 2003) and decreased self-esteem (Rist, 2001).

These aforementioned consequences could lead individuals to social withdrawal and feelings of inadequacy (Link et al. 1989). Furthermore, they give rise to inadequate

coping skills and an overall decrease in self-esteem and social interactions with others (Link et al. 1989, Hayward and Bright 1997, Markowitz 1998, Kroska and Harkness 2006). At the very extreme, labelled individuals suffer from higher levels of depression and anxiety and often consider suicide (Huntington and Bender 1993, Wilson et al. 2009).

Link (1987) claimed that labelling mentally ill patients evokes in them a sense of rejection leading to increased discrimination from the public. Others, in the context of education, have discovered that labelling students could lead to a host of social and psychological consequences, such as lowered self-esteem, self-confidence, and increased delinquent behaviour (Rist and Harrell 1982, Kelly and Norwich 2004, Ladd and Linderholm 2008). However, these consequences could be buffered by familial relationships as well as by school, peer groups, and therapeutic settings (Nind et al. 2010), a contingency not highlighted in LT. Peer relationships, in this regard, are critical to building children's self-worth and esteem (Nind et al. 2010) but are also negotiated and mediated by family resources, children's own personal resources, and individual agency (Nind et al. 2010).

Individuals with physical stigmas tend to elicit positive and sympathetic reactions from the general public (Page 1984), including a willingness to exempt these individuals from normal role expectations (Parsons 1951). In addition, Link et al. (1989) propose a modified approach to Labelling Theory, which acknowledges this variability in the attitudes of the general public. Link et al. (1989) further theorized that the individual's own beliefs could shape the reaction of the general public, and, although labelling could place the individual at an increased risk of other disorders, it does not create mental

illness nor does it always exacerbate it. Using this modified labelling approach, Kroska and Harkness (2006: 344) offered empirical evidence to support the theory that labelling affects individuals' self-perceptions. To illustrate, they stated, "Self identities and reflected appraisals have direct implications for behavior." Thus, peers and professionals can have both positive and negative effects on the labelled individuals: formal labels could provide opportunities for support and treatment; by the same token, informal labels could be stigmatizing and limit opportunities.

In sum, empirical research concerning the tenets of LT suggests that not all consequences are negative and are highly contingent on a number of factors: while some individuals react to labels in highly negative ways, others can respond in vastly different, more sympathetic ways. Finally, the reactions and ensuing consequences from either type of label could vary according to a number of conditions and contexts.

The Self-Fulfilling Prophecy

All of these basic tenets: stigma, limited social opportunities, and internalization of social psychological consequences, are integral to the development of what labelling researchers have called the self-fulfilling prophecy (SFP) -the self-fulfilling effects of Labelling (Thomas 1997:81). The idea of the self-fulfilling prophecy emerged from Thomas's definition of a situation but Merton was first to elaborate and stated that "the self-fulfilling prophecy is, in the beginning, a false definition of the situation evoking a new behavior which makes the originally false conception come true" (Merton 1948: 195).

Within LT, the work of Becker raised awareness of the theme of the self-fulfilling prophecy. He alluded to the self-fulfilling prophecy in his discussion of the criminal career—the "sustained deviant acts" an individual employs in his or her lifetime (Becker 1973: 30). Once labelled as criminals, individuals become immersed in a subculture with expectations coinciding with their deviant behaviours; thus, they are socialized within this subculture, perpetuating their careers as criminals. Jones (1977:90) elaborated that the expectations and reactions the public has towards labelled individuals may set them on a path of criminal careers or "lifestyles." These individuals, vulnerable at the outset, are degraded and excluded on a regular basis (Jones 1977) and succumb to societal expectations (Scheff 1984). Even Goffman (1963) remarked on how mental patients residing in the asylum can avidly act out their shame once given the label. Goffman (1963), describing the institutional aspect of the patient's career, outlined the number of moral changes that took place once a patient was admitted to the asylum. He delineated three phases of these moral changes: the pre-patient, inpatient and ex-patient phase (Goffman 1963), moral referring to patient's beliefs and behaviours as they move through the institutional system. As a result, these labelled individuals perceived that their opportunities were limited (Elliot Ageton and Canter, 1979), which in turn may have precipitated an increase in deviant behaviours (Elliot et al. 1979). And even though Goffman and Becker's concerns are vastly different in terms of their population, the concept remains the same: labelling primary deviance causes secondary deviance.

Both Becker and Goffman placed an emphasis on the career of the criminal and patient. Becker (1973) began by understanding why individuals would commit a deviant

act, discovering the reasoning behind ignorance of conformity to rules and moral codes, but also acknowledging that as they mature, individuals begin to increasingly conform to social expectations. Becker (1973) stated that one of the crucial steps in fulfilling a criminal career is the act of being caught and labelled. Once labelled, the individual becomes part of a group of deviants in which they learn various behaviours and mannerisms, which allows them to exert deviance with minimal effort in society. Goffman (1961), in describing his three phases of being a mentally ill patient, readily admitted that patients take on the label to which they are assigned.

Gove (1970) was very critical of the SFP of labelling and posited that any long-term effects of labelling are merely the result of the primary conditions; in other words, SFP does not exist for those who were labelled. Gove discounted much of LT's evidence for SFP; thus, SFP was theoretically but not empirically sound. This SFP is also affected by the source of labelling: Goffman even asserted that a "relatively small group of pre-patients come into mental hospitals willingly, because of their own idea of what will be good for them, or because of wholehearted agreement with the relevant members of their family" (Goffman 1961: 131). Hence, patients enter the asylum already pre-labelled by informal sources, themselves, or by "moral entrepreneurs." Nonetheless, these basic tenets of Labelling Theory, as outlined by Becker, Goffman, Scheff, Link and others, provide the backdrop for a wide array of applications and empirical research in the areas of sociology of crime, mental illness, and education.

2.2- APPLICATIONS OF LABELLING THEORY

Crime

The foundation of Labelling Theory within the context of crime can be found in the works of Lemert and Tannenbaum (Cullen and Agnew 2006). Both Lemert (1951) and Tannenbaum (Cullen and Agnew 2006) noted that deviation must be socially visible for any reaction to take place; therefore, social reaction is key for understanding deviant behaviour as it is the centrepiece to this analysis. Lemert's study focused on the repercussions that sociopathic behaviour has on the general reactions of the public, in which "admiration, awe, envy, sympathy, fear, repulsion, disgust, hate and anger are felt and manifested by those confronted by departures from their sanctioned ways of behaving" (Lemert 1951: 54). Becker (1973), also interested in public reactions, stated that labels are socially constructed to categorize individuals who defy norms of behaviour and action; further, these outsiders not only gradually accept their labels, but also exhibit the behaviour associated with said labels. Interestingly, Becker also found that in certain groups, labels are pursued more vigorously as a means of social acceptance. In his study of musicians, Becker (1973) observed that this group pursued behaviour that was deemed abnormal as a means of being labelled even more eccentric. This eccentricity legitimated their career and acceptance as a musician. However, Becker (1973) also acknowledged that there are agents, termed "the moral entrepreneur," whose sole purpose is to label others in order to make them more normal, by grouping them and providing them with some sort of punishment or treatment. Labelling, in this case, is a means of rehabilitation.

Most of the crime literature focuses on the harmful consequences and social control mechanisms in place for those labelled a deviant (Rains et al. 2003). The "moral entrepreneur" is merely an agent of social control. Rains et al. (2003) also argued that the

reciprocal is true; namely, social control can cause deviance, an unpopular notion for some. Rains et al. (2003) explained that this could be easily observed by the creation of groupings of deviant behaviour. Arguably, some researchers in deviance do not share this view, suggesting that labelling is not as negative as portrayed and that, from an institutional point of view, labelling can be an "essential component of social order, particularly in bureaucratic settings" (Rogers and Buffalo 1974:103). The main concern for crime researchers is that labelling can lead to a criminal career (Bernburg Krohn and Rivera, 2006) in which the individual is encouraged to fulfill his/her criminal destiny as a result of being given a label. Thus, in the area of crime, few view labels as having positive effects; however, within the next two areas of application, mental illness and education, there is much more to debate concerning the negative and positive effects of labelling.

Mental Illness and Mental Health

Within the field of mental illness research, Scheff is the most prominent theorist of Labelling Theory, remarking that emotions such as guilt and shame lead to compliant behaviours (Scheff1963) and informal labels, accepted by all involved, and prompt secondary behaviours for individuals (Scheff 1963; 1984). However, these informal labels could be transitory. More distinctly, Scheff viewed the labelled individual as suffering the direst consequences while those who were not labelled, but exhibited similar behaviours, may experience some deviance, but it was fleeting (Scheff 1984). Thus, according to Scheff (1984), labels caused secondary consequences, and individuals are labelled to be normalized; yet, if the labelled individuals attempt to revert back to their deviant primary

behaviours, they are punished in various ways, including formal punishments such as increased prison time, additional medications, and similar negative consequences (Scheff 1963). Therefore, these secondary behaviours that develop are seen to be a result of this labelling and not the actual disorder. Researchers who identify with Scheff's work are concerned with the relationship between primary and secondary behaviours and claim that labelled individuals are likely to internalize such expectations and reactions and develop secondary behaviours (Link 1987).

Rosenfield (1997) noted that any presence of stigma decreases patient recovery and life satisfaction. However, key research also identified a variety of mechanisms at work in assessing labelling effects, including self-perception of the label, reaction of the general public to deviant behaviours and labels, and acceptance of such by the individual (Link 1987; Link et al. 1989). Link (1987) highlighted that an integral component of the consequential effects of labelling is the labelled individual's own perceptions of the label. The individual's awareness of the label, the public conceptions of such, and the individual's subsequent self-perceptions are all necessary to understanding the labelling process (Link 1987). This process may lead to negative outcomes, such as inadequate coping skills, overall decreases in self-esteem, and fewer interactions with social groups and peers (Link et al. 1989).

Within mental health research, LT has been revised and termed "The Modified Labelling Approach" (MLA) by Link et al. (1989). This new MLA focuses on the consequences of labelling rather than its causes (Link et al. 1989: 201). MLA acknowledges the role of the labellee's perceptions and reactions to the label on their

social opportunities and relationships. As Link et al. (1989: 201) stated, "[Labelling Theory] does not address the more complex ways in which labelling and stigma may be important in the lives of psychiatric patients." Indicators of the effects of labelling on mental illness are seen across categories, and not limited to more severe categories of disorders: discrimination and devaluation are commonly reported among all groups of individuals, despite their diagnosis (Link 1987; Link et al. 1989). It is the personal reactions to the label that can also form secondary deviance behaviours (Link et al. 1989) unlike what Scheff originally proposed in his work, in which labelling was the cause of such deviance. The acknowledgement of such personal and societal reactions combined to predispose individuals to further mental illness risks (Link et al. 1989). In fact, using MLA, Wright, Gronfein, and Owens (2000) established a study to observe how mental patients in one community experienced stigma and mental illness. They found that the mental patient's own expectations are quite important in the experience of stigma and that community context is essential to underscoring this experience. "Modified," then, means several things for Labelling Theory (Link et al. 1989). It means that labels can have a profound impact on conceptions of self, not only for the labelled individual but also for those who are not labelled and within the labelled individual's social network. Subsequently, others around the labellee would also have their own meanings of the label. Furthermore, there are individual contingencies surrounding the beliefs associated with mental illness and labelling, in general.

Others have looked at how labelling is experienced differentially by various conditions and how agency might play a role by incorporating ideas from both LT and

Parsons's sick role (Morrison 2005). The original tenets of LT overlooked the incorporation of both of these aspects and emphasized that labelling is done solely by "moral entrepreneurs," who work for the state and professionals defending their jurisdiction. For example, one condition that has been examined, but not acknowledged by Labelling Theory, has been social status. Using this variable, Thoits (2005) examined labelling processes and claimed that there have been mixed results. In her study, Thoits (2005) explained that both labelling and self-labelling (whereby individuals label themselves) processes have a tendency to contain overrepresented groups in psychiatric treatment. She elaborated that classic LT emphasized that those with lower statuses will be overrepresented while self-labelling theory emphasized how those with higher levels of education and income will enter at differential numbers. Comparing these two groups— treated vs. untreated populations— did shed light on this "old problem," and Thoits (2005) determined that those with lower status are not overrepresented; those with more education and income are more dominant amongst those who utilized voluntary services. This finding offered partial support for her hypotheses; thus, those with more education are consistently overrepresented amongst individuals who seek out treatment (Thoits 2005).

Morrison (2005) believed that Scheff's emphasis on emotions was overlooked in the experience of labelling. Further, she highlighted the importance of social context in shaping the labelled individual's internalizations. Proposing that different contexts and expectations produce different outcomes for labelled individuals, Morrison (2005) focused her research on how the social movements of current and ex-patients could

largely change the perceived role of the mental patient (Morrison 2005). She concluded that this movement has not only been responsible for combating stigma in mental illness but also challenging the very nature of psychiatric practice. Thus, research within the area of mental health has shed light on several important findings: those who are labelled do face stigma and rejection; however, this is also contingent upon the labelled person's perception of the label. In addition, outcomes for the labelled individual are highly dependent on the social support which is available and other contextual factors, such as socioeconomic status and cultural expectations.

Labelling and Youth with Disabilities

Labelling Theory has been applied to other areas outside of deviant behaviour and mental illness; another application is best seen within the area of youth with disabilities (Gill and Maynard 1995). Within this application, Gill and Maynard (1995) see LT as more of a social activity than a reaction; for example, for Gill and Maynard (1995) individuals are active negotiators in the process of labelling rather than passive. Similarly, a number of studies have applied this concept and LT to youth with disabilities (Gill and Maynard 1995, Green 2003, Green et al. 2005, Russell and Norwich 2012).

Gill and Maynard (1995) criticize LT for not fully appreciating the social context in which labelling occurs and argue that both it and structure are important in understanding how the process of labelling unfolds. In their study, Gill and Maynard (1995) followed twelve families from the time of their child's referral in an attempt to understand this labelling process from all viewpoints (physician, parent, and child). They found that contrary to LT tenets, physicians proceeded cautiously at discussing the

official label with families and children and reciprocally, parents and children were active in the labelling process. For example, parents and children were able to express their views and discuss them with the physician.

Green (2003) finds that family members can also experience was has been termed 'courtesy stigma,' something that LT did not acknowledge in its original form. Courtesy stigma refers to the effect that an individuals' stigma has on family members' overall sense of well-being; thus stigma has an impact on all facets of the individuals' life including those close to them (Green 2003). In both Green (2003) and Green et al. (2005) stigma was found to affect the well-being of individuals and their family members; specifically, stigma can often leave labelled individuals feeling worthless and isolated while at the same time, mothers of the labelled individuals, often felt that they are to blame for the disability their child has (Green et al. 2005). Contrary to this, Russell and Norwich (2012) found that parents of children with Autism Spectrum Disorders (ASD) would cope by managing their feelings by researching the disorder and searching for biological explanations of the disorder to deflect any feelings of blame. These parents also reconstructed ASD in a more positive fashion (Russell and Norwich 2012).

Education

Unlike crime, and similar to mental health and children with disabilities, labelling children has been premised to be beneficial within educational settings. However, most Labelling theorists would argue otherwise, that labelling is a form of punishment both within crime and mental illness (Rains et al. 2003). Within education, formal labelling has been seen as a mechanism for learning opportunity and assessment. This is countered by

Rist (1970) who, through his observations of educational settings and processes, contributed to one aspect of understanding the effects of labelling in education. He noted that formally labelled children experience more social rejection from their peers, receive less support and more criticism from their teachers, and tend to have lowered educational achievement (Rist 1970, Rist and Harrell 1982; Rist 2001). In his original labelling piece, Rist (1970) argued that placing formal labels on children subsequently causes teachers, peers, and even the labelled student to expect much less of themselves; in turn, these lowered expectations decrease the educational outcomes for these children. Essentially, labelling sets in motion the self-fulfilling prophecy. Rist concluded, "Schools existed…to shackle society's least able with "ascribed labels" (Wineberg 1987:32).

Educators also exhibited negative reactions to disability and stigma. Formally labelled students (i.e. labelled as having learning disabilities or ADHD) are often ignored and rejected by indifferent teachers (Cook, Cameron, and Tankersley 2007). According to Rist (2001) and others (Rist and Harrell 1982; Ladd and Linderholm 2008), teachers can view labelled children as uneducable; as a result, the children's opportunities for success are limited. In an effort to advance LT within the educational context, Rist (2001) paid particular attention to the experiential factors that contribute to the labelling of individuals. He stated that as we label, we draw upon various experiences. In the case of education, teachers can draw upon their credentials and their judgments of children's physical and academic inabilities; moreover, they can rely on their previous experiences with children with special needs. Regardless on which experiences educators base their judgments, the effects of labelling students are profound (Rist 2001).

Schools, however, are contexts in which both formal and informal labels are present and are a vastly different environment than that of prisons and mental asylums/ institutions. Informal labels can be very derogatory, particularly for those with physical differences. Thomas (1997:80) noted that "peer labelled students," those who are called more informal names such as fatso, loser, nerd, etc., endure isolation and ridicule from their classmates." Peer victimization is common in schools (Carter and Spencer 2006, Cummings et al. 2006) and students who are peer labelled are often stereotyped, gossiped about, or shunned (Shea and Wiener 2003; Kelly and Norwich 2004). These children are more likely to be socially rejected than their non-labelled peers and may be excluded from peer play altogether (Hoza 2007). Yet, the effects of more formal labels, from professionals, still beg further exploration. For example, within an educational context, the self-fulfilling prophecy is shaped by teacher expectations, peer stereotyping and stigma transference (the child's fear of being labelled or discovered). Although this idea of the self-fulfilling prophecy has been empirically well-developed (Wilkins 1976), the outcomes vary (Eder 1981, Wineberg 1987). Ability grouping is one strategy used by teachers that may encourage the self-fulfilling prophecy. Eder (1981) stated that as students internalize lowered expectations and experience fewer positive outcomes than their unlabelled peers, these children do not achieve the levels of their non-labelled counterparts. Therefore, these lower-ability groupings are often hindered from achieving more than what was expected from them as teachers spend less time with them (Boaler, William and Brown 2000).

Eder (1981) also identified a second type of mechanism influencing the self-fulfilling prophecy: the difference between teachers' expectations and students' abilities. Accordingly, teachers may expect negative outcomes from a student even though the student possesses the ability to achieve positive results (Jussim, Eccles, and Madon 1996). Students are well-aware of teacher expectations and interpret and internalize these cues on a regular basis; despite a student's ability, these expectations shape the student's future actions and decisions (Weinstein, Gregory, and Strambler 2004). Moreover, as Wineberg (1987) stated, it is reasonable to expect that teachers' attitudes and expectations undoubtedly shape the outcomes of students who are labelled simply because these attitudes and expectations guide teachers' instruction practices and content. But, Wineberg (1987) concluded that as teachers get to know their students, their judgments reflect the experiences they have had with these students as opposed to the label the student possesses.

Undoubtedly, LT has been scrutinized for its lack of empirical evidence, and within educational contexts; these results have been mixed. More recent research finds that teacher attitudes largely vary depending on their previous experience with children who have special needs and their accumulated knowledge within special education strategies and resources (Bell et al. 2011). This presentation of contradictory evidence conveys the difficulty in measuring and empirically assessing how informal labels and expectations can have a direct effect on the labelled child's self-perceptions and educational outcomes. What this also exemplifies is that Labelling Theory requires conditional statements to specify just how labels affect children and individuals in varying contexts, an aspect on

which traditional Labelling theorists have not been keen. Overall, by examining literature in these three areas, three major findings can be deduced: 1) There have been mixed findings on the effects that labels have on individuals; 2) To examine the range of findings that have been presented, Labelling Theory needs to acknowledge the range of conditions and contexts in which labelling occurs and the varying types of labels that are provided; and 3) Labelling Theory does need to take into account that labelling can sometimes have beneficial effects.

2.3- CRITICISMS OF LABELLING THEORY

Why has Labelling Theory not been keener to identify this range of outcomes and conditions? Why has it not been more modified from its original version? These questions refer back to Gove's aforementioned main criticism of LT, in which he noted its lack of methodological rigor and approach: "According to critics, LT was vague, simplistic, and ideological, and empirical tests had failed to provide consistent support for the proposition that labelling reinforces deviant behaviour" (Bernberg 2009: 187).

One of the strongest criticisms launched against LT concerned its lack of tools for measuring effects and its paucity of overall methodological soundness (Davis 1972, Wellford 1975, Wineberg 1987, Cullen and Agnew 2006). Furthermore, there is the absence of an ability to define social control and social change (Davis 1972). Davis argued that the focus on reactions by the majority of Labelling theorists has failed to account for the policies and mode of decision- making as well as the essential power divided in making these decisions; instead, the focus has solely been on social psychological consequences (Davis 1972). Thus, Labelling Theory has not been attuned

to the changing social context or the motivations behind labelling (Davis 1972). These criticisms have continued for the past forty years; yet, curiously, few Labelling theorists have attempted to address them, with the exception of Link et al (1987).

Even Wellford (1975) found that Labelling Theory could be categorized into nine different assumptions, most of which are not empirically grounded in criminological data. Specifically, he found the first assumption - no act is intrinsically criminal - was merely an ontological statement. This statement also does not take into consideration how powerful groups, such as the police and politicians, define what is criminal or deviant (Wellford 1975). Wellford concluded that based on these nine assumptions, Labelling Theory should be seriously questioned. Social scientists in all three areas - deviance/crime, mental health and education - have committed to deepening the empirical basis of Labelling Theory (Bernberg 2009); however, not all have attempted to address its empirical weaknesses or all of the assumptions. Any attempts included a refining of ideas as to how primary and secondary deviance differed, a differentiation in the various types of labels and stigma associated with each as well as a means by which these could be measured (Bernberg 2009), and lastly, a focus on reactions both in informal and formal contexts (Cullen and Agnew 2006). In short, some scholars have attempted to refine LT while others have not responded to its empirical criticisms leaving LT stagnant and vulnerable to empirical criticisms.

Even with these differentiations between formal and informal labelling, stigma and public reactions, researchers still rely on data which make no differentiation between formally and informally labelled individuals, and which is restricted to only those

formally labelled (Bernberg 2009).Thus, they fail to use the counterfactual reasoning of what would happen to the same individual had the label not been given. In addition, Labelling Theory argues that labelling has a direct effect on self-concept and self-esteem but has neglected to measure what these mechanisms of change are (Cullen and Agnew 2006). "…labeling research has been invalid because it had failed to examine [these] intermediate processes" (Bernberg 2009: 193). Finally, LT has failed to underscore the context and conditions under which labelling can occur (Morrison 2005, Bernberg 2009). There have been a number of changes within the social context and a variety of new conditions have been identified, which I discuss in the next section.

2.4- CONTEXTUAL TRENDS SINCE THE 1960S

Since the emergence of Labelling Theory, the broader social context has substantially evolved. It is important to acknowledge how this social context has changed (Davis, 1972) given that it informs many of the types of behaviours society labels as deviant. As Link et al. (1989: 402) stated, "the attitude of the community toward the mentally ill can be formed by a variety of mechanisms and thereby can function as part of the generalized other." Thus, just as Link et al. (1989) pointed out, many of our conceptions as a society are formed by what is normative at the time, and these are in part constructed by many different mechanisms and political ideologies. When Labelling Theory first emerged, labelled individuals were believed to have been forced into categories as a manner of social control (Scheff 1963, Rains et al. 2003). Scheff (1984) highlighted the various conditions surrounding the labelling of an individual: the presence of serious symptoms, a lack of power and resources, and an atmosphere in which

deviance was not tolerated. Phelan et al. (2000) found that during the 1950s and 60s (during LT's conception), individuals who were mentally ill were perceived as dangerous; hence, they were socially rejected, and their deviance from the norm was not tolerated.

Yet, as time has progressed, mental illness is less unknown than it once was (Phelan et al. 1999). This was largely due to the antipsychiatry movement, which opposed the power that psychiatrists had in labelling those with mental illness and challenged the inaccuracies that existed. Mental illness has also gained awareness because of the introduction of pharmacological treatments afterwards, which prompted a mass deinstitutionalization of psychiatric patients and closures of mental health asylums (Porter 1997, Shorter 1997). This deinstitutionalization and its effects on those released were studied by Wright, Gronfein and Owens (2000). They investigated how individuals who were deinstitutionalized as a result of a hospital closure were treated and how they self-reflected after such a change, noting that individual expectations of social rejection count for less than the experience of social rejection because social environments profoundly shape labelled individuals' experiences.

More current notions of labelling must consider that we now live in a "therapy culture," which produces a variety of mental health- related labels and acknowledges the potential emotional and psychological vulnerability of individuals (Furedi 2004). Therapy culture pervades most of the present day language and entangles individuals in a web of therapeutic terminology, such as self-esteem, mental health, and self-confidence, as evidenced by the number of times the word "self-esteem" was published in newspapers (Furedi 2004), and by shaping American culture into being therapeutically aware of these

vulnerabilities (Imber 2004, Rice 2004). As a result, many different therapies have emerged for counselling individuals on everything from marriage to personal fulfillment (Chriss 1999; Furedi 2004). This culture penetrates every aspect of our lives including work, schooling, and personal relationships (Rice 2004), and the fundamental basis for such an invasion centres on the idea that "human nature is intrinsically benevolent, positive, and constructive" (Rice 2004: 113).

The beginning of this movement began in the 1960s, in an era of social unrest and of the pursuit of human rights for all (Clément 2008). This discourse prompted social change in a multitude of areas, including social and economic welfare, health services, social security, and education (Clément, 2008). As our culture integrates this therapeutic terminology, such as the term self-esteem, people with disabilities and mental illnesses have also acquired more social rights. Within the educational context, the questioning of individual rights surrounding disabilities began in 1997 with the infamous Eaton vs. Brant County. Eaton vs. Brant County was the case of a family whose daughter had cerebral palsy. The family argued for her to be placed in their neighbourhood school on a trial basis and where she was provided with an educational assistant for her needs versus a private or special education classroom. After three years of her placement, the school felt it was not in the child's best interest to continue and wanted to have her placed in a special education classroom. The parents appealed this decision, arguing that she deserved to be included in a general education classroom with her peers[1].

[1] Information obtained on March 1, 2013 from: http://scc.lexum.org/decisia-scc-csc/scc-csc/scc-csc/en/item/1471/index.do

This landmark case provided for a fundamental shift in the general public's understanding of educational entitlement for children with physical disabilities and furthered the argument for a number of similar cases (Vanhala 2011). Clément (2008: 11) stated, "human rights thus encourage social activists to think of social change as legal change." Lasch (1979) argued, however, that this need for inclusion is truly based on the political decision to calm societal discontent. Lasch (1979) discussed the implications of such political movements in education, highlighting the development of an administrative body governing the learning needs of children who had been labelled "exceptional" or "special needs." Stemming from these social changes, a greater focus has arisen on meeting the learning needs of children and adults in schools, thus prompting increases in access to special education and accommodations within the classroom (Powell et al. 1985, Ong-Dean 2009). Public education has belatedly focused on meeting the emotional needs of all students, something that Ecclestone and Hayes (2009) term "therapeutic education." But such educational growth and change would not be present without acknowledging the proliferation of diagnostic criteria and disorders and other contextual trends emerging in tandem. Thus, broader understandings of human rights have filtered into education through expanding notions of who is "educable"; consequently, this has served to lessen the stigmatizing of educational disabilities, while at the same time, providing more efforts to accommodate individuals.

The Rise of Labels: The Development and Expansion of the DSM

The expansion of therapies has been met with an increased number of formal mental health and physical ailment labels used by professionals. Since its publication in

1933 (Malik and Beutler 2002), the number of labels recorded in the Diagnostic Statistical Manual of Mental Disorders (DSM), has risen by over 300 per cent (Dalal and Sivakumar 2009), and the number of children diagnosed with these various disorders each year has also increased (Conrad and Potter 2000; Ho, 2004; Ecclestone and Hayes 2009). To exemplify this, autism is diagnosed in approximately 1 out of every 88 children in Canada[2] while ADHD is roughly 8 percent of the overall youth population aged 3 to 17[3]. Originally designed to address the more chronic issues affecting soldiers coming back from the war, the DSM- I was published in 1952 in response to mounting pressure from mental and physical health professionals who were concerned with the inadequate coverage of these chronic and rare mental illnesses (Malik and Beutler 2002; Chodoff 2005). However, both the DSM-I and DSM-II (published in 1968) were plagued with validity and reliability problems, which prompted the DSM-III to be reproduced in 1980. This edition was created as a concerted effort to ground itself in empirical material (Malik and Beutler 2002). The DSM-IV, published in 1994, and the DSM-IV-R, published in 2000, both increased the number of available labels with the rationale that more comprehensive coverage of mental health and physical disorders was needed (Pincus et al. 1992). Some have stated that this push to expand the DSM was the result, not of individual measures, but of the motivation of political groups (Conrad and Potter 2000:560) and other factors related to the "socio-cultural" context of diagnosing. And the revising of each edition was due to more criticisms surrounding the embedded biases of its creators (Malik and Beutler 2002). Rogler (1997) found that it was necessary to

[2] Information obtained from http://www.cdc.gov/features/countingautism/
[3] Information obtained from http://www.cdc.gov/nchs/fastats/adhd.htm

understand the historical, social, political, and cultural factors used to shape the revision process for the DSM. For Rogler (1997), the initial and subsequent revisions of the DSM-III were merely a reflection of the remedicalization of the psychiatric discipline and thus grew due to their growing institutional significance. Many, however, would argue that this was also a reflection of the growing awareness of disorders in general and greater general scientific knowledge (Porter 1997). The ever increasing expansion of the DSM is a general indicator of the expansion of psychiatric and medical labels which, as a result, could be considered more normalized within the public setting.

Currently, the DSM contains well over 800 pages and several hundred categories (Ecclestone 2004) and researchers are anticipating its fifth release, set for May, 2013. This new DSM has been the product of these so-called political initiatives but also the collaborative efforts of many organizations, such as National Institute of Mental Health, the American Psychiatric Association, the International Psychiatric Association, the World Health Organization, and the World Psychiatric Association. Markedly, however, the need for revisions emerges from a mix of the political push to accurately assess the diagnostic criteria and validity of each category (Conrad and Potter 2000; Conrad and Leiter 2004; Ho 2004; Conrad 2005; Ecclestone and Hayes 2009)[4]. Moreover, revisions would need to address the increased number of scientific developments within diagnostic and measurement tools (Porter 1997, Shorter 1997). Science has changed substantially in a short period of time, beginning with the advent of physiological and anatomical studies to the use of modern technology within medicine (Porter, 1997). Despite the significant

[4] All information was obtained by http://www.dsm5.org

changes both in the DSM and within medical labelling, LT has not followed suit in changing its' tenets, and thus, suffers from the lack of acknowledgment that therapeutic culture has increased the value of a label and decreased its social and emotional cost. Mental health labels have proliferated and have been largely normalized within mainstream culture; consequently, some can be less stigmatizing and, even, beneficial.

Stigma and Public Policy Campaigns

Part of this context change also includes the proliferation of stigma and public policy campaigns that have strived to increase public empathy, sympathy, and support for people diagnosed and labelled with a disorder (Stuber et al. 2008). Initiatives began with the World Psychiatric Association's "Open Doors Campaign," which furthered anti-stigma agendas by encouraging schizophrenic patients to return home and to "normal" society (Rosen et al. 2000). These initiatives are pervasive; global researchers and policy makers, citing an abundance of research showing the discriminatory effects of labels, have advocated for anti-stigmatizing campaigns (Rosen et al. 2000; Pescosolido 2010a). In Canada, Calgary led the way, launching a series of media initiatives, including a radio ad campaign, which promoted the message to high school students (Rosen et al. 2000). In 2009, the Mental Health Commission of Canada's (MHCC) "Opening Minds" campaign promoted various initiatives in four different segments of the population: health care providers, youth ages 12 to 18, the workforce, and the media[5]. In addition, the MHCC has recently launched an anti-stigma campaign, asking the public to read through the

[5] http://www.mentalhealthcommission.ca/English/Pages/OpeningMinds.aspx

consensus statement, sign and join in the agreement[6]. In 2010, Bell, in partnership with local athletes, implemented the "Let's Talk" campaign; "Let's Talk" gives money to health care providers and agencies focused on improving the mental health of the general public (this campaign is ongoing). The U.S. has also created campaigns, such as "What a Difference," which targeted youth aged 18 to 25 through public service announcements disseminated through television and radio ads to rethink stigma and mental illness stereotypes.

Researchers in the areas of mental health have also advocated for the prevention of stigma associated with psychiatric labels, stating that anti-stigma agendas should be at the forefront of medicine (Byrne 2000, Rosen et al. 2000, Crisp, Cowan, and Hart 2004, Pilgrim and Rogers 2005) and education (Pitre et al. 2007). Drawing on the numerous global initiatives, including the National Alliance of Mentally Ill's Stigmabusters, the Bavarian Anti-Stigma campaign, the Like Minds, Like Mine campaign in New Zealand and other national initiatives already mentioned, Rüsh, Angermeyer and Corrigan (2005) noted that all of these have used three main strategies in their fight: protest, contact, and education. The effectiveness of such campaigns can be great given that many media outlets and the general public tend to be misinformed about mental illness. Stuart et al. (2011) found that providing media outlets, specifically, with the appropriate information prior to reporting can reduce stigma while fostering a more positive image of mental illness. These types of initiatives have also created a new context for stigma discussion, as Wright (2008: 329) pointed out: expression of private problems has "opened up a new

[6] http://www.mentalhealthcommission.ca/English/Pages/join.aspx

discursive space in which it is not only the powerful that can have a public voice." However, the effectiveness of such campaigns is still under much scrutiny (Pescosolido 2010a). Some have determined that these campaigns have been ineffective because they do not target specific disorders and audiences and should be employing the latest social media and advocacy tools (Corrigan and Shapiro 2000; Pescosolido 2010b; Corrigan 2012). In sum, the creation and proliferation of anti-stigma and educational campaigns may serve to mute the negative effects of labelling as the public and professionals become increasingly aware of the possible effects.

Consumer Agency

Since the advent of Labelling Theory, individuals who have been labelled have also been important in this discussion of contextual trends. A missing piece to the understanding of the relationship between individuals and labelling effects is the avid pursuit of labels from both sick individuals and their family members (Rotenberg 1974; Morrison 2005; Demerath 2009; Ong-Dean 2009; Thoits 2011). One clear weakness of Labelling Theory has been its inability to capture why individuals seek out labels for themselves or for those they love (Link and Phelan 1999a; Morrison 2005; Thoits 2011). Today, studies suggest that individuals seek out mental health and educational labels if they feel they have a deficit of some sort (Conrad and Potter 2000) or feel that they are vulnerable in some capacity (Morrison 2005). This is a much different image than what Becker (1973) proposed in his conception of "moral entrepreneurs," whom he saw as creating and then imposing labels upon others. Today, both anti-stigma campaigners and labelled individuals can be considered the new "moral entrepreneurs." Some individuals may

pursue various labels in an effort to increase their mental and physical well-being (Thoits 2011) while others may avoid labels altogether. Both kinds of individuals play an active "moral entrepreneur" role. With the right to access labels, individuals who are labelled are now also playing an active role as advocates of anti-stigma campaigns and disseminating accurate information on various disorders to better educate and raise public awareness (Morrison 2005). Morrison's (2005) focus was on current and ex-patients of the mental health system, but the same can be said for those in education (Ong-Dean 2009): individuals are claiming the right to have a label. No longer are individuals always passive in the process of labelling; many are active in the pursuit of labels and adamant to change their public perceptions (Morrison 2005).

Within the educational context, Demerath (2009) found that parents, especially those in the middle and upper classes, pursue special education labels to ensure that their children's rights to opportunities are secured. Parents have the expectation that they will be heavily and intimately involved in their child's education (Ong-Dean 2009); consequently, they draw on personal resources and knowledge to argue for rights and opportunities, such as educational and economical capital (Demerath 2009, Ong-Dean 2009). In the case of Demerath (2009), parents went so far as to secure better schools that catered to their child's needs and also sought out individual education plans and tutorial services to better enable their children to compete in post-secondary admissions. However, though parents will pursue labels, they also display hesitation (Demerath 2009). Given what has been largely emphasized in labelling literature, it is no surprise that parents are all too aware of the stigma that can result from having their child formally

labelled. Yet, they are also acutely conscious of the treatments and opportunities that are available as a result of the label (Ong-Dean 2009). This might result in what could be termed "labelling ambivalence," whereby parents struggle with the idea that labels bring fortuitous opportunities but could also lead to social stigma in other capacities. Therefore, some labels can be advantageous by bringing resources and educational opportunities while others, as they elicit stigma responses, may not have such positive consequences. Ong-Dean (2009) illustrated these opposing outcomes with terms such as "mentally retarded," "ADHD" and "learning disabled." While the first two terms had attached negative connotations and stigma, "learning disabled" was viewed more positively by the general public.

2.5- INCORPORATING THE SICK ROLE

Surprisingly separate from the conversations of Labelling Theory and its contention about the negative effects labels have on individuals' self-perceptions and self-esteem, an additional paradigm in sociology stresses the opposite. Namely, that being formally identified as "sick" can excuse individuals from normal societal expectations for their performance of key social roles, and thus labelling processes can bring benefits for both society and labelled individuals. Parsons' ideas of the sick role and its repercussions, as well as his notions of the changing societal context of the modern health consumer, offer an alternative understanding of the effects of labelling. Labelling Theory has long emphasized the harmful consequences of labelling individuals; Parsons (1951) emphasized that there were four components to the sick role: 1) The sick individual is not to be held responsible for their condition; 2) The sick individual is to be exempted from

some of their normal social roles and expectations; 3) Being sick is an undesirable trait; and 4) The sick individual must seek out competent help. With the advent of this most important concept in health studies (Wolinksy and Wolinsky 1981) numerous criticisms were launched at Parsons (Segall 1976; Arluke, Kennedy and Kessler 1979; Morrison 2005), particularly that his model was inflexible, did not account for chronic illnesses, and assumed too much. But Segall (1976) stated that Parsons' original model was not meant to be as flexible as his critics point out; rather, it was more of an ideal type. Thus, at the descriptive level, Parsons' concept is empirically valid and most social science researchers in health have accepted the usefulness of its explanation (Segall 1976).

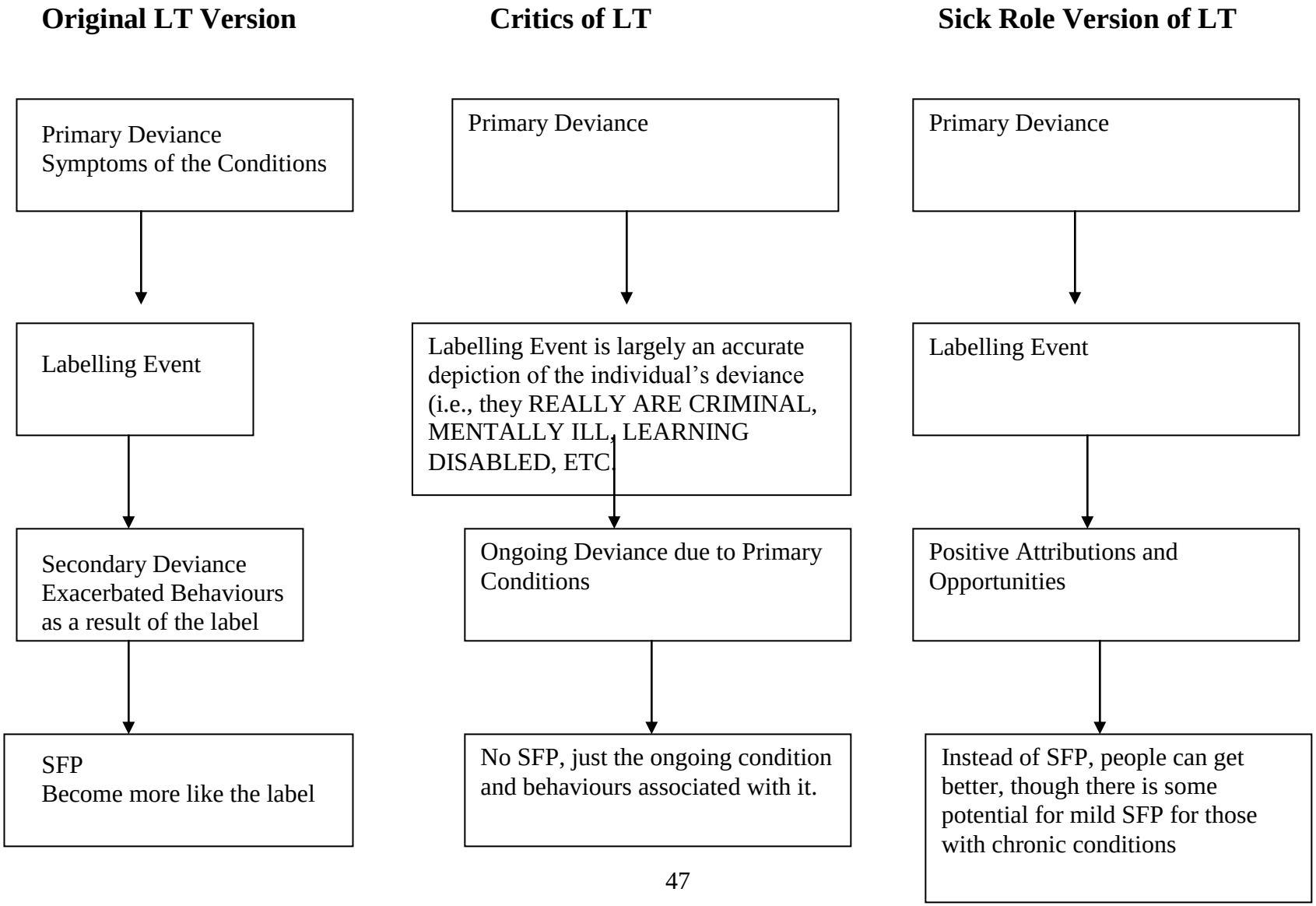
Segall (1976) indicated that there have been numerous applications of the sick role within health research. These include applications and modifications to fit both a variety of physical and mental health conditions (Arluke, Kennedy and Kessler 1979). However, in the six decades since the creation of the sick role, its multitude of applications has garnered two major sources of criticism. The first of these criticisms concerns the four components originally outlined by Parsons and do not capture the variety of expectations that individuals bring with each component (Arluke, Kennedy and Kessler 1979). The second of these criticisms involves how those with more chronic illnesses cannot be entirely analyzed with Parsons' original model because it tends to deal with more acute illnesses, such as colds, flus, and even some cancers (Arluke, Kennedy and Kessler 1979; Morrison 2005). Morrison (2005) elaborated that for many with a mental illness and disabilities, the chronic state is a familiar experience; thus, these individuals may never

experience normality, as Parsons originally outlined in his last component. In fact, they may "remain in a chronic diagnostic state" (Morrison 2005:5).

Despite the number of criticisms Parsons' model has faced over time, and as Williams (2005) suggested, there is still much to be learned from using his paradigm. In fact, Parsons himself also responded to his critics, explaining that his conceptions of illness were not intended to solely mean deviant behaviour. He added that he was not just concerned with acute illnesses (Williams 2005). Shilling (2002) elaborated that Parsons was predicting the changes in health seeking behaviours and the number of cultural conditions which have changed in the past fifty years. In short, when integrated with LT, the sick role can be useful as individuals who are labelled and fall within the confines of this role can benefit from being given a label. Subsequently, they may receive treatments, social opportunities, accommodations, and favourable attributions for deviant behaviour, and thus may seek out labels for these reasons.

In this new cultural context, the sick role can represent an alternative outcome of labelling. It allows for the possibility that labels can have beneficial and positive effects rather than just solely negative ones, originally and continuously argued by Labelling theorists and generally opposite to what Gove (1970) stated regarding the ineffectiveness of labels. The following diagrams illustrate the concept of SFP in the context of these three paradigms: original Labelling Theory tenets, Gove and his critics' views of the effects of labelling, and the incorporation of the Sick Role into Labelling Theory.

Diagram 2: Versions of Self-Fulfilling Prophecy (SFP)



In considering the possibility of beneficial effects, researchers must examine a relatively new label to provide an empirical account of these effects of labelling in such a new context. In the next section, I discuss one such new label that might serve as a valid test case of the incorporation of both paradigms and an exploration of labelling in this new context.

2.6- THE CASE OF DEVELOPMENTAL COORDINATION DISORDER (DCD)

DCD was first medically established as a medical entity in the 1970s, included in the DSM-III-R as a medical category, and currently affects approximately five to six per cent of all children ages 5 to 11 (Cairney et al. 2005, DSM V). It is also known as Developmental Dyspraxia or Clumsy Child Syndrome; however, research indicates that the term DCD elicited the most neutral public reactions of the three labels (Miyahara and Register 2000). Symptoms of and criteria for DCD are marked by developmental delays in crawling and walking and displays of general clumsiness. Children also experience poor performance in handwriting, sports, and daily care activities. These delays cannot be due to any other general medical condition and must interfere with daily living and care (DSM V, Diagnostic Criteria 315.4). Children complain of tripping, falling, and bumping into things and experience a lack of organizational skills necessary for drawing and completing school (Polatajko 1999). DCD is often diagnosed with other disorders such as ADHD, speech language disorders, and learning disorders (Missiuna, Rivard, and Pollock 2004). Children with these co-morbid disorders often fare worse developmentally and educationally than those with a single DCD diagnosis (Missiuna et al. 2004).

These interferences in motor coordination also lead to numerous secondary effects, including lowered academic achievement and increased mental and physical health problems (Martini, Heath and Missiuna 1999, Rivard et al. 2007, Cairney et al. 2009). Delinquency and change in mood and behaviour are often cited by parents when they describe the first indications of a problem (Missiuna et al. 2006a). As a result of these behaviour changes, children with DCD are often misdiagnosed as having ADHD (Rivard et al. 2007).

Educators often misdiagnose children with DCD and cannot comprehend their limitations and abilities because of the lack of information and their own misconceptions (Missiuna et al. 2006c). Previous research suggests that teachers seem to identify more males than females with physical difficulties (Berry, Shaywitz and Shaywitz 1995, Anderson 1997). In Rivard et al.'s (2007) study, teachers did show an increased awareness of gross motor problems with boys, while with girls, teachers gave attention to their fine motor skills. Overall, teachers have been found to consistently identify more boys than girls with gross motor skill and behavioural attribute deficits (Fliers et al. 2008) while physical education teachers have been found to be better at identifying children with DCD than regular classroom teachers (Piek and Edwards 2005). Because of their inconsistencies in identification, the misdiagnosis of these children and the co-morbid nature of DCD with other disorders, teachers often encounter numerous challenges when accommodating children with DCD (Kirby, Davies and Bryant 2005).

As a result, parents of these children may become frustrated when dealing with educators and seek various ways to help their children (Missiuna et al. 2006a). They often

approach professionals; however, accessing these professionals has proven troublesome (Missiuna et al. 2006b). Research indicates these parents have three major areas of concern with respect to their DCD experiences: determining what DCD is, contacting the appropriate professionals to ensure a diagnosis, and negotiating the conflict associated with labelling their child (Missiuna et al. 2006b). And although parents may not know the cause of their child's difficulty, they are nonetheless aware that a difficulty exists (Peters and Henderson 2008). Missiuna et al. (2006b: 14) stated,

> "A number of parents felt that obtaining a diagnosis was critical and meant that they could advocate more effectively for services in the school system. On the other hand, several parents expressed concern that talking with teachers about DCD might have a negative impact on how the teacher viewed their children and/or negative impact on how the school system viewed them as a parent."

Because of DCD's difficult-to-identify nature, Missiuna et al. (2006c) found that children are often labelled as lazy or perceived of as having behaviour problems or as not trying hard enough (Chen and Cohn 2003). In addition, DCD children more frequently have a difficult time socializing with their peers (Missiuna et al. 2006c, Campbell and Missiuna 2011). Although little research has been conducted on these experiences, research does suggest that children with DCD often play alone and veer away from social group settings to conceal their perceived weaknesses (Cairney et al. 2009). Females are also less socially active than males, and Cairney et al. (2009) suggested that this could be due to the high priority many males place on physical activity, which they use as a means to enhance social status. Furthermore, because of the lifelong nature of DCD, these children are more likely to be stigmatized. As Hayward and Bright (1997) pointed out, the more chronic and difficult to treat the disorder, the more often labelled individuals will be

socially rejected by their peers. Therefore, social stigma may not be a result of the formal label at all, but due to the perceived reactions of and stigma by peers. In this case, informal labels can have more negative effects than formal ones.

To date, studies conducted on the self-worth and self-perceptions of children with DCD have yielded varying results, but most suggest that these children view themselves as less competent in numerous ways when compared to their peers (Chen and Cohn 2003). However, Piek et al. (2005) discovered that while children with DCD do not experience lowered self-worth, as compared to their non-DCD peers, girls with DCD may experience verbal victimization (such as gossip, verbal threats and teasing) that can affect their emotional functioning (Rigoli, Piek and Kane 2012). Piek et al. (2005) concluded that the relationship between DCD and perceived self-worth is a complex one that merits more research. Therefore, while reactions to the primary symptoms of any condition seem to create informal labels, more research is needed to fully understand the effects that both informal and formal labels have on individuals.

2.7- THE EFFECTS OF LABELLING IN A NEW CONTEXT: DISCUSSION

Growth in medical labels, the consumer agency, and the movement of anti-stigma campaigns have created a new setting that can alter the effects of formal labels. Thus, new possibilities can emerge in this new context: 1) There may be new incentives for people to actively seek out formal labels like DCD; 2) Some of these labels, like DCD, may have become normalized; and 3) Stigma may have lessened for some of these labels. Given these possibilities, it is also important to assess how informal labels (those given by peers, public and other actors) and formal labels (those given by professionals)

contribute to individual outcomes under these new circumstances. Lastly, it becomes necessary to capture the process of labelling; namely, how these two different labels, formal and informal, can change possible outcomes for a child. Gill and Maynard (1995) stated that this has been one weakness of Labelling Theory: its inability to capture the labelling process and its role of individual agents.

Pertinent to this study is how, within the educational context, parents advocate for their children's educational rights and needs (Ong-Dean 2009). In response, educators have created a curriculum that addresses individual emotional and academic vulnerabilities with a vast array of special education strategies (Furedi 2004; Ecclestone and Hayes 2009). In addition, educators provide parents with documentation that is intended to facilitate their child's educational career path; this documentation includes an Individual Education Plan (IEP) that tailors student learning and needs to curriculum objectives. Furthermore, educators have been found to accept and accommodate student needs within elementary and secondary settings (Mcintosh et al. 1994; Idol 2006). This willingness to accommodate children who are labelled is in direct alignment with the "sick role" outlined by Parsons. Despite Parsons' lack of attention to chronic illnesses and to the disconnect between his discussion of such with LT tradition, there is still validity in Parsons' original theory, mainly how culture affects health behaviours. Educational research highlights the importance of combining Parsons' concept of "sick role" with LT. Higgins et al. (2002) provided a glimpse into the life of children labelled with LDs. While most of these children grow to accept their labels, they must first pass various stages. These stages include acknowledging that they are different from their peers, either

academically or socially; experiencing frustrations and acceptances when being tested to attain their formal label; and struggling with both the meaning of the new label and the need for additional help (Higgins et al. 2002). Although there are other stages not mentioned here, the premise still holds: despite experiencing outside ridicule, judgment and perceived weaknesses, labelled individuals gradually come to accept the labels and view them as a positive force in their current lives, mainly because these labels result in new opportunities (Higgins et al. 2002). In fact, many children with LD stated that the LD was part of their identity but was also a problem that provided them with a community (Raskind, Margalit and Higgins 2006). Hence, labels can bring benefits under certain conditions and within particular contexts.

Empirically assessing such propositions and conditions requires drawing on a relatively new disorder, such as DCD. By employing a qualitative field study, researchers can explore the effects of both informal and formal labels. This can be accomplished by comparing two groups of children: those who display symptoms of the disorder and those who have been diagnosed with it. This kind of empirical research can advance Labelling Theory by discovering conditions under which labelling has negative or positive effects on individual outcomes.

I propose the follow research questions:

1. In terms of social stigma, how do peers and teachers treat children with DCD, both before and after the label is ascribed? What kinds of qualities, traits and problems do they associate with these children's abilities? What happens to children with DCD traits who are not formally diagnosed with that label?

2. In terms of a self-fulfilling prophecy, how do children feel about themselves before and after being labelled? What self-attributions do they make? What attributions do non-labelled children make?
3. In terms of opportunity, does the formal label of DCD serve to expand or restrict children's opportunities in schools and in social relationships?
4. What role do parents and teachers play in acquiring labels for children? What are the experiences of these agents in the diagnostic process? What types of attitudes do each hold concerning labelling of children?

2.8- CONCLUDING REMARKS

Labelling Theory, in its earliest guise, was an influential theoretical paradigm for scholars in explaining how labelled individuals suffered from various stigma and social reactions and were denied or limited in their social opportunities and thus, would engage in further deviant behaviour, or secondary deviance. Plainly, the theory contended that formal labelling worsened behaviours. Applied originally in criminal justice, subsequently in mental illness/ health and education, Labelling Theory underwent much scrutiny. While it has continued to be popular, many have noted that it lacks empirical grounding and can be vague on components of measurement and definition. For these reasons, some have modified it to include emotions and the role of family and have elaborated on both informal and formal means of labelling. One of the most important criticisms of Labelling Theory has been its inability to capture how social context shapes the internalizations of labels and how individuals themselves pursue labels for their own benefit. But societal contexts have changed substantially since the time of LT's inception;

many individuals now actively pursue labels, the number of mental health and learning disability labels has grown remarkably, and individual agencies have mounted numerous anti-stigma campaigns to combat negative reactions from the public. Labelling Theory did not consider such societal changes though Parsons (1951) did, to a certain extent, in his account of the sick role. This disconnect has prompted the debate of whether labels create more favourable outcomes within the confines of formal labelling. There needs to be a re-evaluation of LT's original tenets and an exploration of the range of conditions and contexts under which labelling can occur, including a discussion of the effects from both informal and formal labels. DCD provides an opportune time and case to observe these issues.

Chapter 3: Methodology

3.1- SUMMARY

The components of this research project are informed by its two fundamental goals: to uncover the formal and informal labelling processes involving DCD and to discover the experiences and roles of parents and teachers. Given these goals, I chose qualitative and exploratory methods whereby I observed children in their school, home and extra-curricular activity settings and interviewed children, parents and some teachers. These were open-ended interviews and were done at the convenience of the participant families at a children's rehabilitation and treatment centre. This study compared children diagnosed with DCD with those who were awaiting a diagnosis (whether with DCD or not, but who were exhibiting a number of symptoms classic of DCD). Those with a diagnosis were interviewed at various time durations after receiving the diagnosis; however, much effort was made to assess children as close as possible in time to when they received the diagnosis. This entailed interviewing parents and comparing outcomes and analyses of both groups with their non-diagnosed counterparts.

Although the sample was relatively small, consisting of nine children and sixteen parents, the qualitative nature of this study made the sample size large enough to draw some preliminary conclusions and findings. These findings are not generalizeable; rather, they provided in-depth understanding of experiences suitable to this segment of the population. This study's time frame took place from late April, 2012 to the middle of June, 2012, roughly an eight week period.

3.2- SETTING, RECRUITMENT AND SAMPLE

This study was conducted in cooperation with a children's rehabilitation centre located in Northern Ontario as well as with the four local school boards. This treatment centre is a charitable, non-profit organization that dedicates itself to the treatment of children's disabilities and the promotion of children's well-being across the North. All interventions are conducted under one roof, including occupational therapy, speech-language therapy, physical therapy and pediatric assessments and appointments. The centre offers a wide range of services for all children in the North Eastern Region, in both urban and rural areas. Children are referred by their community pediatrician or general practitioner to the centre for services; the centre also houses all pediatric services for the North Eastern Region. Children receiving services range in age from infancy to twenty-one years of age. Within the group of healthcare professionals, there are two teams: a preschool-based team serving children (ages zero to six), and a school-based team serving children through adulthood (ages six to twenty-one). This study involves the school-based team. When fully staffed, each team consists of roughly 20 individual personnel. The centre has rooms that contain double-sided windows used for the parental and child interviews for this study.

Participants were recruited through the treatment centre and the local school boards. Additional recruitment of parents and children was completed by therapists and a pediatricians' office. Brochures and posters were also used to recruit parents and children (see Appendix C). These were given out to parents and guardians of children who were in the process of being diagnosed or who were already receiving therapy for various motor delays. This differentiation between participants provided for a comparison group of

sorts, pre-labelled children who have similar symptoms but have no label attached (as identified by occupational and physical therapists). The brochure, email and poster contained contact information as well as a brief description of the study; thus, contact was left to the parent/guardian and was voluntary. Parents were also given a consent form with the letter of information discussing the details of the study, or it was conveyed by telephone using the same details. In the case of teachers, recruitment occurred by personal invitation. Reasons for using all facets of recruitment (by pediatrician, therapist, or poster advertisement) were due to the types of participants needed in this study and the relatively unknown nature of DCD within the Northern area.

The sample consisted of nine families and ten children, two of which were siblings in the same family. The sample was collected in multiple ways: through the professionals at the children's treatment centre (such as the OTs and PTs) as well as through advertisement at the local pediatricians' offices and newspaper. In total, 4 participants were collected through the centre, 2 of which were given the official diagnosis of DCD and 2 were suspected cases but not yet confirmed by the pediatricians. Two other diagnosed children were recruited through the paper and one child who was given the referral to a paediatrician for DCD by an OT but not officially diagnosed. Three suspected cases came from the local ads and were told that they were being evaluated for DCD among other things. These sampling and recruitment methods were utilized given the unique nature of the population in this sample and the rarity of the diagnosis within the study's area. Ages of this sample ranged from 3.5 to 17 years of age and consisted of

8 boys and 1 girl. Please see the end of Chapter 4 (pg. 94) for a chart summarizing the demographic data of both the children and their parents included in this study.

3.3- METHOD OF DATA COLLECTION

Observations

The primary assumption in this study is that social reactions, self-perceptions, and opportunities can be elicited through interviews and observational methods. Observations of the children, their families and their teachers and peers were completed in this study. To delve deeper into the issue of labelling and the variety of contexts in which it can occur, all children were observed over a five day period for each child and took place in each child's home, school, and other locations relevant to their health, academic and social activities. Some flexibility was utilized to ensure that observations were made within all types of settings and environments. Observations were made by sitting in on the children's classes over the week allowing for a few days for other children to adjust to me. In some cases this would involve becoming a participant observer, engaging with other students, helping them with work but also remaining close to my participants. Observational notes were made while in the field but also after observations were completed for the day. Reflections on the observations were also made each day. The focus here was on the child and not their peers per se; rather, how the child was engaging with others or, perhaps, not engaging; what types of encounters the child had; and how the child responded to their peers. It was also necessary to capture peer relationships in extracurricular activities such as Girl Guides, Scouts, and sports related events.

Interviews

This study also used interviews in order to understand the knowledge set of children, parents and teachers of DCD but also to evaluate the self-perceptions of children with and without a label, the parental involvement and experience of the diagnostic process, and educator experiences overall with DCD. A variety of actors were interviewed: the children themselves, parents, and teachers. Children were interviewed using the PEGS instrument as a tool to facilitate conversation. In this particular study, the Perceived Efficacy and Goal Setting System (PEGS: Missiuna, Pollock and Law 2004), was employed to elicit responses from children who were diagnosed with DCD and those in the process of being diagnosed. This system, designed for use with children with DCD, uses illustrations of children completing various daily activities to assess children's perceived self-efficacy in such activities. It elicits conversation about abilities involving motor skill and can lead to questioning children on their perceived efficacy performing various activities. Using this information, professionals can set goals for treatment and intervention. This system has been designed for children aged six to nine but can be used with children as old as twelve (Dunford et al. 2005). PEGS involves showing the children pairs of cards. The first depicted a child who performs a task easily; the second, a child who struggles. After selecting one of the cards, children were asked, "Is this child more like you or a little like you?" PEGS has been designed to create and stimulate conversation between children and health professionals about everyday activities.

Because some of the participants were over the recommended age limit for PEGS, an interview guideline was created based on both this instrument as well as some of the factors suggested by Missiuna, Gaines and Soucie (2006). These interviews were open-

ended, allowing for probing and elaboration if needed (see Appendices A for interview questions).

This study used PEGS or interviews with both the diagnosed and undiagnosed groups of children. This allowed for comparison of responses across each group. Prior to this activity occurring, children were given an assent form to read and sign (or sign while in the interview); these assent forms were developed using age appropriate comprehension and reading level, and in some cases were read to the child by either myself or the parent (see Appendix A for examples of each type of assent form). These flexible interviews took approximately 15 to 30 minutes each. Children were offered a break halfway through to have a snack or drink, or to use the facilities. As a thank you for allowing the research to continue in their facility, occupational therapists and physical therapists were offered the completed PEGS for each child which they could use to guide goal development for the child. This instrument provided an idea of what children felt they were competent at in terms of certain activities.

After the interviews, children were asked to engage in one last activity to gain a deeper insight into their peer and social relationships (something which the PEGS does not measure) by drawing various scenarios. Scenarios such as a time at school, home, with friends, and doing their favourite activity were all discussed; adding a second component, a drawing activity, stimulated conversation with the child on various topics. In this activity, I drew in front of the child, using shapes and forms, instances in which s/he is at play, at school, recess, and in various extra-curricular activities (that are pertinent to the child), and asked them to do the same. The focus was not placed on the

picture quality but on what the child drew and their explanation for it. If instruments are provided and emphasis is placed on the meaning of the drawing and not on their skill, drawing is an activity that may encourage children with DCD and one they can actively enjoy. [7] Thus, I had a variety of instruments, such as pencils, markers, pens and various sizes of each available to children for this activity. Questions included: "Tell me what is going on in this picture?" "Why did you draw a picture of this?

Parents were invited to watch their children's interviews using the rooms with double-sided windows; this allowed parents to intervene if a child felt overwhelmed or was uncooperative and to observe the child's behaviour and responses. For convenience, parents were interviewed at the same time while children were cared for by the Research Assistant in a separate room. In addition, teachers of all children were invited to be interviewed concerning their attitudes and recognition of symptoms of DCD as well as their overall experience with children who have the disorder or may be receiving services for DCD symptoms. Parents were interviewed first, to ensure their comfort with me and to help reassure them of my qualifications and the care I would take interviewing their child.

3.4- CASE STUDY DESIGN AND ANALYSIS

Given the small sample of this study and its in-depth approach, it was apparent to draw on case study methodology. According to Lewis and Ritchie (2003), a case study consists of multiple perspectives and voices on the same issue—in this case, parents' and

[7] Personal communication with Dr. Cheryl Missiuna and unpublished manuscript: Posavad, J., K. Vanderzwet, W. Campbell and C. Missiuna. 2011. "Interactive Interview Activities for Children: Eliciting In Depth Information about Social Experiences."

children's experiences with the labelling process. Insights gained from a case study can inform a larger study and offer a better understanding of individuals' meanings and processes (Stake 2000, Berg 2001). Yin (1994) suggested that case study designs are more appropriate for questions that concern how the environment cannot be manipulated or controlled; in this case, Yin suggested using both interview and observational methods in collecting data and answering these questions. I used both methods, observation and interviews, to answer the research questions outlined in the previous chapter. Observation of both the children who were diagnosed with DCD and undiagnosed children who were receiving services for symptoms associated with DCD was conducted over a period of five days per child. These children were observed during their school time and extracurricular times for social interaction with peers. Observations remained focused on the child with DCD and not their peers. Although case studies can be time-consuming (Yin 1994), they can undoubtedly yield benefits in uncovering complexities of human meaning and understanding (Yin 1994; Stake 2000, Berg 2001); these complexities can be addressed by interviewing multiple actors in combination with an ethnographic component.

3.5- RESEARCH WITH CHILDREN: THE USE OF INTERVIEWS, OBSERVATIONS, AND DRAWING TECHNIQUES

One of the most important sources of data within this study comes from children themselves and, although research with children is fraught with controversy, it does have its advantages. Christensen and James (2000) found that research with children is not as problematic as is portrayed and suggested the use of more non-traditional methods, which

are neither invasive nor harmful, to elicit the experiences and truth of children. Along with others, (Prosser and Schwartz 1998; Fargas-Malet et al. 2010) they believed that these non-traditional methods are valid measures for understanding and discovering the social experiences of children. Three non-traditional methods were used to elicit conversation from children and associate meanings with labelling as a process. One non-traditional research method was drawing with children; Driessnack (2006) stated that using this drawing technique allows children to verbally express what they know when they cannot find the words. Drawings, therefore, can be seen as a "facilitator of communication" (Driessnack 2006:1430). Children are viewed as creative and active agents in this research process by the use of drawing exercises (Punch 2002), and as a result can be more engaged, yielding more in-depth results and data. This drawing exercise was done with all children.

In an effort to gain an additional perspective on peer relationships and social opportunities, this study used observational methods in a variety of contexts. This afforded a better understanding of social experiences, provided for a comparison of interview data and observational data for triangulation purposes and also allowed for comparisons across different settings. As Berg (2001) asserted, this type of observational method places the researcher at the heart of it all. This method of ethnographic work is not uncommon and can elicit rich sets of social experiences to capture the complexities of social relationships and the dynamics of such with perceived self-competence (Berg 2001). Goffman (1989) found that field-work is a means of observing social reactions in a naturalistic setting as it enables researchers to "get as close as possible to the individual"

(Goffman 1989:129). However, all observational methods carry a potential for harm. In an effort to remain non-intrusive, I maintained my distance from the child being studied. At times, this meant playing a role as an assistant within the classroom and in the playground and as a family friend while in the home and at extra-curricular activities. Notes were made during and after the time of observations as well as reflections. According to Adler and Adler (1987), for a researcher to become a peripheral member in an ethnographic study, great efforts may be taken to maintain social distance. However, they may also take on specific roles with which they are more familiar to make observational data as reliable and valid as possible, such as in this study in which I took on a teacher role not only to gain entrance to the classroom but also to obtain the perspective of the teacher. In this role, I would sometimes be given lessons to teach, but for the most part, would supervise children in work and playground times; however, I remained with my participant for the entire duration. For example, if I was told by the teacher to help the students with their printing I would go to my participant's group to help.

It is noteworthy that other sociologists have gone on to complete successful ethnographies of this nature and complexity in the past. Lareau (2011) followed twelve families throughout their everyday activities to explore how children experience life depending on their social class backgrounds. She sent her proposal to many families and received a 90 percent response and approval rating; from this, she selected these twelve families. She observed children through activities in church, home, school, playground and even medical appointments. Lareau carried a tape recorder at all times and wrote

extensive field notes each day (requiring an additional eight to twelve hours out of her day). These observations were not conducted consecutively; rather, Lareau followed these children for 20 days out of the month. Through an intense two months of observation, Lareau (2003) was able to identify ways in which parents of various class backgrounds transmitted different life experiences to their children.

Because of the time constraints, I limited my observations to five days per child, requiring a prior meeting with the child and parents to orient myself to the family and ease any of their concerns. I used a tape recorder as well as extensive note taking as my method of data collection. Reflections on my day with each child were also necessary to capture ideas and instances not fully covered by observation. In combining all of these methods, Punch (2002) believed that it can invariably create more in-depth and rich data to use for analysis and more fully and reliably engage children in the research process.

3.6- INTERVIEWS WITH PARENTS AND EDUCATORS

Interviews were also conducted with the children's parents to discuss their lived experiences during the process of diagnosis and to ascertain if they observed benefits as a result of the label (see Appendix A for a list of parental interview questions and appropriate letter of information and consent form). These interviews were also used to reveal the role parents and guardians had in the diagnostic process; parents were asked prior to the interview to list all of the contacts they made before they received either a diagnosis or referral to the treatment centre. For the convenience of participants, parent and child interviews were scheduled to coincide with their appointments for regular services at the treatment centre. Volunteers were available to provide child care while

parents were interviewed. Parents and children were offered snacks and beverages on site and received a $20 gift card (to a local children's activity and learning store) as a thank you for participating. In addition, children were given a certificate of participation as a momento. All parents consented to an interview in this study.

Lastly, teachers of each student were invited to participate in an interview concerning their overall perceptions of the disorder itself and their awareness of its nature and symptoms, experiences in accommodating the students within their own classrooms and their perceptions of student and peer relationships. Children's teachers from the year prior to the formal label being given were also invited for an interview to make comparisons of how labels may have changed teacher perceptions. This invitation was made by phone or in person and with the permission of parents, school board, and principals; consequently, all four boards were invited to participate and then solicited for research and ethics approval (Please see Appendix B for interview guides and letters of information and consent). As a token of appreciation, all school boards were offered a workshop for all of their teachers outlining what DCD is, its symptoms, and subsequent effective strategies in accommodating students with this disorder. The intended interviews with all three parties (children, parents and teachers) addressed how these labels (or diagnosis) provided for changes in social opportunities, changes in self-conception, and changes in peer relations and stigma. Interestingly, of the 17 teachers who were invited, only six accepted the invitation and participated in interviews.

Although this study is primarily an exploratory case study, it does have the potential for retrospective bias, inherent in this kind of data. In terms of recall, children could

potentially report events and experiences either more negatively or more positively, depending on the meanings they have associated with that particular event. This retrospective bias can also be present in the parental and teacher interviews in which both actors are being asked to recall information from time periods of up to ten years prior to diagnosis or referral. And similarly to the children, these two actors may also report events and experiences with more positive or negative lights. To somewhat account for these potential weaknesses, I recruited a comparison group for each actor involved. Furthermore, parents were asked to provide any medical documentation they had regarding their child's symptoms and/or diagnosis to triangulate with more personal accounts that they and the child's teacher provided, creating richer and more reliable data. While there are limitations, the exploratory nature of the study aims at describing and uncovering important aspects of the labelling dynamics at play, in an effort to inform larger future studies.

3.7- ANALYTICAL METHODS AND TRUSTWORTHINESS

In using purposive sampling, this study does acknowledge that the potential for researcher bias is inherent, but given the nature of the sample needed for this study and the setting it was not possible to randomly sample subjects. However, given the small sample and the nature of the questions, the data can be considered credible given the research methods used in this study (Shenton 2004) as they were well-established in previous studies of this nature (Shenton 2004). After collecting the data from all interviews were transcribed and put into NVivo (QSR, Version 10), each participant was sent a copy of their interview transcript, including their child's interview transcript, to

provide comments and feedback. None of the participants changed their transcript information but merely corrected editorial mistakes. Comments from the participants surrounding the interview were quite positive. The interview and observation data were rigorously analyzed for major themes and patterns using LT as the guiding analytical framework but also for themes not accounted for by LT. Returning to the theoretical framework is essential for analysis to be considerable reasonable (Yin 1994). Coding, however, first began as a series of small themes emerging from the data; these preliminary themes were subsequently analyzed for clarity and connections to the larger theoretical propositions put forward in the research questions but also for themes not accounted for in the LT literature (Reid and Gough 2000) (Please see Appendix A for diagram).

In an effort to ensure that these themes were capturing various components of the research questions proposed in this study and larger ideas, I further refined them according to LT into major concepts which included, child characteristics, daily struggles for parents and children, diagnostic journey, labelling attitudes and experiences, parental roles, and peer and social experiences for both parents and children. This process of refining was completed to reflect the original propositions of my study and some of the weaknesses of Labelling Theory. In addition, each theme was derived by triangulating all of the data sources available to form these themes by drawing on both interview and observation data from all sources (Shenton 2004) while also keeping propositions in mind. It is essential in any case study to triangulate data and use all sources in discovering

emerging patterns and themes to accurately answer the research questions (Baxter and Jack 2008).

After the analysis was completed and preliminary findings were composed, I mailed parents a summary. This summary was broad and did not contain any quotes from the interviews because participants had already been given copies of their transcripts. If participants wanted further evidence, they were given the option to email or phone. After receiving the summary, most participants responded positively while some did not respond at all but were happy to have received it, as voiced by all. The children's treatment centre was also enthusiastic about the findings and requested a workshop to help clarify and elaborate the findings of this study.

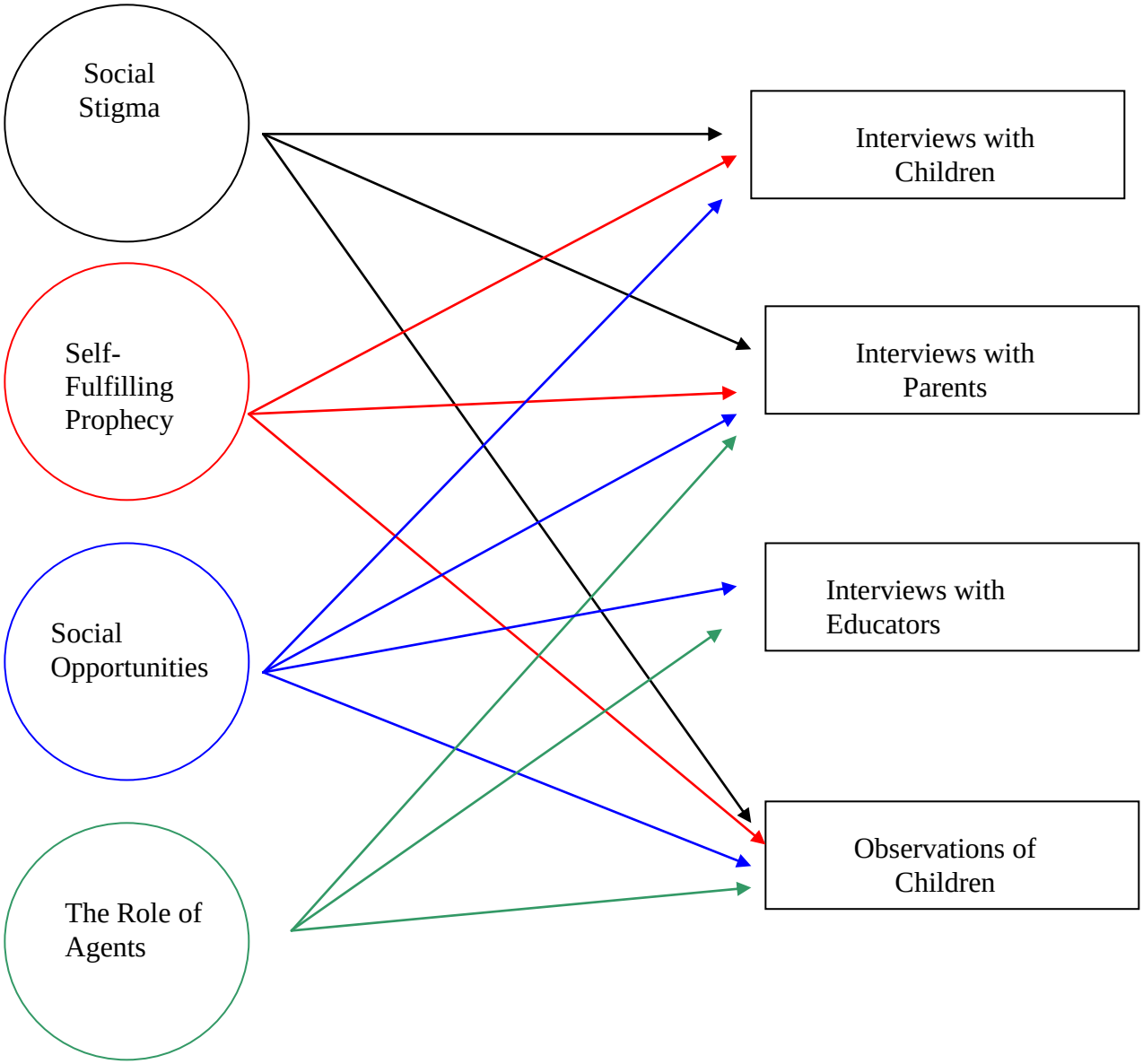
3.8- CHAPTER SUMMARY

To summarize, this study interviewed three sets of actors: child, parent and teacher. The purpose of these three different levels of interviews coincided with the four research questions. In an effort to discover how the child views themselves prior to and after receiving the label of DCD, all children who participated in this study were interviewed using the PEGS instrument or with a developed guide and participated in a drawing activity. This created some potential for retrospective bias, but this was minimized by triangulation with all three sets of actors. Parents were also interviewed to address how they view their children's self-perceptions and overall experience in the diagnostic process. To analyze the effects that labelling may have for children at the school and peer level, I interviewed some of teachers concerning their perceptions of how student participants fared in their classroom peer interactions, the children's self-worth and

behaviours, and their own attitudes about integrating children into their classroom lesson plans and strategies (see below for a diagram summarizing the research questions and the sources of data to fit each). Moreover, previous teachers of children were consulted regarding their experiences with the child and their perceptions. Lastly, to enrich these interviews, I directly observed all children for a period of five days in school, home and extra-curricular environments for social reactions and peer relationships. These observations elicited insight into the peer interactions of these children, allowing for close observations (Goffman 1989). Peers were not discussed but observations elicited the information needed to infer how labels affected social reactions and peer relationships. Thus, the overall design of this study makes comparisons along two dimensions: between labelled and non-labelled children and among labelled children. Both groups of comparisons were informed by interviews with parents, teachers and educators affiliated with each group, and utilized both retrospective and present impressions of their experiences with each group of children.

3.9- DIAGRAM 3: RESEARCH QUESTION AND DATA SOURCES

RESEARCH QUESTION THEME **DATA SOURCES**



Chapter 4: Family and Child Narratives

This chapter introduces the reader to and provides a contextual background for each participant family involved in this study. It is largely a description of facts and events that transpired, according to medical records, educational records, and parents' own accounts; however, it also provides a description of every day family life and daily struggles. I begin with an overview of those children who were undiagnosed in my study, then move onto the mid-diagnosis child, and end with a discussion of the diagnosed children, ending with the oldest child in my sample. At the end of this chapter, a summary chart is provided on child and family characteristics, a resource that helped me focus my analysis and can serve as a referral guide for the proceeding chapters and discussion.

4.1- UNDIAGNOSED CHILDREN

4.1.1 Tracey[8] and Kevin and their parents, Felicia and Kody

Tracey and Kevin, two of my youngest participants, were brother and sister, and both were in the health care system receiving therapy for a variety of issues including fine and gross motor delays. Tracey was three and a half; Kevin, six. By all accounts, Tracey and Kevin were both hyperactive and engaged children. During my interview with Felicia and Kody, both children required attention and prompts at all times from either parent. Although, quite chaotic, it was a realistic portrayal of this family's life. This family lived in a small semi-detached home that had six individuals; it was filled with numerous toys, furniture and paraphernalia like any home with six occupants (Felicia and Kody had two

[8] All participant names used in this study are pseudonyms. All identifying information has also been changed or removed.

other children). The neighbourhood had a park located just down the street and many hiking trails to explore. It was a classic middle-class suburban setting.

The parents explained to me that the process of acquiring a diagnosis for either child had been difficult and there were numerous individuals involved. Both children were under the care of a General Physician, Pediatrician, sleep doctor (Somnologist), and other health professionals, including a range of therapists and resource consultants. By all accounts, these parents had manoeuvred through the system well, given that they lacked economic resources (in comparison to my other participants). However, Kody did mention that Felicia had an astute awareness of the health profession given her career as a personal support worker.

Felicia had told me that both pregnancies were difficult; with Kevin, she had had an emergency C-section because she had lost amniotic fluid and he was pressing down on his cord, cutting off his blood supply. Tracey was also born via c-section and had complications from birth. She had an allergy to cow's milk early on and was consistently sick from birth until about three months. Felicia and Kody did not elaborate on what illnesses she had but only said she was sick "all the time." Both parents described constant difficulties with feeding, dressing, movements of any kind, breathing and sensory issues for both children throughout their young life spans, and both parents elaborated that they had to be patient. Given Felicia's career and past experience in health care, she knew that accessing a doctor's care would be crucial to each child's development; as a result, they had seen approximately 20 to 25 individuals to receive the necessary services.

A typical day for this family seemed hectic as Felicia worked full-time shifts while Kody was unemployed. He had left his job as a transport driver due to a disability, the long hours and child care needs. He was working towards opening his own business. Tracey and Kevin both needed around the clock care and, in addition to having their own two children, Felicia and Kody had adopted her niece and nephew and had them in her care, as well. Having such a busy household did not keep them from spending time with each of their children and maintaining routines. As a family, they were active in extra-curricular activities such as Cubs and soccer, and also participated in church activities every Sunday and throughout the week. During the spring and summer months, each child attended swimming lessons and a few times I was invited to watch the family as they all participated. This was in addition to the appointments that were scheduled and various group activities sponsored by the treatment centre.

4.1.2. Kyle, and his parents, Stephanie and Eric

Kyle, the next in my undiagnosed group, who at four was still fairly young, was receiving treatment in school from the centre for fine and gross motor delays. Kyle, who was in Junior Kindergarten (JK), was referred to the centre by his teacher. His parents, Stephanie and Eric, felt that some of his identified issues might resolve as time progressed, and they were reluctant to seek out treatments or inquire about his delays. Stephanie was a photographer and stay-at-home mom while Eric was an educational support staff member for a local board; both were well educated but expressed some concerns over having Kyle formally labelled with any disorder. Stephanie expressed in the interview that they had never really noticed anything wrong with Kyle, but that the

teacher had pulled them aside stating that he was slouching quite often, could not grasp pencils or crayons and had trouble cutting with scissors. After the referral to the centre was complete, both parents received regular updates on the progress of his therapy via mail, but nothing in person. Both expressed that none of these issues had been noted in the daycare setting that he was in prior to JK.

The one marked difference between Kyle and the other children in this study was that Kyle was not enrolled in any extra-curricular activities outside of school. His parents expressed to me that he would attend relatives' houses on the weekends and would also play outside with his parents periodically. His typical day consisted of going to school, coming home for dinner, watching TV or playing outside with his mom, and finally heading to bed, which was early due to his age. His parents did quite a bit of travelling all over the country with Kyle, stating they once drove all the way out East with him and he was perfectly behaved. Eric was not Kyle's biological father but had accepted him as his child, and Kyle had accepted Eric as his father (as stated by the parents). Stephanie pointed out that though Kyle had had some problems initially accepting Eric as it had been only she and Kyle from birth on, their relationship had developed as time progressed.

This family lived together in a small apartment resulting in their making numerous trips out at the end of the day or during the summer because of the lack of space for Kyle to play in. Both parents also stated that the apartment complex atmosphere was not one they wanted Kyle to be raised in and that they did not like where they lived because of the types of families that lived in the apartment complex. It was for these reasons that they

did not want Kyle to associate with the other children, and, although they were actively looking for a new place to live, they were in no rush. Stephanie and Eric were not married but living together and both had a middle-class income but used this income to take trips as a family unit rather than focus on other material things or extracurricular activities for Kyle.

4.1.3- Larry and his parents, Barbara and Kris

Larry, age seven, was receiving treatment for fine and gross motor delays and had been informally labelled with ADHD by his family physician. At the time of this study, his parents were seeking out more information on his inabilities and were being referred to a pediatrician for further observation and consultation about his motor delays and potential ADHD. Barbara worked in the health care sector as a nurse; Kris, at a local engineering company. Both worked shifts, which made it difficult to arrange for child care and pursue medical advice and help for their children. This couple lived on the outskirts of town in a house with a large amount of property, but were not close to any neighbours or family. Larry was the older of two boys as Barbara had recently had a baby.

Barbara began describing the first time she noticed anything amiss with Larry and stated that it began at birth when he was diagnosed with digestive problems. In the beginning, Larry had feeding and sleeping issues that required him to be hospitalized in the Neonatal Intensive Care Unit. Later, they discovered he had an allergy to milk. Larry had torn a tear duct in one eye which required surgery for vision loss. At 14 months of age, this eye was repaired and his vision was restored to 20/20. At approximately 2 years

of age, Larry was being followed and assessed by a Speech Pathologist, and by the age of three, he was informally identified with ADHD by his family physician who referred the family to a pediatrician for further testing. Barbara sought out speech therapy as she felt there was a noticeable delay for his age.

The pediatrician felt that the best course of treatment was behavioural therapy and to place Larry on Ritalin at the age of six, but his parents both worried about the side effects and ceased the Ritalin therapy. In addition, Barbara and Kris both stated that Larry had trouble with wetting the bed, complained of tummy pains, and night walked and screamed in his sleep. It was obvious that these parents were overwhelmed but were adamant about attaining help for Larry. They attributed some of these issues to the fact that Kris was also ADHD and wondered if perhaps it was passed down to Larry genetically, but they indicated that his sensory issues were perplexing. These sensory problems included not putting on certain socks because of the feeling they had on his feet, not wanting to do buttons up, instead, wanting plain shirts and pants he could easily slip on and off. Finally, both parents complained of his lack of organizational skills and that Larry often left messes wherever he went. This was something they were trying to work on with him when we talked.

In senior kindergarten, Larry was transferred from a French immersion program to an English program within the same school because educators felt he was not able to keep up with the French curriculum. At the beginning, Larry's parents were somewhat disappointed but trusted the school's decision. However, at the time of the interview, they were seeking out another school board and French program for Larry to attend as they

reported being "disappointed with the lack of communication from the principals and teachers" and believed that he could handle such a program. They also expressed that his needs were not being met in the current classroom and that he would be better served by a board that would acknowledge his learning issues. Finally, Larry, although hyperactive, was not active in any extra-curricular activities at the time of this study; but his parents did express that he was very interested in dance and had been in the program once, displaying a lot of interest and enjoyment. Their plan was to have Larry back in a dance program within the next year.

4.2 MID-DIAGNOSIS CHILD

4.2.1- Ken and his parents, Jill and Kevin

Ken, age twelve, was a mid-diagnosis child; namely, he was labelled as having characteristics of DCD by his occupational therapist but was in transition to a pediatrician who could formally diagnose the issue. Ken's parents, Jill and Kevin, did not formally request the pediatrician access and were rather ambivalent about the label. Both felt that the label might do more harm than good for Ken but in the interview expressed that they should have paid attention earlier on and, perhaps, Ken required more help than they had initially thought. Jill and Kevin were both prominent in community activities and had well-paying careers. Jill worked in law; Kevin, in Forestry, and, combined, had a family history rooted in the city's growth, unlike the other families interviewed. But much like most of the participant families, they had an abundance of social and economic resources available at their disposal. Their house was located in a very prominent neighbourhood and had an excellent view, for which the area was known. Jill and Kevin also stated that

they had chosen the school Ken attended because of its outstanding reputation for students and teachers, and as a result, drove him to school on a daily basis.

They stated that the first instance they felt something was different about Ken was when his kindergarten teacher called them with her concerns about his inability to grip a pencil and print properly. When prompted by a question, Jill stated that her son usually complained of being tired and that when he was young, often had trouble going to the bathroom and frequently wet his bed. In fact, she felt that he was also sometimes deficient at dressing himself. These concerns, as well as the teacher's, led them to seek out a pediatrician who speculated that Ken may have ADHD. As a result of this statement, Jill and Kevin both decided to wait, feeling that ADHD was too stigmatizing a label for their son to have and perhaps, he would outgrow some of these issues as time progressed. The issues which led to this speculation of ADHD were Ken's inability to focus or sit still when seated on the carpet; when prompted, Ken would often answer questions indirectly or state something he was thinking about rather than answer the question posed at all.

Ken was a quiet child when I first met him (I was invited to attend a family party to get to know his parents, relatives and Ken prior to my direct observation time). Throughout the entire study, he often kept to himself and was articulate when asked questions. Interestingly, despite his parents being adamantly against Ken having an IEP, Ken had an informal IEP in the school so that teachers could strategize to meet his learning needs in the classroom. Teachers were fully aware of his inabilities in articulating written thought and his parents mentioned that Ken's report cards did not seem to reflect his ability to express ideas when they saw him at home. They stated no

concerns with his peer groups, explaining that he was "well-liked by the kids." However, his parents did acknowledge that Ken had issues daydreaming in class which was often the case in my observations; frequently, the teacher would have to redirect his attention back to his work. Ken was not disruptive but rather was unable to complete work given to him because he only focused on his thoughts and not the task at hand.

On a typical day, Ken would be driven to school by one of his parents and sometimes was a few minutes late for class. Ken, the older of two children, had a sister who was a few years younger and did not get along with her. This was evident from his behaviour both at home and at school. After school, both children would walk a few minutes from the school to their after-school care provider who had been with them since infancy. Each child walked on their own without acknowledging the other. While in the care of Lily, an elderly woman, Ken was responsible for bringing bins back in from garbage day during the week and for getting his homework accomplished. Lily mentioned that she was persistent in getting Ken to finish his homework and would often take the children on hikes through the neighbouring trails afterwards to keep him active. She would feed them a snack once they arrived home and ensure that they did not watch television, something on which she said she prided herself.

After returning home, Ken was often able to negotiate what he wanted for dinner from his mother, asking for pizza, waffles, anything easy to make. Sometimes, he would head out to play Nerf guns with his friends at the lake, but, on his computer more often than not, he would play various online, multiplayer games. Once a week, he would attend swimming lessons (during the appropriate season) or Cubs with his father. His father

would occasionally drive him out on the weekends to another property they owned in town to play Nerf guns with his friends.

4.3- DIAGNOSED CHILDREN

4.3.1- Dylan, and his parents, Kendra and Donald

Dylan, age ten, was a relatively calm and very introverted child. Though he played with his peers, these peers were always younger than him. His parents, Kendra and Donald, were both very successful in their respective careers, one in education; the other, law. Their large house was in a prominent and affluent area located on the outskirts of the city, with beautiful scenery. Both parents also had experience with children who had special needs: Kendra's primary career was in this area, and she and Donald had two children with special needs, one who had sadly passed away. They both described how they knew Dylan was a bit different and that something was wrong, drawing upon their experience in navigating and negotiating the system to pinpoint Dylan's issues. Dylan's older brother, who was in secondary school, had a learning disability and his late older brother had Cerebral Palsy and was born with hydrocephalus.

Kendra stated that the first time she realized something was wrong with Dylan was when he was beginning to speak (around one and a half to two years of age), and she noticed his speech was "off" (as she put it), and was delayed for his age .They told me that Dylan was born with hypernephrosis, a dysfunction of the adrenal glands and more commonly known as congenital adrenal hyperplasia. As a result of this diagnosis, he was on antibiotics for the first year of his life and monitored by health professionals. They began by finding a Speech Language Pathologist (SLP) who referred them to an

Occupational Therapist (OT). Based on this previous knowledge and Dylan's medical issues, he was assessed as a toddler through a local centre.

It was through these assessments that the SLP determined that Dylan's muscles were the issue and began working with him from that time on through to school age, when Dylan encountered Physical Therapists (PT) and SLPs through school services. During this time, they were referred to a pediatrician who diagnosed Dylan with DCD and began working with Dylan to ensure he had services and treatments. Dylan began receiving simultaneous accommodations within his classroom. Kendra and Donald were in constant communication with principals, teachers and the resource teacher to help explain what Dylan's limitations were and what the diagnosis meant; therefore, they educated the teachers on Dylan's diagnosis and how they could accommodate him in the classroom but left the strategies to the teacher. Having the diagnosis confirmed provided an explanation as to why Dylan would spill milk every morning, eat with his fingers or why he did not have energy for activities with his older brother.

Dylan, despite not having energy, was encouraged to engage in activities such as skiing and squash and also to build things with his father and on his own. His parents advised me that he often willingly took on projects to build structures with Donald's tools. In one instance, Dylan built an entire shell for a gazebo, which gave his parents great pride. Both stressed that they fostered his interest in not only these activities but also extra-curricular ones. For example, Dylan was enrolled in a local gymnastics club that he attended once a week after school. His parents allowed and encouraged him to walk to this activity from school each week. The remainder of the week, Dylan was bussed to an

after school program where two to three times per week, he met with his father to play squash. The other day of the week he played at the after-care centre either outside or inside with the other children; often, though, this was solitary. Both his parents stated that they were persistent in teaching Dylan these types of physical activities step-by-step, despite the frustrations they encountered along the way, and were successful at doing so. Dylan also had weekly piano lessons close to home after his squash lesson.

4.3.2- Andrew and his parents, Elaine and Nathan

Elaine and Nathan were married, both over the age of 50, and had one child, Andrew. They explained to me that Andrew was a difficult pregnancy and delivery. Elaine had had gestational diabetes, culminating with toxaemia, and once dilated to eight centimetres, she had had to have an emergency C-section because labour was not progressing. Because Andrew was presenting with signs of distress, and Elaine had stopped breathing during the C-section, both she and Nathan felt it was in their best interest not to have another child. Both indicated that Andrew's difficulties began at that point, and when they returned home, these issues did not end. Andrew had had a difficult time nursing and, as a result, lost a large amount of weight. The medical staff wanted to readmit him to the hospital; however, Elaine resisted by seeking out a lactation specialist and other more natural remedies.

This was the first sign of their ability to fight and argue for services for Andrew. Both Elaine and Nathan started their careers as teachers— Elaine as a resource teacher; Nathan, a high school computer teacher. Consequently, their educations and careers exposed them both to skills of negotiation. At the time of the interview, Elaine worked in

early childhood development while teaching at the post-secondary level; Nathan, as a computer specialist for a local company. They lived in a larger middle-class home in a family-friendly area of the city. Elaine mentioned on several occasions that she had adamantly pushed for a seat on the special education advisory committee for her school board and advocated throughout Andrew's school career for his services. Nathan mentioned that he also advocated with his wife, attending meetings with teachers, principals and board administration on a regular basis.

Andrew's journey to attaining a diagnosis of DCD began when Elaine contacted a friend, a physiotherapist at the time, asking her questions about whether Andrew's development was normal or whether he was lagging behind in these milestones. This friend referred Elaine to a pediatrician in the city who happened to be their neighbour and friend. The pediatrician recommended first seeing an occupational therapist and also referred her to a resource centre where she could obtain more information. Some of Andrew's delays included not being able to walk until close to the age of three and requiring a stroller that was larger because of his weight and height. He was not toilet trained until much later, and his inability to grasp utensils proved to be difficult for his parents; everything was a challenge for Andrew, and he took longer than normal to develop. As a result of these lags in development, he was diagnosed with global developmental delay. However, both of his parents and the pediatrician did not feel this was satisfactory, and they were referred to Sick Kids hospital in Toronto for further investigation. Andrew subsequently received the diagnosis of DCD from a pediatrician and was also referred to a neurologist for some of the autistic tendencies he displayed.

The suggestion of characteristics of autism did not resonate with Elaine and Nathan; they have yet to pursue this diagnosis. However, receiving the diagnosis of DCD was a confirmation and affirmation for them. They told me in their interview and several times during my stay how they had to explain this diagnosis to teachers and board administrators. Consequently, Andrew now has accommodations in his learning and educational outcomes.

Currently, a typical day for Andrew consists of walking or being driven to school which is approximately 15 minutes away from his home on foot. His parents encourage him to walk so he gets some exercise. Andrew is a tall and lean boy especially by Grade 8 standards. Andrew keeps mostly to himself throughout each class but does associate with one girl in particular, who Elaine and Nathan informed me has been a friend throughout elementary school. His parents specifically chose this school board because of their exceptional services in special education and feel Andrew's needs are consistently met by his teachers.

After Andrew finishes at school, he often walks home by himself. Elaine and Nathan have laid out chores for him to accomplish every day, so he has a routine after school time. As soon as he arrives home from school, Andrew is responsible for putting away the dishes left in the dishwasher, setting the table, letting the dog outside, peeling and prepping any vegetables for dinner, and has to accomplish his school work in that time. His parents felt that he needed responsibility to remain disciplined; additionally, they both worked full time and required his help to keep up with the household chores.

In particular, his parents stressed the need to be a cohesive family unit, stating that they often went to "the camp" – a site where, every weekend during the spring and summer, they would bring their trailer and cottage and would take a few weeks off together. They shared numerous photos with me of their family events, their beloved, old family dog and Andrew's accomplishments throughout school. It was evident they were a proud and close family. Andrew also showed me the train collection that he built with his father and the meticulous detail they both displayed in painting and crafting the actual set.

4.3.3- Owen and his parents, Tina and Ethan

Owen was the second oldest of my participants who was diagnosed with DCD. At the age of 16, Owen was more independent than most other children in my sample. He was generally a very happy child and was just beginning to really explore his independence, as stated by his mother. Tina was a stay-at-home mother who used to work in the health care system as a nurse. Her husband, Ethan, was a doctor at the local hospital. Their knowledge of the health care system gave them access to the resources Owen required from an early age. Owen was the youngest of three children and the only one with special needs who required medical intervention and therapy. Tina and Ethan's careers and affluence enabled them to live in a large but modest-looking house in the most prestigious area of the city, known for its prominent homes and family-friendly atmosphere.

Initially, it was thought that Owen had a mild form of Cerebral Palsy which prompted the pediatrician to send the family to Toronto's Sick Kids Hospital for further observation and assessment. This marked when Owen was first diagnosed with DCD (or clumsy child syndrome as it was known then), and he began working intensively with a

physiotherapist. Because they had two older children, Tina stated that she knew something was not right with Owen's development but also mentioned that her husband had had difficulty accepting this. He would often state that Owen would catch up and that he was a boy and boys often fell and lagged behind in development. Other symptoms she became concerned with were his habits of not eating with a fork and knife and using his hands instead, hitting walls, difficulty getting dressed and when he walked at the age of three, stumbling often. After receiving the diagnosis from a neurologist in Toronto, Tina began researching the disorder and found that it confirmed for her what Owen was experiencing.

This family, by all accounts, was and is a very cohesive unit. Tina and Ethan take numerous trips with their children and often live at their cottage during the summer months. Although Ethan is often busy with work, he still remains dedicated to his family. Ethan, although dismayed at the identification at first, gradually accepted the disorder that Owen was given, and being a doctor, he has taken an interest in some of the brain research that has emerged on DCD. Tina is an active parent, attending all of her children's events and although her two eldest children are now off to post-secondary schooling, Owen remains well-connected with his siblings. Tina encourages Owen to engage in other activities, and he is active in drama and sports activities. Tina registered Owen for the local theatre group, which I had the privilege to watch. She also had him enrolled in special education sports and Olympics which Owen remains active in to this day. In addition, Tina and Ethan have ensured that Owen receives private physiotherapy at a local gym and personal training once a week. In addition, Tina acquired a private

drumming instructor to work with Owen once a week in their home as she found that taking him to lessons was too structured and he required more flexibility.

4.3.4- Keith and his mother, Rebecca

Keith was the last and eldest of the diagnosed participants. Keith was particularly interesting, given his history with the disorder. Keith, a very warm and energetic young man, was in his second last year of secondary school. He was very articulate and keen on completing school work, despite his limitations in some areas of reading and comprehension. For the most part, Keith was a visibly larger (both height and weight) boy compared to his peers, but was friendly and well accepted by all.

Rebecca and her ex-husband separated approximately twelve years prior, and she has been the primary caregiver for the family. Keith had one older sibling with whom he remained close. However, his mother pointed out that his father, although a bit distant, still helped with the care of Keith. Rebecca was successful in her career working for the city, travelling periodically for weeks at a time, but still cared for her son via email and phone. She and Keith lived in a modest middle-class home in a family-friendly neighbourhood. Rebecca told me during the interview that she had recently had many renovations done to the house. The neighbourhood was a mix of lower and middle class homes for families, singles and students, which is reflective of most parts of the city.

The initial issues that presented and caused Rebecca's concerns were Keith's general clumsiness. He would consistently bump into and drop things, or hurt himself in the process of doing something. It was not until Keith was approximately eight years of age that it was suggested by his occupational therapist that he might have DCD.

Consequently, he was referred to his general physician for further investigation. The doctor agreed with this diagnosis, and he was formally given the label. Rebecca often stated that her relatives would criticize her for "babying" Keith too much and hovering over him too often (or what one participant called being a helicopter parent). Rebecca felt that she often had to justify why she was still cooking for and helping him get dressed at the age of 10 or 12. She stressed to me that even now at the age of 17, Keith is only allowed to microwave meals for fear that he might cut or burn himself because he is still so clumsy. She relayed a story of how even at the age of ten, she would have to put him in the grocery cart when she was shopping because he would often complain that he was tired from just walking around.

Now Keith is quite functional as he gets dressed on his own; yet, Rebecca still has to tailor clothing so that buttons are manageable for him, and she places zippers where buttons were. Keith has friends at school, but Rebecca stressed that she only knew of one real friend who comes over to watch TV with him or play video games. She has tried to encourage him in other activities, such as hockey and soccer, but has failed to keep him enrolled as he complained of being too tired and not engaged enough in the game. As a result, Keith has taken a liking to sports statistics instead of playing them, something that both annoys and concerns Rebecca. Keith had tried things such as riding a bike and jumping on the trampoline but did not enjoy either activity. Rebecca stressed that these were a struggle for Keith physically and her with being patient. Her concern now lies with his desire to drive independently. To discourage this, she convinced him to walk to and

from school, moving closer to the school as a result. She stated this was one way she kept him physically active.

For the most part, Keith had his shares of trials and tribulations throughout childhood and because little was really known about DCD, Rebecca found she had to move forward with trial and error and develop her own strategies to help Keith cope with the disorder. Keith had been bullied, would constantly fall, and in some cases, could not stand for long periods of time. He never found a sport he was particularly good at except fishing, something that Rebecca encouraged. To cultivate this skill, she took him to the cottage every chance she could. Like Owen's parents, Rebecca groped in the dark, so to speak, when the diagnosis was given as the doctor and the OT were unaware of any strategies they could provide.

4.3.5- Tanya[9] and her son Fraser

Although I did not have adequate time to observe Fraser, in her interview with me, Tanya explained her son's issues and how Fraser came to be diagnosed with DCD. I felt it valuable to include Tanya without observation of Fraser as her insights contribute to other areas of findings and discussion. Fraser's data was not used to triangulate any of the children's' experiences presented in the following chapters. Tanya, a recent single mother and researcher, had two boys. Fraser was six years old and the younger of the two. As a result of her recent divorce, she decided to move within the city, closer to her own siblings, for familial support and nieces and nephews who could play with her children.

[9] I have decided to use Tanya as a participant but only in the discussion relevant to parental resources, and the diagnostic procedure. I feel it is still relevant because her experiences are no less valid because of my inability to observe her son.

Through her interview comments, it was evident that her concerns lay with establishing and maintaining this family support.

Her initial concerns began when Fraser was approximately two years of age. He had had a consistent drooling problem, and she described how she would often have to change his clothes and that eventually she had a bib on him at all times, replacing it often. Once he was brought to daycare, Fraser was identified as having speech delays, and the provider recommended that he be assessed. Tanya sought out this assessment using what she called her motherly instincts, as her ex-husband felt that he would grow out of it, that Fraser was just being a boy. Tanya knew, however, that something was wrong and stated in her interview that as she reflects back on past events, she sees the concerns she had initially but never followed through with.

After she had the assessment done, Fraser was referred to a free speech language clinic. Subsequent to these appointments and therapy, she was referred to a psychologist. Here, she expressed her concerns about Fraser's drooling even at the age of three and his toe-walking. Approximately ten months later, Fraser was referred to a drooling clinic in Toronto where an OT and a clinical psychologist finally diagnosed Fraser with DCD. After receiving the diagnosis, Tanya stated she then began to seek out her own private PT for in-home treatments, and Fraser received some in-school treatment from local, government-funded programs. She stressed in her interviews that, despite all of the delays Fraser experienced, he was still a good child but needed to be scaffolded into transitions or change. Tanya had to do this research herself, reading various books and meeting with several professionals because of Fraser's behaviour in daycare and later in school. She did

mention that she did this work because her ex-husband was like “an ostrich with its head in the sand” and wanted to ignore the obvious signs that something was wrong; he often explained Fraser’s explosive behaviour as being rooted in insufficient discipline. Currently, Fraser is still receiving both private and in-school occupational and physical therapy for his delays and disorder but is managing much better as a result of the diagnosis, something that Tanya assured me of in her interview.

Name of Child	*Parents Names*	*Parental Occupation*	*Age*	*Siblings?*	*Diagnosis?*	*Residential Information/ Parental Income*	*Parental Status*	*Parental Occupation*	*Extra-Curricular Activities*	*Child's Interests*	*IEP and IPRC Present*
Tracey	Felicia and Kody	Personal Support Work and Unemployed	3.5	1 Brother, 2 Step Siblings	No	Semi-Detached, $37,000	Married	Personal Support Work and Unemployed	Swimming, Soccer	Too young to assess, does enjoy making stories up and manipulation of smaller toys	None
Kevin	Same as above	Same as above	5	1 Sister, 2 Step Siblings	No	Same as above	Same as above	Same as above	Swimming, Soccer, Cubs	Enjoys building items, puzzles and making his own puzzles	None
Kyle	Stephanie and Eric	Photographer and Education	4	None	No	Apartment over $50,000	Cohabiting with non-biological father	Photographer and Educational Support Staff	None	Enjoys playing with trucks, building forts and structures, playing in the sand	None
Larry	Barbara and Kris	Nursing and Engineering	7	1 younger brother	No but ADHD informal diagnosis	Single-dwelling home, outskirts of city and over $100,000	Married	Nurse and Engineer	None- but used to be enrolled in dance classes	Video games, trampoline, some dancing	None
Ken	Jill and Kevin	Law and Forestry	12	1 younger sister	No formal but informally diagnosed with DCD	Single- dwelling home, within city, over $100,00	Married	Administrator in Law and Forestry Specialist	Cubs with father,	Playing with nerf guns, hunting and fishing	IEP but no IPRC
Dylan	Kendra and Donald	Education and Law	10	1 Older sister and brother, 1 deceased older brother	Yes- DCD	Single Dwelling- outside of city but in a residential neighbourhood, over $100,000	Married	Education Specialist and Lawyer	Squash, Piano, Skiing	Building things, cottage, swimming, and extra-curriculars	IEP and IPRC
Andrew	Elaine and Nathan	Early Childhood Development and Computers	14	None	Yes- DCD	Single-dwelling home, within city, over $100,000	Married	Early Childhood Educator and Computer Specialist	Cadets	Video gaming, building model train sets	IEP and IPRC
Owen	Tina and Ethan	Stay-at-home-Mother, Medicine	16	2 older sisters	Yes- DCD and other concurrent disorders	Single dwelling, within city, over $100,000	Married	Unemployed and Physician	Special Olympics, Drama Clubs, Personal Training, Snowboarding, Drumming	Video games, drumming	IEP and IPRC
Keith	Rebecca	City Worker and Administration	17	Older brother	Yes- DCD and Autism (questionable)	Single dwelling, within city,	Divorced, Single	City Worker and Administrator	None	Video games, watching sports on TV, playing yugi-o with friends	IEP and IPRC
Fraser (Not Observed due to time constraints)	Tanya	Researcher	6	Younger brother	Yes- DCD and Speech	Single Dwelling, outside of city, Over $70,000	Separated	Academic Instructor	Unknown	Unknown	Not sure

Chapter 5: Findings

In total, there were nine participants in this study who were considered for the purpose of this study as two separate groups: undiagnosed but receiving treatment for gross and fine motor delays and diagnosed with DCD. Five participants were placed in the undiagnosed group while four were diagnosed. Children's ages ranged from three and a half years to sixteen. One of the undiagnosed children was in the process of being diagnosed; he was receiving treatment from his occupational therapist and had been referred to a family physician as having DCD, but was awaiting diagnosis from a pediatrician.

Due to time constraints, I was unable to observe Tanya's son, who was diagnosed with DCD; however, I still felt it valuable to include her in the discussion of the findings as her perspective on the diagnostic process and related experiences were insightful. In total, 15 parents were involved in the study, three of whom were single mothers, and one couple who had two children receiving services. Interestingly, of all of the children, only one was female, and she was receiving services for delays but had not yet been diagnosed. This largely coincides with research that has already shown that boys are diagnosed with DCD at a rate of 2:1 in comparison to girls (Barnhart et al. 2003).

Family income ranged from $35,000 to $100,000 or more; most of my participants made more than the top income stated. This skew in income is not surprising as the majority of participants were well-educated and recruited through the children's treatment centre. This treatment centre posted advertisements in pediatricians' offices and common family areas and also referred potential clients to the study. Previous literature has shown

that parents with greater wealth and income are more likely to access special education services for their children, including accommodations in the classroom, therapy with specific professionals like OTs and SLPs, and hiring private tutors (Ong-Dean 2009). This level of income, however, does present a problem regarding access to health care services and educational accommodations which I will explore later. I have arranged my findings according to the research questions posed in previous chapters with a summary at the end of each section, followed by a reflection on these findings in relation to the theory and literature already presented.

5.1- RESEARCH QUESTION 1

In terms of social stigma, how do peers and teachers treat children with DCD, both before and after the label is ascribed? What kinds of qualities, traits, abilities and problems do they associate with these children?

To answer this question, I needed to draw from multiple sources of data: observation and interviews. All interviewees – parents, teachers, and children - were consulted; however, the parental interviews shed the most light on stigma while my field observations yielded interesting results about informal labelling processes.

Andrew's parents, Elaine and Nathan, pointed out several occasions, during their interview, his educational and social growth and when stigma and informal labelling were apparent. For instance:

> *E: … we had actually borrowed a stroller from the Easter Seal, and (laughing) we are older parents.*
>
> *I: Yeah.*

E: And you should have seen the size of Andrew.

I: He is tall!

E: He is very tall; he's thin.

N: He is tall and big.

I: Really!!

E: He's always been that way.

N: You'd get people looking at us, when he was in a stroller, like why is that kid in the stroller.

E: Yeah and very rude, you know remark. He still has problems with...he will prefer using his fingers instead of using a fork and spoon.

I: Ok.

E: Especially a fork, and so you know go to the restaurant and people would look at you, you know he's supposed to use a fork and spoon, right, because of his size, too.

I: Yeah.

E: Because he also had delays, so you'd hear, you know…

I: Hear snide remarks (both parents nod head in agreement).

These parents raised other instances of informal labelling and stigma:

E: We'll keep on doing what we're doing so that summer he finally toilet trained, about a week before going to school, and I thought that's he's going to school, not toilet trained, but that's sad. I am asking for an EA as he has a right to go to school.

I: Yeah.

E: And I was really advocating for services and so the JK teacher had come over to the house and had visited with us and, so, I said here are all these assessments that we have.

I: Yeah.

E: You know, special needs and some, and there was a change of principal at the school, so somehow there was miscommunication between principal and teacher that he was coming with delays.

I: Yes.

E: And 8 days into JK, I started my new job, and I get a phone call from the school, saying he's been suspended from school; you need to come and get him. Eight days into JK… and I thought OK, they were warned, what is going on? So I got to the front desk, I said to the girl, "I realize it is a different principal," and I said, "Um, I am here to or for Andrew?" and he said, "Yes, he hit the teacher." And I said, "Could you be fair and go and get his file?" So she went to go and get his file and as soon as she opened the file cabinet, and saw his name and saw how thick was file was, she went, "Oh my God, are we dealing with a child with special needs?" and I said, "Oh yeah!"

(Both interviewer and participant are chuckling)

E: And I said you and I are going to talk. And so that's when I said, "What happened?" Supposedly he had hit the teacher, what she said was, and I told this

teacher, you need to break it down. He cannot follow more than one step directions.

In this instance, the label of "special needs" changed the demeanour of the meeting for the principal, the perspective of the child's action and the school's view of the student. This was not the only example of informal labelling or misperceptions of students made by teachers. I also witnessed firsthand how teachers could informally label students who were not diagnosed and were exhibiting the symptoms of DCD in the classroom. Take for instance the case of Kyle:

Interestingly, when I tell Kyle to pull up his pants before break, the teacher comments to me afterwards that, "It is really pure laziness as to why he doesn't pull up his pants" (personal observation). She also blames his parents saying they never give him a belt to wear (Observation).

In another observation of Kyle, I analyzed the persistence and frequency of informal labelling:

The teacher remarks "…that it was normal for Kyle to lag behind and be a snail." She comments that it takes him forever to get dressed as well (Observation).

Larry was also a victim to peer and social stigma even without being formally labelled. This is another example from my observations:

The teacher asks Larry who he wants to work with, and he says one little boy. The boy says he doesn't like to work with anyone, especially Larry. Larry puts his head down and then says something back. I cannot discern what this is. The look and expression on his face points to some disappointment, but he tries to be nice

about it. The other little boy looks quite serious (Observation).

Stigma and pre-conceived notions from educators and peers were not uncommon in my interview or observational field notes. Tanya relayed her own perspective on this and how, prior to receiving a diagnosis, she was saddened and embarrassed by the drooling problem that her son had:

T: He drooled terribly from four months of age and people said," It's teething. It's teething."

I: Yeah.

T: He never outgrew it. He was three and four years old at daycare and teachers in winter, with this enormous bib, outside on his winter coat, because if they didn't put it outside his winter coat, it would get soaked, and that wouldn't be good, right?

I: Right.

T: So I was always looking for bibs. I remember Walmart had the best bibs because they had plastic on the underside. His teachers didn't want him to wear a bib, and I didn't want him to wear a bib, because other people would see the bib, but, if he didn't, his shirt within five minutes would be soaked, and I would have to change it. I remember once having people over. I didn't want to put a bib on him, to have him wear a regular shirt; I remember a friend said, "Boy you must have changed his shirt three or four times."

Teachers were more than willing to offer their opinions of why the child's behaviour occurred. In one case, a special education teacher remarked that Dylan's behaviour was due to the parents' expectations:

> *At recess, the special education teacher comes to discuss my observation and time. She seems very friendly. She believes that Dylan marches to the beat of his own drum and prefers to work alone. She says the kids all like him and get along very well with him. "It's not like any of them don't like him." She also says that his "...parents want him to be a superstar, and we just want him to be average as he is!" She also states that Dylan hates that his "...dad is all about the competition. He always wants him to win and he doesn't care about winning. His parents always push him to do things he doesn't want to do." (Observation)*

As a result of not receiving a diagnosis, Keith and his mother also both faced stigma, but from two different sources:

> *R: Um, telling people at school like his gym class, that you know might be 10 minutes but he's not going to be able to do the full hour.*
>
> *I: Yeah.*
>
> *R: The school says right! Even my mother was just saying, "He is so lazy." So, at the cottage, "Can you do this for me, Mommy, can you do that for me" and she'd be like, "You're pampering him too much. He's just a lazy kid."*

Thus, in some cases stigma and blame were transferred to parents who wanted to encourage and support their children through their inabilities. These kinds of opinions and blame were, for the most part, few and far between in my study.

5.1.1- The Use of the Autism Label:

Some parents utilized the well-known autism label to evoke sympathy from the public and attain services. I call this a form of strategic labelling meant to obtain services from the school and centre and to elicit positive responses from both educators and the public; a sort of self-created sick role to lessen the expectations for their child or garner accommodating resources. For example, I had three participants who sought out the autism label, and received it, to elicit not only educational services from the school board but also positive instead of negative reactions:

> *"When he turned 7, and they diagnosed him with ASD, that was easier because people know that diagnosis. So, all I have to say now is that, "He doesn't cause trouble, you know, he has an autism spectrum disorder, and he won't give you any trouble." He likes to follow the rules, and he won't socialize unless he is encouraged to. And so they were aware of something that they could give him that made more sense (Tina, Mother of Owen).*

Teachers felt that the use of an autism label seemed unwarranted and did not fit the profile of the student but understood why the parent wanted it.

> *"You know I don't see it; I don't see the autism. But I do see why she got the services for him and that a label of DCD is not recognized, as you say, especially by the board" (Owen's teacher).*

Keith's mother did not mention anything about him being diagnosed with autism; ironically, the teachers were only aware of this autism label and not the DCD label. His

mother did note that he had a fascination with numbers and this tendency reminded her of autism, but never stated that his official diagnosis included that of autism:

> *Most of Keith's teachers have told me that they are only aware of him having autism and nothing else; interestingly, Keith's mother has not mentioned this in my interviews and only in passing has stated that the doctor believed he had some tendencies but was not officially diagnosed (Observation).*

When autism was suggested as a possibility for Kyle, Stephanie and Eric rejected it outright and found other explanations to justify the symptoms that they described:

> *E: Often he doesn't make eye contact with new people.*
>
> *I: Ok.*
>
> *E: It is confrontational for him.*
>
> *I: Ok, so are you saying he is a little bit more shy, or reserved maybe?*
>
> *S: Yeah, you can see it. When I have noticed when he gets tested, some people observe him, and he gets really self-conscious.*
>
> *I: Ok.*
>
> *S: And you can see that's when he kind of drools.*
>
> *E: Or he gets bored, frankly. Like, if we are talking to him, and the TV is over there, we can have a conversation with him, but he will always be fighting to look at it, and even when we are in the room, he isn't really looking at us at all.*

5.1.2- Attributions after the Label

Attributions that were made after the label was provided were quite different. In most cases, children who had been labeled as DCD were seen as positive, well-developed, and

motivated in various aspects of schooling and peer interaction. Take, for instance, these examples of both Owen and Keith (two of my oldest participants):

I: How do you find his organizational skills?

Mr. Z: In my class, that is one thing he is very good at it.

I: Good.

Z: And he is always on time.

…

I: Have you seen him kind of grow from the first term to this term?

Z: I think mostly talking to other kids, which I'm happy to see. It's nice to see that he can chat with other people too, especially with my classes. There are a couple of hockey players that he associates with too from time to time.

(Interview with Keith's teacher)

I: He seems to love music.

Mrs. D: Oh yeah, and he loves the drama, he loves the music, but he so limited in what he can do in those areas. He can't read music. The teacher says he can keep the beat, kind of, he often does his own thing, so when they are doing dadada, he's doing ping, ping...and you can see kind of him looking around. And so he follows, and so the teacher gave him a bit of a mentor, one of the older students to kind of follow along. The drama same thing, he is limited, right? He can't read. Right now, he is reading at a grade 2 level, so right off the bat, in these scripts and any

memorization, any roles, he's got to have a very small role, but he is given them and he is determined.

(Interview with Owen's Teacher)

Parents were optimistic about their children' abilities and potential after receiving a label, mentioning their key attributes and interests as a result of receiving the label:

He's very sensitive, very warm, and a loving child (Rebecca, Keith's mother commenting on Keith's best attributes).

E: He just likes to mind his own business.

I: He likes to line them up. That's interesting.

E: He's very, he has a big, big fascination with them, for sure.

…

I: He says he loves his bike.

N: Yeah, that too.

I: So I could see that.

E: To this day, he'll ride, you know.

N: Drive.

E: Drive the cars or playmobiles, or you know.

I: Yeah.

N: Whenever he is leaning in, he is looking at the wheels, he's still does that.

(Nathan and Elaine, Andrew's parents)

Most parents offered to share the positive attributes of their children, whether diagnosed or not; however, as discussed subsequently in this chapter, those with a label were viewed more positively by their teachers, parents and themselves.

5.1.3- Summary

It is interesting that DCD, a physical disorder, manifests itself in ways that are visible to others, and thus, can be stigmatizing. Some observers characterize children with DCD as "lazy," "spoiled" or just "clumsy." More importantly, some of the parents utilized a more common label - autism - not only to acquire services but, also, seemingly, to destigmatize their child's behaviour, perhaps trying to elicit some form of sympathy for their children by using a well-known label. Overall, children with a label of DCD, who prior to diagnosis, faced stigma in various domains, such as within the public, familial, and educational context, faced less of such as a result. Therefore, even though they had well-founded concerns about informal stigma, these parents still pursued formal labelling. Some parents were strategic in finding a label that would accomplish this task as DCD was not recognized in the school system. Those children without an official DCD diagnosis seemed to be stigmatized as lazy, unmotivated, and other unworthy characteristics. Yet, after receiving a label, children were described as social, motivated and loving. All of the labelled children were accommodated by their teachers within classroom activities, something that is discussed more fully in the next two sections pertaining to the research questions. I will now discuss evidence about the self-fulfilling effects of labelling.

5.2- RESEARCH QUESTION 2

In terms of the social-psychological consequences of labelling, how do children feel about themselves before and after being labelled? What self-attributions do they make?

To address the next two research questions, I drew on both observation and interview data but also made comparisons across diagnosed and undiagnosed groups. I present the data from the undiagnosed group of children who were respectively between the ages of three and a half years of age through to eleven. At the upper end of this category was the 'in-transition' child, currently on a wait list for a diagnosis from a pediatrician.

According to Labelling theorists, the self-fulfilling prophecy occurs when the individual accepts their label and behaves like it over time. Formal labels, in this view, have direct causal power to change people's behaviour. In contrast, critics of Labelling Theory believe that ongoing deviance is not evidence of a self-fulfilling prophecy; instead, it is a continuation of the original conditions. The theory of the "sick role" (Parsons 1951) would hold that formal labels can actually bring additional support and perhaps even improve the person's original condition.

To test these theories, I begin by exploring how children in the undiagnosed group felt about themselves which, at times, was difficult given the parameters of their language skills and their young age. Furthermore, I engaged in a discussion of the types of difficulties they experienced. I proceed with how the mid-transition child felt about himself to those who were already diagnosed. While this is a small sample of children, the insights into their feelings of self-worth, body image, and their own daily struggles are

valuable for understanding processes of labelling, subsequent long-term outcomes and clarifying whether children undergo a self-fulfilling prophecy. It also outlines how informal and formal labels can shape children in vastly different ways.

5.2.1- Undiagnosed Children's Perceptions of Self

Interviews with Kyle, Larry, Kevin, and Tracy utilized the PEGS instrument and a drawing exercise in which they were asked to draw a time (whether good or bad) with their friends, at school, and at home. These children offered many insightful and honest replies. Two of the youngest participants, Kyle and Tracy, ages five and three and a half years, respectively, both answered that they did not have friends and that only some kids would play with them at recess. However, both perceived that they were very good at doing all things physical and sports related. Kyle, who was slightly older in age, was fully aware of his inabilities, stressing that he was good at some sports but not all. Larry, the oldest of this group, conveyed he was not good at any sports but enjoyed playing some of them. He did emphasize that he played with one particular boy at recess while enjoying a game of tag. All four of these children, whether they stated it or not, preferred to do sedentary activities for the majority of the time such as playing video games, playing in the sand, etc.

Tracy, who was being assessed for fine and gross motor delays, preferred to be alone and often played games on her own or read to herself; however, there were times she would interact with other children but often she had a hard time with such activities and transitioning from one routine to the next. Take this observation for example:

> *Tracy says to me, "I am not in circle." The teacher asks her to put her book away, but she says no. The teacher picks the book out of her hands and places it on the shelf. She then tells her to get going, but instead, she defiantly grabs her drink. The teacher ends up picking her up and carrying her down the hall. She puts her down, and Tracy refuses to budge. I ask if this behavior is normal, and the teacher tells me yes, that Tracy has a hard time transitioning from one thing to the next* (Observation).

It was hard to ascertain what attributes Tracy would have for herself in this instance due to her young age. However, by gathering information from her parents and teachers, I learned that Tracy is very independent and needs to be "scaffolded" or introduced to an activity or skill (such as reading, playing with puzzles, playing at centres or even transitioning from one activity or event to the next) logically and by sequencing events to each activity as she has a difficult time joining activities and lacks self-confidence. In this case, Tracy's difficulties were informally labelled by parents and educators; these informal labels included words such as "disorganized" and "hyperactive" by her parents and "unsocial" and "attention-seeking" by her educators. In most instances, these informal labels structured her play and behaviour. As another example as evidence:

> *While playing soccer, Tracy is pulled from playing by her parents at the break because she is not interested in the game. Instead, she sat out watching and occasionally would act out or misbehave; her parents would suggest to her to "go back and try playing," but she would run around the field behind them (Observation).*

Tracy's parents explain her behavior as needing this discipline because she lacked self-confidence and her own self-discipline. Her educators also stated that she needed discipline in order to behave and conform to classroom routines. This type of informal labelling can then ultimately shape a child's self-confidence levels; however, because of her lack of maturity and age level, it was hard to assess her own feelings of self-confidence at this point. Lack of self-confidence was a predominant theme for those who were undiagnosed and slightly older. For example, Kyle did not lack confidence in participating in any activity and got up to dance even though he fell most of the time and could not follow the teacher-prompted movements. Despite having challenges with gripping pencils and scissors, etc., he was proud of attempting these activities. However Kevin, who was a year older than Kyle, began to lack self-confidence according to his teachers. For instance:

> *Kevin's teacher comes up to me after music class and tells me she thinks Kevin has become even more self-conscious this year. Last year, he used to join into class and sing along and dance. This year, he doesn't even stand with the rest of the group as she puts it. He will not join in singing or dancing (Observation).*

In this case, Kevin had become quite reserved over the course of the year and no one could offer an explanation. However, his parents believed he was progressing quite well and felt he was much more social and self-confident as evidenced by his participation in extra-curricular soccer activities. His parents often commented to me that he had been quite shy the previous year and almost afraid to play soccer, but this year, he was running and laughing while playing. My own observations at two of his games indicated that he

was not social with his other friends and played according to his own rules, but this could be due to the relatively short time frame of my stay and the fact that his parents may be comparing his previous social abilities to present day.

Eight year old Larry, on the other hand, was also self-confident but not in particular sports and activities. During his interview, Larry frequently mentioned that he did not enjoy sports all the time and instead preferred doing things like jumping on his trampoline and riding his 4 wheelers. He especially enjoyed playing video games with his father. He did mention that he was not good at drawing or math. More importantly, I started to note his behaviours by observing his coping mechanisms as they related to his own inabilities within the classroom. For Larry, this often meant touching his belly button and sucking on his thumb when he felt things were out of control or he was frustrated. In this observation, for instance:

> *He gets in trouble with a teacher for talking while she is also talking. He puts his hand over his mouth and sits cross legged, facing her. The belly button playing ensues when the teacher glares at him; this somewhat confirmed to me that belly button touching could be a coping mechanism for Larry* (Observation).

On the same day during a reading exercise, the same reaction from Larry was observed:

> *Larry is called on by the teacher to come over and do some word practice. He is asked to pronounce words from a hand held flip chart. He has difficulty with very simple words and commonly mistakes b and d's in his pronunciation. As a result, he becomes visibly frustrated and begins pressing on his belly button and moving around in his chair. According to the teacher, Larry is apparently well below*

grade level in reading and struggles with the memory of sight words practiced all year. This could be because of his transition from the French to English program, but the teacher suspects there is more going on (Observation).

5.2.2- Mid-Diagnosis Child

As I proceeded to observe Ken, I noticed that he was quite explicit in his interview about how he felt about himself. For example, when interviewed about what he felt he could change about himself, he stated:

I: Is there anything that you would want to change about yourself?

K: Um, my weight.

I: Your weight? Why?

K: I am overweight.

I: Who told you that?

K: I know that.

I: Do you think you could change that?

K: Um, probably could.

As I delved further into the issue, I discovered part of his reasoning was related to the extracurricular activities he was involved in, such as Cubs:

I: And do you still get those little badges or whatever?

K: Yes.

I: Do you have some?

K: Yes.

I: Do you have lots of them?

K: Yes, except I don't wear my uniform because I have been in Cubs for three years and I am bit too big for it.

I: Do you have lots of friends at Cubs?

K: Not really.

For Ken, self-worth seemed to be dependent on his weight and friendships. He had some friends with whom he played Nerf gun; however, he did not do this regularly. The activities he was placed into were not of his own volition (as I observed and was told by his parents and peers). I saw his lack of self-confidence during his baseball tournament. For example:

While sitting on the bleachers watching the B team play, one of his friends asks him why he didn't try out for the baseball team this year, and he responds that he wasn't sure he would like it. The little boy responds that, "If you don't try it, you won't

The following is another example with Ken (mid-diagnosis child), in an interview with his parents:

> *J: Buttons, I remember him saying, I would put him in a pair of jeans in his younger grades and he would come home, and he would be bursting to go to the bathroom. And I would say, "Didn't you go to the bathroom at school?" "Mom I can't do my pants up" or "I can't undo my buttons." So, he would be going all day without going to the bathroom. He's a kid that never wet the bed, never. Trying to transition from diapers to the toilet was a pretty big deal for him, but once he got it, he got it. But he's never been a kid to have bed wetting issues, but bowel issues, if we send him to school in the morning, and he hasn't gone to the washroom, he will hold it until he came home that night. But then we have problems with constipation. There have been many times when in the morning he was slow getting dressed because he had to go to the washroom, so finally, and I asked him if he had to go to the washroom, and he would sit on the toilet, this little guy. He would sit on the toilet with a towel on and sit there, and sit there, and sit there, and there were many mornings he was late for school, and I would call the school and say we are going to be late this morning. Rather than having him go to school and be uncomfortable for the day, knowing he hadn't gone to the washroom. Um, but there are many times I would have to put in the bathtub, let him soak around and let him relax and then put him back on the toilet.*

Lastly, take Dylan, who was diagnosed with DCD:

Dylan leaves the classroom to be excused to the washroom and comes back after about 10 minutes. Apparently, he does this regularly, according to the teacher (Observation).

Writing, cutting, and/or gripping tools were also common difficulties for those with DCD:

Kyle (undiagnosed) receives his special scissors. These special scissors are connected at the top so that when a child grips them all, they have to do a squeeze. This seems to encourage building strength in his hands.

Owen is very verbal and can't work on his own. When he does work on his own, his printing is illegible (according to the teacher). His writing is curvy, large, and very primary. As a result, his teacher has let him use a computer to complete his written work most of the time (according to the teacher) (Observation).

Other areas of difficulty for all of the children include eating, dressing and in most cases, even walking. Most started crawling and walking very late and were still quite clumsy, falling often and injuring themselves. However, the diagnosed children were accommodated in their classrooms for these difficulties in physical education and provided with coping mechanisms through therapy or treatment by various professionals, something which is discussed in the next research question.

5.2.5- Summary

It seems that children's self-confidence can be attributed not only to having a diagnosis, but also to their age, social context, and other varying factors. Younger children seemed to have an abundance of self-confidence; yet, this waned as children

were more exposed to their peer groups and valued associations with those peer groups. As time progressed, children gradually began to learn to accept their limitations and devise their own strategies for coping and integrating to the best of their abilities. They were also given more accommodations, contributing greatly to increasing their own self-confidence levels. Interestingly, as the children grew older, they were generally accepted by their peers, at least at face value, and even by those with whom they did not associate. Prior to receiving labels, children often expressed behaviours that were self-conscious, or rather, shy and inward; however, this was highly dependent on age. Once children reached an age of recognition of peer scrutiny, self-attributions became about personal weaknesses.

Children's primary coordination difficulties do not change over time; they continue to struggle with physical issues as they grow. Yet, one factor does change for those with a formal diagnosis: they are given more accommodations and strategies for coping and treatment. This finding is inconsistent with a core tenet of Labelling Theory; namely, labelling or any accommodations would encourage children to settle into their deviant role which, in turn, worsens their primary conditions. But in this study, children who were labelled, although having suffered from stigma in the beginning, did not, for the most part, have lower self-confidence levels or more peer stigma. Thus, having a label may have made things more manageable.

As time progressed, it seems those children who became labelled gradually accepted the label, suggesting that the self-fulfilling prophecy is not all or nothing as is portrayed by some theorists. In fact, these two children showed no profound effects from

being labelled and instead showed more adaptive and positive attitudes towards their diagnosis rather than succumbing to the proposed limitations that are placed on them from having a label. Hence, children adapt and learn about their abilities in other areas. Informal labels that were given by teachers and peers, for example, did not seem to have long-term effects on children either; children who were labeled with DCD seemed to flourish with time and accommodations were made.

Andrew was keen on participating in Cadets, something that his parents said he enjoyed. As a result, Andrew was sociable and enthusiastic. Keith was also confident in his abilities and even voiced that he was fully able to still participate and do things, stating that he was "proud" of his accomplishments. Keith's case is particularly telling as he explains in his interview that, although he is aware of what DCD is, it still does not stop him from trying new things. He is aware of his limitations. Thus, the core idea that the formal and informal labelling of a primary condition leads to secondary deviance which then leads individuals to passively conform to this label was not evidenced in this study. Conversely, I found that formally labelling children with clear primary conditions brought accommodation and treatment, and their self-perceptions appear to depend on varying factors, discussed in the last two sections of this chapter.

5.3- RESEARCH QUESTION 3

How do labels affect educational opportunities in schools and social relationships? Do labelled children experience expanded or restricted opportunities?

5.3.1- Undiagnosed Children

One common aspect among the undiagnosed children was the amount of negative attention their behaviours received from their teachers; this attention was sometimes warranted, and at other times was not, based upon my observation. As discussed earlier, this type of informal labelling voiced and portrayed by teachers was profound and I believe it has a direct effect on the expectations that these teachers had for children. Take these observations of informal labelling for example:

> *Interestingly, when I told Kyle to pull up his pants before break, the teacher commented afterwards to me that it was "really pure laziness" as to why he doesn't pull up his pants (Observations).*

> *The teacher comments that she thinks that he is very egocentric and can be very defiant. She finds that she is surprised by the fact that he hasn't had more cuts and bruises/ stitches (Observation).*

Kyle's physical education teacher commented on his limited abilities:

> *The physical education teacher, who is different from the regular teacher, says Kyle lacks the ability to be truly empathetic or sympathetic with friends. And he doesn't read social cues very well (Observation).*

In all of my observations, I did not find one positive comment about Kyle's behaviour or abilities from his teachers, something I found intriguing. Tracy's teachers also showed the same pattern, dwelling on her negative behaviours with no positive comments. For example:

> *The teachers comment to me that, although Tracy has her bad and good days, most often she has a difficult time transitioning from one routine to the next. She often acts out defiantly and does not interact with peers well (Observation).*

These negative expectations did not end within the younger grades. In fact, teachers often expected the children who were undiagnosed to only act in prescribed ways. Take for example, Kevin's teacher's comment:

> *The teacher comments to me that she wants me to observe the way Kevin's behaviour can escalate and how she handles it (Observation).*

In this case, the teacher expected his behaviour to escalate and cause disruption in the class lessons. This frame of reference can be limiting for teachers as they expect social and classroom behaviour and perhaps ignore other forms of behaviour. In this regard, Kevin's teacher was adept at mentioning his more positive attributes at times. For example:

> *Kevin comes in from painting his place mat, and the teacher exclaims, "What a great painting." She then commented to me that he was the only one who painted his placemat with any sort of purpose. She found that interesting and stated that Kevin usually has purpose to his projects (Observation).*

However, these instances are ways in which teachers can also limit their expectations and the abilities of students. Because none of the unlabelled students had an IEP, none were accommodated or expected to be. Kevin's teacher and Larry's teacher (as discussed below) devised their own strategies based on what they knew of the students from prior conversations of colleagues and behaviours exhibited in class.

In Larry's case, his parents also informally told the teacher and principal that they were seeking a label for him, thinking it might be ADHD. This news was given to the teacher, who passed it on freely to her occasional teachers. For example:

> *I came into the classroom and found out there was a substitute teacher for the next few days as the regular classroom teacher was at a workshop. However, the regular teacher was there as the occasional came in. The occasional asked for the daily plans and then asked if there were any children who were troublemakers that she should be concerned about. The regular teacher commented on three boys, one of which was Larry* (Observation).

As Larry's parents had informed the teachers and principal of their pursuit of a label as well as the deficiencies already pointed out by the teacher in his previous year, the current teacher had accommodated for him in a more informal manner by giving him more direct instruction and attention. Yet, at the same time, his teacher had informally labelled him as a "troublemaker" and passed this information along to other teachers.

We can also clearly see informal accommodations with Ken's case as he was mid-diagnosis and had informal accommodations following him year to year. However, in the case of Ken, informal labelling was seen in a much subtler way:

> *The educational assistant goes over to keep Ken focused. She told me she constantly has to prompt him and help them organize his binder and desk. A little while later, I observe Ken as he lays back and watches the other kids around him. The educational assistant informs me of this as well by pointing to him as she is*

sitting beside me and stating that it is his regular classroom behaviour (Observation).

The educational assistant in his class organizes the baseball tournament every year. She decided to bring Ken to the tournament as an assistant because all of the other boys in his class were going. She did not want him to feel left out (Observation).

In this case, the EA stated she knew that Ken has some learning needs and her informal labelling actually prompted more attention to Ken. In fact, she stated she often helped him out with his work and organizational skills because he lacked the work ethic to do it himself, even though this was not in her job description. Thus, by having an accommodated IEP and learning needs communicated to her by the classroom teacher, the EA helped Ken out in the classroom. An accommodated IEP is a piece of paper which follows the child year to year, explaining that accommodations are being made but there are no formal accommodations and diagnosis yet provided, nor any curriculum expectations. In this case, the teacher elaborates on what this means to him:

G: The classroom teacher does the IEP and it is collaboration kind of between me and the special education teacher. So it's accommodations, he is given extra time to complete tasks, where available, he is given a scribe, the use of the alphasmart as an accommodation, so he's still expected the do the class same work, but in some cases it might be reduced.

I: Ok.

> *G: When I mark, when we do our journals in the morning, the bell work is just kind of spending time, and it is practice of concepts, but the journals are actually writing up a small piece, and so with that he's given as part of one of his accommodations, the IEP marking scheme. So where everybody else is expected to write 8 sentences to get that 5 marks for writing, he only has to write 5 sentences kind of thing.*

As Ken was aware of his inabilities, and because of his parents' discussion of possibly obtaining a diagnosis, the teacher and special education resource teacher devised accommodations to help provide Ken with more educational opportunities; in fact, Ken's teacher was meeting with Ken's OT the day of our interview to discuss further strategies.

5.3.2- Diagnosed Children

In comparison with those who were undiagnosed, children with a diagnostic label exhibited some similar behaviour but had noticeably different attitudes towards education and opportunities as perceived by both teachers and themselves. All the teachers of the diagnosed children who engaged in an interview mentioned the various strategies and accommodations they used to provide opportunities for learning. For example:

> *In my class, I would say probably that giving him more one-on-one time, but it's hard because I don't have enough time with him. Like, two blocks per week is not enough and I have other students in the class that I have to accommodate, but I do my best with the adaptations that I give him and provide as much time as I can (Andrew's Visual Arts teacher).*

R: Keith takes a lot of time. We can be sitting and doing stuff, and I can walk around and trying to see, and he always says, "I will be a couple more seconds."
I: I noticed that you were scrolling down the article the one day. You said, "Oh no, I will leave this for a little bit longer."
R: I try to do that, and it isn't that often that they have to take notes in my class, but I try and go slower when we do (Keith's business teacher).

I mean he has access to an area that is quieter if he wants to write his tests. Or if he needs more time or you know those types of considerations, but he chooses not to, and there's no real need for him to use a lot of his accommodations. He might need to have questions explained to him, but he, I've, the way I treat the IEP, I let the kid on his own over the first few weeks, to see what the capabilities are, and communicate a lot. And he was very clear that he was fine and he wanted things the way they were. And I said I was there if he needed anything, but we haven't needed to do any accommodations in the class, because he is so strong academically (Keith's English teacher).

Dylan's teacher remarked that he would often teach Dylan skills in physical education or in other areas and allow him to watch prior to attempting it. He also ensured Dylan was accommodated in his writing assignments and daily classroom tasks by working from his IEP. In fact, he reviewed Dylan's work prior to his handing in a hard copy. For example:

Dylan shows his work that he has printed out to the classroom teacher. The teacher responds that he isn't including enough detail like they had discussed in

class. He tells Dylan to pull out his duotang with the class examples and lists and work from there and to add it into what he already has. Dylan agrees and goes over to work on it (Observation).

In the case of Keith, his mother commented in the interview:

R: And he is just ecstatic. He has sworn to himself that he is going to have honours for the next four years of high school. Some of them are adapted.

…

R: Like I said, he knows every teacher in the school because he goes and introduces himself, and I mean he was in the principal's office the very first day of school because I said what? 'Cause the case worker calls me and says, or his helper there, "Ah, your son was in the principal's office," and I said, "What?" Oh no, it was all good; he went to introduce himself.

…

R: And the school called me and told me they were offering this course, and so instead of Keith taking regular gym class where he would struggle quite a bit, they offered this health class where they learn about life skills and health, etc. I can't recall what it is actually called.

For instance, when observing the principal for both Andrew and Keith:

The principal comes and talks to me during lunch about the kind of environment he's trying to create and foster. He is a very dynamic individual and he loves his job; this is noticeable. He states that it is very important for him to establish

> *relationships with all the children and to foster a school environment where all are accepted (Observation).*

Andrew and Keith's teacher remarked that although they both had groups of friends to hang out with, they were generally well liked by their peers.

> *The students really like him and they are very empathetic to him, because he is so kind with them and he reaches out. Whenever he reaches to a student, the students are so respectful and they talk, know how students can somewhat be clique, they all accept Keith, which is great (Keith's English Teacher).*

> *His friends? I find, like I mentioned earlier, I find that he does his best and he is a lot more happy. He tries to be way more social and makes an effort and is way more accepted by others (Andrew's Visual Arts teacher).*

Interestingly, most of these diagnosed students, with the exception of Keith (who was given the option), used assistive technology (AT) in their day-to-day lives. Even Ken, the mid-diagnosis child, was provided with a computer and Alphasmart, he could have the ability to be successful. However, for some of the children, such as Keith and Andrew, the AT was more of a stigma symbol. Take this instance of technology use for Andrew:

> *On the second day, I notice that Andrew has been given a laptop to use in the classroom. Apparently, yesterday, the occasional teacher did not know he needed to nor had the option to use it. Andrew grabbed it and started it up but then quickly shut the lid and told the teacher it wasn't working. He told me later that*

> *the software wasn't working properly, but the teacher remarked later to me that it was; he just didn't want to use it (Observation).*

In the case of Ken, technology was more of a hindrance because:

> *He types with one finger and then pays attention to the teacher's conversation. Ken asks for help, but the educational assistant is engaged in a conversation so he is ignored and left alone. Ken just looks around and doesn't complete his work on the computer* (Observation).

Dylan was the only child whom I observed using AT enthusiastically, and in this particular case, all of his classmates were using iPads. Dylan was using the iPad and a laptop and did not mind having the different equipment, although he paid more attention to the iPad.

Generally, diagnosed children had groups of children with whom they affiliated and were engaged on a regular basis. Andrew's teacher remarked:

> *I would say that he doesn't have many "friend-friends" that he would hang out with on the weekend, but he gets along well with a couple of boys in the class that accept him. He has one friend in particular that he always does his work with and tries to sit beside him and talk with (Andrew's Visual Arts Teacher).*

But she also stated:

> *I find that helps because, if not, he wouldn't move from his seat – like he never makes the 'first move' so I have to tell him to go and sit with them. Sometimes he's hesitant like, "I don't know, I don't want to, I'll do it alone," but I just give him a little push and he is good.*

So, in this instance, the teacher not only mentioned that he did have some friends who accepted him in the class, but that she also helped him with his social skills and group work activities, providing for both educational and social opportunities. Although teachers were more than willing to help out those children without a diagnosis, these children still seemed to be pegged with negative expectations. Those with a diagnosis received more attention and aid from teachers, special education resource teachers, and/or educational assistants. This was not the case for the students without a diagnosis.

5.3.3- Social Opportunities with Peers

In terms of the effects of labels on social opportunities, I compared those who were not diagnosed to those who were. Children without a diagnosis were often left to play on their own rather than being incorporated into a group. For example:

> *At the end of the day, a boy shows Ken how to hit the ball and he tries throwing the ball a few times up in the air and hitting it. But a group of boys just laugh at him. He tries a few times, but ends up giving up and just looks around and avoids playing with the boys all together (Observation).*

> *In daily physical activity, the students begin their walk and run around the school. Ken takes part but only walks with one other boy. They have a conversation while walking together. He lags behind his classmates the rest of the time. Another boy joins in, and Ken disengages and ends up walking by himself (Observation).*

While at the craft centre, Kevin engages in a conversation with the other children there. He cuts some paper then glues a mass of sticks together. One boy comes up to him and offers a suggestion for the glue. The boy is trying to help him but leaves him after a few minutes so Kevin is on his own at the craft centre for the rest of the period (Observation).

Kyle asks a little girl if he can go to her birthday party, and she ignores him. But then she says, "I am talking to so and so." He talks to himself. He asks her again if he can come to the girl's birthday party as she says, "You have to be sitting beside me or across from me. So the whole table is coming except for you." So he says, "Why not me?" and she says, "Because it wasn't written on my calendar." He seems sad so he says, "What about your next birthday?" and she says no (Observation).

At recess, Kyle plays with some of the children but tends to play alone. I notice that some of the time he stands and just watches the other kids completing and doing various activities. He climbs and runs, goes down the slide. After recess, he gets into an argument with another little boy (Observation).

The teacher asks Larry who he wants to work with, and he says one little boy. And this boy says he doesn't like to work with anyone, especially Larry. Larry puts his head down and then says something back. I cannot discern what this is. By the

look and expression on his face, it seems he is fine but disappointed. The other little boy looks quite serious (Observation).

However, there were instances in which all of the undiagnosed children would successfully play with other children. In fact, all of the children had at least one child with whom they would play often, except Kevin who played with other children randomly, never consistently. On these occasions, playmates were younger or had similar behavioural characteristics; however, for these undiagnosed children (including Ken, the mid-diagnosis child), peer interactions were very rare and usually only with one child. The following two examples of peer play for Kevin illustrate this contrast:

At recess, Kevin plays in front of the swings on his own but talks to a girl on the swings. The girl gets off and tells him to get on the swing. He gets off after few minutes and then runs around with a group of boys playing tag. He does so for a few more minutes until the bell rings (Observation).

Kevin runs outside for recess and begins to play tag with a group of boys from his class. He tries to engage with the group by running around and around with them, but he is ignored. This sort of behaviour continues in the classroom when he tries to engage with two other boys at a centre, but they ignore him (Observation).

With Ken, the mid-diagnosis child, friends were often around but never with him consistently. He was not left out of activities if he joined in, but he was never really prompted to play with groups of boys his age. His one close friend was in another class

and a grade below him, and he would only play with him during the recess period. To illustrate, take Ken's experience during free time:

> *The class goes out for free time. Ken goes to play on the equipment with the other kids in his class. He plays a game of tag and he is it; however, he seems to hold back from the others but does become more engaged in the game as time progresses. He pulls away from the group, circles round and round, and ends up being it again. He chases other kids around but not vigorously. The other kids taunt him to entice him to chase them, but he just hangs back (Observation).*

Ken did not become involved in the group chasing him and he seemed to give up, but this could be because of his limitations. At other times:

> *Ken attempts to play four-square with some friends at recess, but I notice he just stands watching and will only participate sporadically. He isn't talking to many of the kids, only one boy in particular and even with him, it is sparse conversation (Observation).*

Interestingly, Ken's parents voiced some other concerns with respect to peer relationships:

> *J: He has a lot of friends. Um, but some of the things I worry about now it seems like he had um, more friends when he was younger as he is getting older, they're…*
>
> *K: They are fewer, and he is not active as they are, they are sort of bypassing, sort of.*
>
> *J: Well, they will be sitting on the, watching TV, and he loves Star Wars, and he will be sitting and watching Star Wars, and I will be looking at the kids out the*

> *window, some kids, he has friends up the street, and I will see them go by the house, where they used to come up the driveway and call on him, and I just, I worry about that a little bit.*

Among undiagnosed children, I observed a consistent pattern: If they associated with any other peers at all, they associated with those who were younger and/or had similar behavioural characteristics. They rarely engaged in group play, and if they did so, the child would appear to be a bit out of place. Diagnosed children, however, had clear groups of friends or in some cases, such as those of Dylan and Andrew, had a few select friends with whom they stayed. Those who were older, such as Owen and Keith, seemed to associate with peers who had similar interests altogether. For instance in these examples:

> *At recess, the students head out to the yard, and Andrew begins playing with a friend with a ball in the back of the field, away from other students. He is quite physical and plays with only the one boy. The EA remarks that this is what he does every recess. Sometimes it is alone and other times, it is with the same boy or two. They take turns kicking the ball while the other runs behind the wall and throws it back (Observation).*

> *During recess, Dylan runs around with a group of three boys, one of whom is the boy I saw him playing with yesterday, and another is the boy who has a moderate level of autism; they seem to play frequently together (Observation).*

While at his drama group, Owen leaves the cafeteria by himself, while the rest of the assembly drink water and socializes. I noticed that he is actually not alone outside and has gone to another group of friends to socialize while on break. When he returns, he walks in and talks with another boy, but eventually, the group is inside again and heads back outside to the other group (Observation).

At lunch, Keith sits with a group of his friends in the cafeteria and discusses last night's hockey game. He is very rowdy and loud, quite opposite to his demeanour in class. He has approximately six or so friends, one girl and the rest are boys. They sit and chat for a while, and after about 20 minutes, they head upstairs to the lockers and sit and play a card game. Apparently (according to his teachers and Keith,) they do this every day (Observation).

5.3.4- Summary

Having a diagnosis seems to have made a substantial difference in being provided opportunities within the educational system. Although all undiagnosed children in this sample were receiving treatments for various fine and gross motor delays both outside of and within school settings, teacher attributions of those delays seem to be linked to the opportunities they were afforded in the classroom. Kyle's teacher, for example, stated that she believed he was just lazy; his physical education teacher stated that he did not participate well in physical activities and was not empathetic towards his peers. These attributions could have limited their awareness of his strengths. Thus, it seems that informal labelling and stigma were ultimately linked to limited social opportunities, even

in the case of peers. Undiagnosed children had a more difficult time integrating socially with their peers and this was also highly dependent on age, such as Kyle (for undiagnosed children) and Dylan (for the diagnosed group). More importantly, diagnosed children, if they were young, often associated with younger peers. However, as children aged, it seemed that again, social opportunities changed. They were accommodated by educators and school boards, and they found with whom they could associate on a daily basis, whether it was a group, or a few select friends. Thus, it seems that once the label is given, children adapt but are given more opportunities as time progresses.

5.4- RESEARCH QUESTION 4

What role do parents and teachers play in acquiring labels for children? What are the experiences of both of these agents in the diagnostic process? What types of attitudes do each hold concerning labelling of children?

Parental resources illustrated a heterogeneous grouping of skills and materials which helped in advocating for their children; however, these skills were only put to use if the parent wanted a formal label or help for their child. Parents in this study played a very active role in the labelling process. This idea of being active in the labelling process and acquiring opportunities is relatively new within the area of Special Education and Sociology (Demerath 2009, Ong-Dean 209). Using a similar approach to what literature has done, I have divided these resources into material (or economic), cultural and social resources. In addition, parents also had varying attitudes towards labelling and the consequence of such which is discussed in more detail in the next section.

5.4.1- Fears of Labelling and Justification Making

Parents of the undiagnosed children voiced a number of contrasting attitudes towards labelling itself. For example, Ken's parents expressed a number of fears that began when teachers felt he might have ADHD:

J: Here he is in Grade 5, and I am thankful that he doesn't have ADHD, but I am just realizing that now that he has another disorder that we should have taken a little more seriously, or understood a little better.

I: Did you have fears about him getting labelled?

J: Oh yeah.

I: What were those fears?

J: We didn't want him to, you know, to be known as a kid with ADHD, as opposed to here comes Ken.

K: And then they pour the drugs into kids like that and there is no way in the world that I was going to have my kid drugged in order to go to school, no way in the world!

I: So that fear was more about the kind of…

J: Stigma.

I: The stigma and the drug and the stereotype.

J: Well and you know, when you think about um, kids with ADHD and I am sure, this is a stereotype, but you think about the kid you know off in the corner and the teachers can't do anything with them, and I knew that wasn't Ken's situation.

These same parents voiced concerns over having an IEP for Ken as a result of being labelled:

J: It scares me about IEP, and I know in some respects, it would probably help, but um, I wonder if, I guess it depends on the teacher, but they get their class list and they find out they've got x number of students with an IEP and those kids are sort of written off or pinned with a certain perception before they are even seen. And I don't want that to happen with him.

All parents expressed some fear of labelling. For instance, Tanya and her husband's reaction:

T: I guess the issue was my husband. He was like an ostrich with his head in the sand.

I: Right.

T: He did not want to see it, did not want to see that anything was different about his son, and so he was trying to convince that it was just me, that I was just a helicopter parent. He felt that I didn't discipline our child enough. If I had just spanked him, he would be better behaved.

Tanya felt that a visible disability could lead to more sympathy but her husband felt differently:

T: The world is more sympathetic when it is visible.

I: Sure.

T: The world is not sympathetic when your child looks to be ok, but then acts in ways which are unacceptable, like hits another child in the park.

I: Ok.

T: So I think DCD is extremely trying on parents, and I think his delays were one piece why my marriage broke down, because my husband was unaccepting. He did not want me to seek supports for our son. He thought it was unnecessary. He'd say, he called the diagnosis bullshit. Our son would grow into his big body, into his big feet, that he was born a big baby, and was like his friend who grew to be six feet 8 inches tall, was uncoordinated all through high school, but he then he took up rowing and now he is very coordinated and very fit. That he would eventually catch up to the size of his body.

Similarly, Owen's mother, the wife of a physician, said:

I: Ok, so um, how do you think it was for him, your husband?

T: My husband.

I: Yes.

T: It was hard on him, 'cause he is science based. He's a physician; he's published a few papers and research, and I think he is very science based, he just felt we had to let him um, grow up and that we were being too quick to look. He's changed.

I: Ok.

T: Now that Owen is 16, and his difficulties still exist, not just in terms of coordination but others, his social, his learning and all that, he's more, he's much more accepting.

I: Ok.

Kyle's parents also voiced their fears about the label and their justification for not wanting it:

I: How willing are you to go along with a label provided by a GP?

S: It depends on what extent. Basically, I don't want him to be labelled and then treated differently.

I: Ok.

S: I don't, if it helps him yes, I don't want his peers or his teacher to give him special treatment or not accept that he can do something.

I: Yes.

S: Um, that's my major thing.

E: And my bias, and this is my bias, there is a lot of motivational deficits that kids are overlooked or are considered skill deficits. So I am thinking, if his teacher doesn't have enough time or to really pay him the attention, you know, if it was us as parents it would be, you are going to colour that colour and when you are done that you can go outside, but, of course, the teacher doesn't have that option.

I: Right.

E: You have to send them along. You don't have the time to, to force everything.

S: Yeah.

Here, the parents felt that labels were misused and resulted from a motivational deficit or the teacher's inability to work with each child. Thus, a label was not a guarantee of improvement in this case.

5.4.2- Benefits of Labelling

Many parents of both undiagnosed and diagnosed children voiced benefits of labelling for their children. Here are a few examples:

T: I think it's hugely important for children to have the diagnosis.

I: Ok, why?

T: Otherwise, the teacher just thinks they are lazy, or uncooperative, or won't sit upright, during circle… It seems to me like at that time, that these were just kids that are a little awkward and now they are giving them a diagnosis and people weren't buying into it, by the sounds of it.

I: Yeah.

T: My husband is a physician.

I: Oh, yeah.

T: He was really skeptical. He was just like, he didn't like all the labelling anyways.

I: Yeah.

T: And I agree with him to a point, but I think you have to do that to get the help that you need. But, that is where I am coming from to get him some help, or some services or whatever he needs, and let's do it. But he didn't like the whole thing (Owen's Mother, Tina).

Subsequently in the conversation…

T: He (her husband) still doesn't like the labelling.

I: Yeah.

T: But you have to do it.

I: Yeah.

T: You have to, you know, this is just what it is, you, for um, you know for the school and for services you have to do that, but it doesn't change the way we…

I: Perceive him?

T: Yep, and the way we deal with him, and the things we try to teach him.

Or for instance, Dylan's parents:

I: Do you find it has helped you in getting a diagnosis?

K: It's helped to explain a lot of mysteries for us, and it has also explained some of the things that I didn't realize were connected to it and helps me to advocate for him.

I: Ok.

K: With having a diagnosis, it just gives me a little more ammunition to say to people that he has these special needs, in particular in the school system.

D: It helps me understand him better.

K: And then, yeah.

D: So when I am dealing with him, I'm not getting more frustrated.

I: Yeah.

D: He spills a glass of milk, normally I would be upset, but now…

I: But now, you are ok?

D: So it just helps in our daily interaction other than getting really angry, just say, "Dylan eat your breakfast, stop looking out the window, let's get going." Yeah, so that kind of stuff. So if we are always reacting to all these unusual behaviours, he would have an even harder time.

I: Ok, it's undoubtedly benefitted then?

K: Yes.

Rebecca, Keith's mother, also echoed this benefit to labelling as a justification for the child's non-normative behaviours:

R: Well, it explained some stuff to me of why I didn't feel he was growing up properly or and me thinking I was over babying him, and always, like even when he was uh, probably six or seven, "Mommy, I am tired. Can you carry me?" People would go, "Put him down. He is old enough to walk." Um, but it was the fact that his uh, his muscles were giving out and um, even up to I think it was about age 12, I think that he finally started recognizing when he would fall, because he would be standing in the kitchen and all of a sudden, he would stop and then he would fall.

I: Collapse kind of thing?

R: Yeah, collapse.

I: Yeah.

R: And um, I didn't really realize what that was all about except that it had to be related to, he doesn't recognize when his muscles are going to give up.

Andrew's parents also echoed the idea that a formal label helped explain a lot of behaviours and with aiming the therapy towards the child's learning stages:

E: And that's, you know what, and that's for any special needs.

I: Yeah.

E: The earlier the intervention you can give them the better, right?

I: Yeah.

E: The families I work with right now who are in total denial and you know that.

I: Yeah.

E: And I keep on telling my staff that, even though we don't have a label, let's work with what we have.

I: Yeah.

E: And we might not have the OT, or the PT.

I: Yeah.

E: To come in and specifically do stuff, but we know we can implement this and this in the classroom, so let's do it.

5.4.3- Parental Resources and Roles

Many of the parents in my study were materially affluent. This may be a result of an inherent flaw in the health care system. This flaw prevents parents from easily acquiring pediatrician care on their own; rather, they need a referral for such care from their Family Practitioner which, in the Northern community, can be difficult to access. As previously discussed, one family in my sample had a neighbour who was a pediatrician and that neighbour eventually provided the DCD label for their son. This kind of access is quite unusual. Here are some other examples of material resources and the benefit it had on both diagnosis and accommodations for the child.

For his drum lesson, Owen gets a private lesson from a young man. His mother said it was so he could be more accommodated. Where he went previously was too structured and so this was a better option for him. The family has purchased a

new drum set for him to use in these lessons and to practice on, as well as an assortment of music sheets and equipment to accompany, on top of the private lessons which he receives each week (Observation).

Owen's mother comments in her interview about other resources that she and her husband pay for to ensure that their son is receiving treatments and is incorporating socially with his peers.

T: And they still, just as of recently, they were just kind of following him on an as needed basis, and we've always got, you know, programs that we are supposed to be working on with him, but we were always, because our family is active, and we do all those activities, we consider that to be, I mean, how much better physiotherapy can you get than wakeboarding and snowboarding?

I: Yeah, that's right.

T: So we don't actually do a physiotherapy program.

I: Ok.

T: But we do, we do keep him active, and I have a worker who takes him to the base, once or twice a week.

I: Ok.

T: And they do some cardio and they do um, toning and weight training and stuff like that.

Another single mother, Tanya, hired her own private speech therapist to work with her child with DCD:

T: Since that centre, I've hired a private speech therapist.

I: Ok.

T: So she's great, I've had her for almost the past year. She comes to the house and works with him (her son).

Kendra and Donald, Dylan's parents, one who is a Special Education teacher; the other, a lawyer, discussed how their child was involved in a number of activities:

D: You would observe him carefully. Whenever something is new or different, he is not able to respond with any fluidness, and that's fine, except our goals are being met that he seemed to be, um, average so we haven't been, downhill ski racing, too, and I have been playing squash.

I: Yeah, he mentioned those two things.

K: I can remember when I first took him skiing. I was so proud of him emotionally because the simplest thing, like you have to point your toes together, and I can remember standing, and I am doing all the "make it like pizza" we are on flat ground, we haven't gone anywhere yet., And I can remember him looking at his feet, and it was the longest time that he was looking at his feet and his face was so tense, and he was trying to move his toes and they weren't moving. And then, I have to try to help him, and I just thought, my goodness, we haven't even hit the hill yet, and he can't even, he can't figure out how to turn his feet.

I: Yep.

D: And this is after having him walk around the house and backyard with the ski boots, after it was me having a bunch of leaves and having him on skis and kick a bunch of leaves. So this is all, it took a lot of time.

K: So now he ski races along the path and we're happy he's sees himself as a ski racer.

I: And he's doing it.

K: He's quite an accomplished skier (Dylan's Parents).

They described being very focused on meeting their child's needs:

D: Our friends are the same way as us, our kids are number one. It is a little hard on our relationship because we would like to go out more often, but the bottom line, being wealthy or poor, we would still focus a lot of our time and effort on that. And that's the number one key, the fact that we want to strengthen our kids. We are prepared to spend the time with them.

I: Yeah, so having that mindset that it is about your kids, and you want to see your kids flourish, that is what you are saying?

K: And you want the best for your kids, you're deeply involved, you don't just drop them off. You see what they do in their activities and you know about their activities and you find activities that are suited to them.

5.4.4- Cultural and Social Resources

Numerous times parents made mention of their educational backgrounds and social connections to advocate for their child or to understand the diagnosis/treatments being used. Kendra and Donald had already experienced the birth and death of a disabled child. As a result, they had become very aware of the system and its advantages:

K: Um, when he was having difficulties speaking, I guess we just had a previous child with significant disabilities, so we were pretty familiar with all the services and agencies…

I: Oh, ok.

…and further in the conversation

I: Ok, so that, to me, that's interesting, as well, because to me that experience for you really provided you with social resources, let's say.

K: Yes, definitely.

I: To know how to navigate the system in a certain way.

K: Yes, definitely.

D: Had we not had that, it would have taken us longer.

I: To get to where you needed?

D: Yeah, and we might have not been sensitive to begin with.

J: Yes.

D: You are sensitized because you are always looking, right?

I: Right.

D: So we're observing with greater interest.

This involvement with the child and advocating for them involved more than just taking an aggressive approach to receiving services but also possessing background educational knowledge. Tracey and Kevin's parents were the least affluent of the group (in terms of income), but displayed a good working knowledge of the medical system:

F: So what had happened, even when I switched from one pediatrician to the next, the paediatrician told me that the file will just transfer over, and I'll have to sign for it. Which was a huge task because apparently that is not legal so then, after we went through the whole process, then we found out that we have to start an entirely new file, and then I had to re-explain everything, and I, at that point, was lacking sleep. I am not going to give every single detail because I am not an organized person. I can't keep track of everything. My house is better than it was, like a year and a half ago, like we just don't have time for things.

I: Uh huh.

F: It wasn't easy; it was really hard. Referrals not so much, because my doctor just referred. Most things you can self-refer, the only two things you can't are pediatricians and the infant program.

K: If she was working, I don't think they would have been where they are today.

F: No, there would have been no way I could have done any of this. Our children would have been neglected, um, specialist wise, because there was no way I could have been able to do this if I was working at all. It is hard, because we'd be running. Like, one would be in speech, the other would be on, so it would be constant back and forth. And I had to, oh, and then I got them into some subsidized preschool, to help with their social skills. But...

K: It is one on one that has helped with our children and the fact that she knew the medical system.

Andrew's mother elaborated upon her knowledge of the special education system, explaining that sitting on the special education advisory committee for her son's board helped her to advocate well. Her husband also made mention that the centre where they received services was brought about by his own family connections. Thus, social, cultural and economic resources were of the utmost importance for these parents and were used at every opportunity to acquire opportunities and treatments for their children. Therefore, parents play a very active role in the labelling process and advocating for their children's rights (as evident with Andrew's parents consistent patience with teachers who informally labelled Andrew). In fact, all of the parents involved in this study strove to enrol their children in extra-curricular activities.

5.4.5- Summary

Parents offered numerous justifications for pursuing a label or not. Although labelling was actively pursued by most parents in this study, most were ambivalent due to its unclear social implications. Parents were thus conflicted between actively pursuing labels and this ambivalence. This ambivalence did not hinder these parents from using every source of capital they could in acquiring treatments and labels; most of the participants drew from the considerable educational and health care knowledge in acquiring treatments and services from their family physicians. Parents relied on their own economic resources for professional services and their own form of therapies and treatments to build their children's self-esteem. These took the form of extracurricular activities, such as soccer, hockey, other sports and musical lessons as well as specialized services in tutoring and occupational therapy. These sources of capital proved to be very

beneficial for parents and were used in numerous ways in support of their active pursuits of formal labels. Even those parents who were quite fearful of acquiring a formal label used their resources to benefit their children, such as in the case of Kyle and Ken. Both sets of these parents used their extensive amount of social, economic, and cultural capital in providing positive experiences for their children. For example, Ken's parents provided him with Cadets, swimming lessons, fishing and hunting, while Kyle's parents liked to travel on a regular basis to provide him with "rich social and cultural experiences."

5.5- CONCLUDING REMARKS

This study had four research questions as its focus. The first two concerned how children were characterized both before and after receiving a formal label the forms of stigma they and their parents experienced, and some of the effects the formal label had on children's self-perceptions. Children who were not yet formally labelled with DCD had some experiences of informal labelling; they were called lazy, unmotivated, trouble makers by educators, family, and scrutinized by the public for their non-normal behaviour. However, with the mid-diagnosis child, this informal labelling was not assigned (during my stay) by educators, and, as I continued my observations of those children with DCD, informal labelling was not an issue. Thus, being given an official label seemed to reduce some of the stigma from educators and, potentially, some family members. In most instances, a formal label, such as DCD, provided parents with a valid explanation for their child's behaviour for both themselves and others. The stigma seemed to diminish as the child grew older and, as evidenced by the preceding research

questions, they were funnelled into their own areas of interests either by parents or by themselves.

Children who were younger and did not have a formal label were self-confident until they began to value peer comments and friendships; the source of informal labelling, like that of peers, was an important factor in the development of self. For instance, Ken, who knew he was different from his peers, felt that being overweight was a drawback and he was not athletic enough to participate in baseball try outs. Dylan, who appeared to be confident and was given the formal label of DCD, did have some trouble socially interacting with his peers; in these instances, he tried to perform at athletic activities while his teacher accommodated for his inabilities in his classroom subjects and activities. Yet, as the children with a diagnosis matured, their self-perceptions increased and gradually, these children began to accept their inabilities and labels and found ways of being productive and successful. This acceptance was in large part due to the accommodations and the treatments they received, which were also affected by parental roles and resources. Thus, children's experiences did not follow what the original Labelling Theory would predict, nor did they really conform to the scepticism of Gove and his followers regarding any self-fulfilling effects of labelling. The long-term consequences of labelling largely depended on a wide variety of factors, such as age and parental role and parental resources and capital; it is these long-term consequences which contribute to the self-fulfilling prophecy that Labelling theorists tout. This is further elaborated on in the following sections and proceeding chapter.

In relation to the third research question, teachers provided educational opportunities when a formal label was given. Even in the case of Ken, the mid-diagnosis child, opportunities were provided after the formal label was negotiated by his therapists. His accommodation stipulated ways of providing Ken with opportunities within the classroom that could better his educational outcome. Informal labels seemed to restrict opportunities, while formal labels expanded these and in some instances, even elicited sympathy from educators. Social opportunities with peers seemed to be augmented for the child as time progressed. Thus, younger children tried to socialize but were generally isolated; while in middle childhood, they seemed to associate with one or two friends who were younger or had similar maturity levels. As formally diagnosed children aged, they seemed to be well-liked and established their own niche and circle of friends.

Lastly, the fourth research question asked what role parents and teachers played in acquiring formal labels and what their experiences were in the diagnostic process. In this study, parents played an active role in acquiring not only formal labels but also services and treatments from a host of health care professionals. In addition, parents drew upon their considerable social, cultural and/or economic resources in acquiring these formal labels and services and frequently used them to make more informed decisions. Teachers also played a minor role in referring children for services as in the case of Kyle and Kent. It was left to parents, however, to pursue the formal labels even after being referred for services. And while they were active in pursuing labels, parents were generally quite vocal about the diagnostic process if a formal label had been given. For most, it was a complicated, stressful task that required time and effort on their part. In the end, I found

that parents were ambivalent about formal labelling; they actively pursued labels, yet were still concerned with their negative repercussions. Most stressed that formal labels offered the only way to acquire additional educational opportunities. In the final chapter, I will elaborate on these findings and discuss the larger implications for Labelling Theory, future research on DCD, and health and educational policies.

Chapter 6: Conclusion

6.1- Summary

This chapter summarizes the main findings of this study and discusses its limitations and possible alternative explanations. It then delves into major implications for Labelling Theory, health care, educational policies and future research.

Given today's societal context of label proliferation, stigma reduction, and rise of educational accommodations, the major goal of this study was to re-evaluate the original tenets of Labelling Theory by examining social reactions to DCD, a relatively new disorder and to question whether conditions have changed the original intent of the theory. This study included nine children, who were observed during their home, school and extracurricular activities, and all nine had symptoms characteristic of DCD, and thus, each was informally labelled. But only five had a formal diagnosis of DCD and four did not; hence, there were two groups who could be compared on their experiences. All participants, including parents and teachers, were interviewed. With this basis, this study asked these four research questions:

1. In terms of social stigma, what are the experiences of children with and without the disorder?
2. In terms of the social-psychological effects, how do children feel about themselves before and after being labelled? What self-attributions do they make?
3. In terms of opportunities, does the formal label of DCD serve to expand or restrict their opportunities in schools and social relationships?
4. What role do parents and teachers play in acquiring labels for children?

Drawing on the experiences of a small sample of children with and without the diagnoses of DCD, I discovered that children who are not formally labelled are often more stigmatized by their peers, extended family, and the general public in many ways. These include being called "lazy" or stared at with derision by those around them, such as in the case of Andrew and his parents who used a larger stroller for him as he had a difficult time walking for long periods of time. Often, those unlabelled children were socially isolated and sometimes earmarked as "trouble makers," clumsy, or non-athletic by these agents. However, those children who received the formal label were often more easily integrated into the classroom through educational accommodations and generally found their own peer groups to interact with daily. Before receiving the formal label, children were frequently self-doubting, socially isolated, yet nonetheless bright. After being formally diagnosed, some of these children grew to be proud of their accomplishments and more confident in their social and athletic abilities and developed their own skills in their favourite past-times and hobbies. Thus, having a formal label seemed to create opportunities for these children in school and their social lives.

For those parents who sought a formal label, the diagnosis was a means of justification in the pursuit of accommodations, treatments, and extra care. Those parents who rejected a formal label, such as Ken's parents, regretted their decision as they later found their children did have legitimate problems. Most of these parents, whether they rejected the label or not, were ambivalent about acquiring a label for their child, as they felt torn between the opportunities it brought versus its possible social consequences. Lastly, all of these parents drew upon their considerable resources to either pursue formal

labels or expand their children's opportunities; these resources included economic assets such as income, social capital; namely, social connections to therapists and doctors, and cultural capital such as background education and careers.

6.2- Study's Limitations

This study has some limitations, such as its small sample size. As DCD is rarely diagnosed, with a prevalence rate of approximately five to six percent of the general population, I found that relatively few of the professionals I interviewed knew what DCD was, other than the occupational and physical therapists at the centre and one pediatrician. However, even these professionals noted its rare diagnosis within the study's given region. By necessity, this became a 'small n' study, and as a result of the small sample size, it is not possible to generalize its findings.

To augment my data, I decided to pursue a more in-depth exploration of participants' experiences in the both the formal and informal labelling processes. Each family participant was treated as an individual case study. I collected considerable, detailed information for each child and family. This study offers a concession: a small sample size but with considerably more in-depth data and analysis of each case than would be permitted in a "large n" study; this study can be seen to be more exploratory in nature than confirmatory. Due to the small sample size, this study identified a series of possible contingencies that would alter the outcomes for labelled children such as type of formal label given to the child, when the child was labelled and by whom. A larger sample could provide more evidence and possibly shed light on other contingencies which have not been accounted for in this study.

The second limitation of this study was the short time frame. A longer period would provide more insight and valid evidence, particularly for the self-fulfilling prophecy, which is said to be a process that emerges over time. The retrospective questions within the interview spanned the entire lifetime of each child. Hence, in some of my cases, parents were recollecting on events which occurred over ten years prior. A longitudinal study could follow the same sample over a given period of time, reporting on and comparing outcomes between the formally labelled and unlabelled control group. However, Labelling Theory has rarely drawn on longitudinal data of any kind. This study provides a step in the right direction by at least examining the relatively short term impact of formal labels.

This study only examined a single label, and this too necessitates a concession. Previous research has already indicated that multiple formal labels can elicit multiple responses from actors and by evaluating the effects of only one label, the study avoids confounding the effects of multiple labels. This confounding factor was hopefully eliminated in this study. On the other hand, other studies of other labels might yield different results, perhaps demonstrating that some labels may be more stigmatizing than others and individuals with comorbid disorders may have completely different experiences. For example, findings might be different for a label in mental health or even within education, such as Tourette's or ADHD, illustrating that there are contingencies and differences for formal labels within and apart from these areas, something that LT has not acknowledged. In addition, this study was confined to one particular area and setting (Northern Ontario) where the disorder is not well-known by practitioners, educators, or

parents. Therefore, we do not know whether we can generalize from this particular setting. However, this setting offers an opportune moment to evaluate the use of informal and formal labels as DCD's clearly visible symptoms render it easily informally labelled. This is in contrast to more established labels such as dyslexia or ADHD and those that lack the outward manifestations that are so clearly visible, such as depression. This point was already purported by the original Labelling theorists such as Goffman (1960) who elaborated on those individuals with outward manifestations of stigma versus those who could hide it (discredited versus the discreditable). According to Goffman, those who were discredited were often more stigmatized, such as those with physical disabilities that are visibly apparent. These individuals are stigmatized because of their obvious flaws. Lastly, the low number of females in this sample created some bias, but this is a reflection of the bias inherent in the diagnosis of DCD within the youth population. This was not of great concern as it is already well established within literature (Rivard et al. 2007, Fliers et al. 2008).

Finally, the lack of teacher involvement and interview data is a concern. I collected an abundance of data from classroom observation, with which teachers generally cooperated. But only a few teachers were interested in being interviewed. It was beneficial to interview teachers to gather their knowledge set of DCD, of the child themselves (whether they were formally labelled or not), and their perceptions of the child's abilities and inabilities. I collated this information and compared it to my observations and parents' own perceptions of classroom reality for their child. For example, Ken's parents believed that by not acquiring a formal label, he was being saved

from the ridicule from teachers and students. Yet, in reality, his classroom teacher was fully aware of his inabilities and physical symptoms and was readily accommodating them. In his interview, this teacher even stipulated that he tried to meet with the parents to discuss steps in Ken's educational attainment. That lack of interest from most teachers in this study, however, limits the contribution of teacher perceptions to my conclusions. It also highlights the need for effective ways to negotiate cooperation and trust within the researcher-educator relationship. Maxwell (2013) stated that negotiating relationships, entrance, and trust with gatekeepers can require time and constant re-negotiation; the time constraints posed by this study may have limited such trust. More interviews with teachers can shed light on how they informally label children and how they accommodate children with formal labels. Overall, more research is needed on the role that teachers play in both the formal and informal labelling process. This study revealed some of that role, but the topic needs further exploration.

To summarize, this study has several limitations and offers numerous trade-offs. On the one hand, it has a small sample size, is located in a single community, and focuses on one disorder, all of which limit its ability to support broad generalizations about either the impact of formal labels in general or the impact of the DCD label in particular. However, on the other hand, this study has a number of strategic characteristics: it contains two groupings, including a good comparison group with symptoms that would appear similar to DCD to most lay people, and by focusing on one disorder in one setting, it avoids other confounding factors; this is not typical of case study methodology. An ideal study, one with a large sample size that was longitudinal in its design and had a

control group, simultaneously examining multiple labels and not just a single one and providing for in-depth data, could be prohibitive and even difficult in a real-world scenario. Furthermore, it may not allow for the contingencies, like those in this study, to be discovered.

6.3- Competing or Alternative Explanations

In this section, I offer some competing or alternative interpretations for aspects of this study's findings. One alternative interpretation to why children with a formal label would experience positive consequences is that the children's IEP, rather than their DCD label, afforded them the accommodations. As a reminder, in this study, five of the nine children had IEPs, one of which was an IEP without an official diagnosis. I argue that the DCD label prompted the formal IEP process for four of the participants while for my mid-diagnosis child, having the symptoms and an OT suggest DCD prompted an accommodation IEP. Parents can also play an active role in acquiring an IEP just as much as they did acquiring the formal label. It could be argued that the IEP brought the accommodations and opportunities for students; however, despite the truth of these arguments, as the IEP is the formal means of assigning accommodations, it is, in essence, a formal label from the OT prompts the need for an IEP initially.

Another possible explanation of differences between labelled and unlabelled children is their varying maturity levels. Older children who were labelled seemed to be more socially adjusted and interactive. However, most developmental theorists will argue that, by the age of eight, children have a strong sense of self and are fully aware of their abilities and inabilities, often comparing themselves to their peers (Tassoni 2007) and

most developmental psychologists argue that social play with peers evolves sequentially as the child progresses in maturity levels. Thus, most children can perform complex play and social interaction by the age of four (Howes and Matheson 1992). As a reminder, this study involved children who ranged in age from three and a half to seventeen; within the unlabelled group, children's ages ranged from three and a half to twelve, while in the labelled group, children's ages ranged from ten to seventeen. Thus, both groups ranged widely in age, but the labelled group was indeed older. To determine whether this differential age composition between groups s directly responsible for some of my findings, longer term longitudinal designs are needed with larger sample sizes. But further, the effects of labels may not be spurious. Instead, age could be another contingency in the outcomes of formally labelled children, something unaccounted for in the original theory.

6.4- Implications:

Despite these limitations, this study furthers the application of Labelling Theory beyond its past assertions and empirical shortcomings. Its findings have several implications for three main areas: Labelling Theory's main tenets, health care and educational policies and future research.

6.4.1- Classical Labelling Theory and Sociology

This study makes a profound contribution to Labelling Theory and Sociology overall: it provides a more open-ended and non-restrictive exploration of the theory by incorporating several theoretical and cultural concepts to evaluate the practicality of LT tenets in a different era. The original version of Labelling Theory is still quite viable

when applied to the realm of criminal justice. But within the realms of mental health and education, I argue that some of its original tenets may need to change in order to reflect new societal conditions and various contingencies. I next examine these needed changes by each of LT's three main tenets.

Social Reactions

While formal criminal labels usually elicit non-sympathetic reactions, the same cannot be said for medical and educational labels. Reactions to the latter are mixed for various reasons. Firstly, reactions to medical and educational labels have progressed over time due to anti-stigma movements, as evidenced by studies in mental health and as discussed in previous chapters. Secondly, reactions to criminal labels are less variable than those within the mental health and educational fields; simply put, the public consistently negatively reacts to the formal criminal label by often avoiding these individuals, cutting off contact, and even limiting various social opportunities for them. In contrast, the public has become much more accepting of various formal labels in mental health and education. For example, labels such as depression and learning disability are more widely accepted by the general public than they were 50 years ago; yet, the criminal label still remains highly stigmatized. Thirdly, reactions to these mental health and educational labels are also contingent on various factors and conditions as proven by previous literature in both mental health and education (Chambers et al. 2010, Bell et al. 2010). These contingencies include: the type of label, such as ADHD, which often elicits more negative informal labelling such as calling a child a trouble maker or unmotivated, autism, and Developmental Coordination Disorder, which can elicit neutral or more

positive reactions, such as teachers who wish to provide more educational opportunities. The experiences of the person reacting and the age of the child in question must also be taken into account. For example, teachers who had more experience with children with special needs often reacted more positively to children with DCD in this study; again, however, more research is needed to confirm this.

In this study, behaviour from Tracy, Kevin, Kyle, and Larry could be explained by their young ages and not the disorder or informal labelling. However, children such as Ken, who was mid-diagnosis, and Dylan, who was diagnosed but still young, had some of the same characteristics of being socially isolated and awkward with their peers. Perhaps these children exemplify that social skills and confidence levels can develop at any age, but these are mitigated by the types of experiences these children had in being formally and informally labelled.

In addition to peer relationships, some extended family members expressed negative reactions to unlabelled children and scrutinized parental practices. Once the label was given, or even suggested, parents used this as a valid excuse for their choices regarding child management. Thus, reactions to labelling depend on several factors: the type of label, whether it be an informal or formal label, the individual who provides the label, and closeness of the relationship to the child. Labelling Theory has not accounted for these variations and conditions. Similarly, Link and Phelan (1999) noted that having a mental illness can have both negative and positive consequences; individuals can receive treatment but simultaneously be subject to negative stereotypes just as this study found.

Thus, formal labels can lead to a host of opportunities; by the same token, informal labelling can diminish self-esteem.

Social Psychological Consequences

In this study, children demonstrated a multitude of social and psychological consequences both related and unrelated to the formal label. What is apparent is that children who were formally labelled showed varying ranges of perceptions of abilities and inabilities. Older labelled participants were much more confident and established in their perceptions of self. Younger children who had a label were very socially unsure of themselves; yet, these perceptions were also dependent upon the setting and activity in which they were engaged. While some participants were socially uncomfortable in school settings, they exhibited much different social behaviours when in activities they enjoyed. Labelling Theory clearly states that often formal labels leave negative social and psychological consequences for individuals, eventually leading to a self-fulfilling prophecy. Many labelled individuals can eventually learn to cope and not be debilitated by their labels (as stated by Higgins et al. 2002). In fact, giving these children formal labels can serve to deflect some of the negativity these children experienced from their informal labels, as seen in the case of both Owen and Keith who were more socially adept and exemplified pride in their abilities.

Limited or Restricted Opportunities

The criminological version of Labelling Theory purported that the formal criminal label tends to restrict employment and further educational opportunities. In contrast, much of the literature cites the positive effects of psychiatric labels by providing

treatment for mental illness and overall well-being (Link and Phelan 1999); LT does not address the vast differences that formal labelling can have in these two different areas nor does it acknowledge the benefits from providing a formal label. This study highlights the benefits of various educational accommodations and found that children with observable symptoms but who lacked formal labels were often stigmatized as 'trouble makers' by teachers. Thus, they were not accommodated with the extra help they required. Yet, once they were flagged as having legitimate learning issues or given a formal label, they received accommodations based on a formal or an informal IEP. Labelling Theory does not account for the expansion of opportunities that formal labels can elicit in today's educational system.

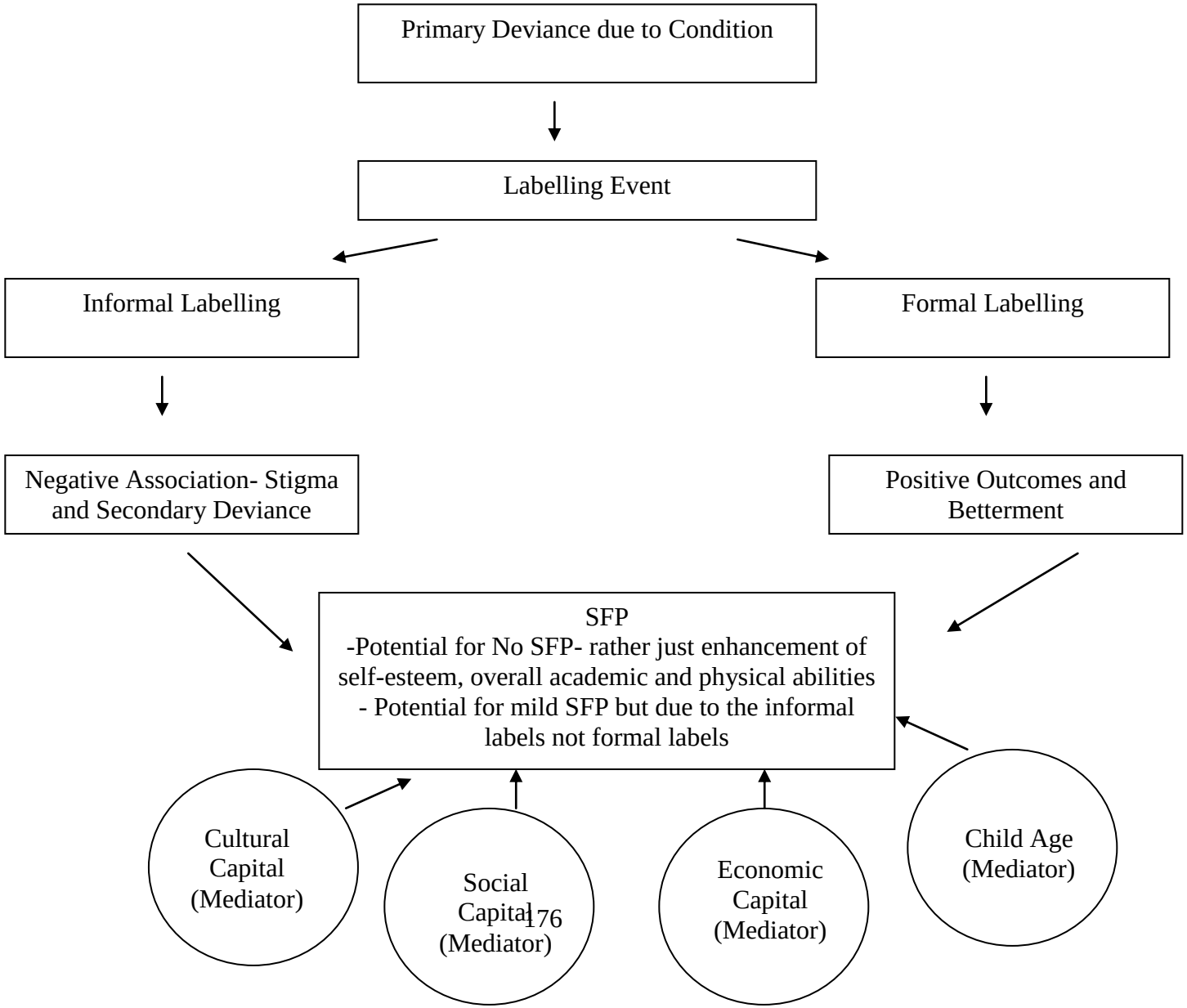
Self-Fulfilling Prophecy

Although I could not study whether an SFP develops over a lengthy period of time, my relatively short-term investigation suggests that the LT tenet that individuals eventually succumb to their label may be inaccurate. I found that individuals with a medical label did not always feel negatively about their self-image or abilities; in fact, some emphasized their accomplishments and seemed to be well-adjusted as they advanced through school.

This concurs with the views of Higgins et al. (2002) who showed that individuals who were formally labelled with a learning disability were eventually approving of it as it helped them in future learning and opportunities. Furthermore, my study showed that certain negative consequences of informal labels (lowered self-esteem, fewer peer relationships, and lowered self-perception of abilities) were counteracted by positive

consequences resulting from the provision of formal labels (such as accommodations and opportunities for learning). Moreover, the formal label was gradually accepted by some of my participants (as in the case of Keith and Owen). Formal labels did not seem to have the negative effects that the original LT proposed. As a result of the findings in both social reactions and social-psychological consequences, I propose the following ideas for the SFP. This is further discussed in the proceeding sections.

Diagram 4- Proposed Version of Self-Fulfilling Prophecy and Labelling Theory



6.4.2- Future Research:

a) Visibility of Symptoms:

My findings have several implications for future research on labelling. One is the need to distinguish possible different effects for formal labels based on symptoms that are visible versus invisible. Individuals who receive formal labels for highly visible symptoms, such as DCD, may have different consequences than those individuals who are labelled with conditions that have less visible symptoms, such as a learning disability. For example, those with highly visible symptoms are often targeted by health professionals at the outset, and parents are fully aware there is something "wrong" with the child's development. Conversely, those individuals who have non-visible symptoms can often go undetected for longer periods of time and be targeted informally as "unmotivated" by the educator. Another contingency is the type of symptom displayed, as in the case with the ADHD child. The public and educators can often view these children as "bad" where DCD children are seen as "spoiled" in some cases; these symptoms are often informally targeted in the same negative manner. Thus, the visibility and type of symptom all need to be researched for a more in-depth understanding. Hence, the visibility of a disorder has profound effects on all three areas of LT's tenets: reactions, social-psychological consequences, and limited opportunities. More to the point, do more visible symptoms mitigate the reactions from individuals and limit opportunities more extensively than those disorders without visible symptoms? Does intervention or treatment of a disorder which changes symptoms lead to a different outcome versus those children who have DCD and the symptoms do not change. Furthermore, do these lead to

increased social-psychological consequences? Future research would need to determine these answers.

b) Social Reactions across Domains

Future research needs to acknowledge how reactions to formal labels vary across particular domains. For example, criminal labels elicit much different reactions than do educational labels. Studies within Labelling Theory need to differentiate between these domains and the vast differences in social reactions. Even within domains such as mental health and education, reactions vary by type of labels. Accordingly, within the context of education, children with behaviours related to ADHD might be perceived more negatively as their symptoms, although visible, can be highly stigmatized as just "being a bad child" or "undisciplined" in comparison to children who have symptoms related to a learning disability or Developmental Coordination Disorder. Research has already shown that educators tend to rate children with ADHD more negatively than any other child. Can these reactions change once a formal label is provided and do these reactions vary across educational labels? If they do indeed vary, why? More research is required to investigate these variances and subtleties.

c) Social-Psychological Consequences

In general, more social-psychological consequences were seen with informal labelling while an increase in self-confidence and self-esteem were observed with a formal label of DCD and maturity level. Yet, as aforementioned, this study can only generalize its findings to the sample studied. However, this study could not accurately determine that this increase in self-confidence was due to the formal label. It would be

noteworthy for future research in LT to distinguish the types of social-psychological consequences according to informal and formal labels, how they differ across these two groups, and how they ameliorate or worsen with time.

d) Limited or Restricted Opportunities

Future research needs to delve more into what opportunities are limited or restricted for both labelled and unlabelled children and who determines this. Although this study found that providing a formal label expanded the potential for educational success by offering an IEP, it could not be determined whether social opportunities were expanded with a label. Ideally, providing a formal label exposes individuals to expanded social and educational opportunities, but whether this is always the case remains to be seen.

e) Variety of Data Collection Techniques

This study also highlights the need for a mix of data collection methods to be employed when exploring the experiences of formally labelled individuals. Combining direct observations with interview data from several actors can offer a more complete image of what really occurs in a given situation rather than relying on a single actor or method. Such mixing enhances the triangulation and validity of themes and responses.

6.4.3- Policy:

This study also has a number of profound policy implications. Firstly, the fact that many parents are active in the process of seeking formal labels but vary in their experience and success highlights their distinct abilities to access and navigate both the mental health and educational systems. This variability is similar to what Demerath (2009), Lareau (2011) and Ong-Dean (2009) discovered: parents with more social,

cultural and economic capital had more regular access to health care professionals and thus to labels. The implication here is that equitable access to healthcare opportunities and education requires the dissemination of solid information to educators and medical practitioners as well as the general public. Many teachers and school board administrators in this study were unaware of what DCD was. The rarity of this diagnosis left parents and educators to "grope in the dark" when searching for strategies to help children. Consequently, many parents were left to fend for themselves when researching not only strategies for helping their children succeed in the classroom but also in activities and social situations outside of the classroom. In a recent email, one parent was also adamant about seeking the right label and resources for his child, and this left me pondering on what makes parents feel that their child has the right label? What constitutes for them the correct label for their child?

The unequal capacity for parents to attain beneficial formal labels and accommodations for their children implies that formal labels and accommodations need to be *more accessible*, not less accessible to less advantaged families. Perhaps sociologists can help determine which formal labels can be beneficial and subsequently uncover ways to make them equally attainable for all, not just those with advantageous forms of capital.

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Appendix A: LOIs, Consent Forms and Interview Guides

McMaster University
Inspiring Innovation and Discovery

Verbal Assent Script for Minor to Participate (Ages 6 and Under)

Plain language study title: Understanding Developmental Coordination Disorder and Its Effects on Children

Researcher's name: Christina DeRoche

[Beginning of verbal script]

My name is ***Christina*** and I am a student at the McMaster University. I work in the Department of ***Sociology***. Your parents are letting me to talk to you about a project that I am working on with a couple of other people. The project is on how you feel about yourself and your friends. I am going to spend a few minutes telling you about our project, and then I am going to ask you if you are interested in taking part in the project

I want to tell you about a study that involves children like yourself. I want to see if you would like to be in this study too. Are you ok with this?

I am doing a study where I want to find out about how you feel about yourself, what kinds of things you do with you and your friends, and about some of the times you have in class or on the playground. I also want to know what you think of One Kids Place and the people who work with you there.

If you decide to take part in this study there are some different things we will ask you to do.

- First, I will ask you to look at a certain picture.
- Second, I will ask you what you think about the picture.

- Third, we will talk about the picture for a little bit and maybe some of the same things or different things that you do.
- It will take you about 30 minutes to finish the pictures and questions. We will take a break in between so that you can have a snack or go to the washroom. If you need a break, you can always tell me.

What I find in this study will be used to help other children and parents like you. As far as I know, being in this study will not hurt you and it will not make you feel bad. If I ask you questions that you do not want to answer then tell me you do not want to answers those questions. If I ask you to do things you do not want to do then tell me that you do not want to do them.

The things you say and anything I write about you will not have your name with it, so no one will know they are your answers or the things that you did.

I will not let anyone other than me see your answers or any other information about you. Your teachers and therapists will never see the answers you gave.

You do not have to be in the study. No one will get angry or upset with you if you don't want to do this. Just tell me if you don't want to be in the study.

And remember, if you decide to be in the study but later you change your mind, then you can tell me you do not want to be in the study anymore.

You can ask questions at any time. You can ask now or you can ask later or even during the interview. You can talk to me at any time during the study.

Do you understand this study and are you willing to be in it?

[End of verbal script]

TO BE COMPLETED BY PERSON OBTAINING VERBAL ASSENT FROM THE CHILD/SUBJECT:

Child's/Subject's response: ☐Yes ☐No

CHECK WHICH APPLIES BELOW:

☐ The child/Subject is capable of understanding the study

☐ The child/Subject is not capable of understanding the study

_____

Child's/Subject's Name (printed)

_____ _____

Signature of Person Obtaining Verbal Assent Date

_____ _____

Signature of Child's Parent Date

McMaster University
Inspiring Innovation and Discovery

Assent Form for Minor to Participate (Ages 7 to 12)

Title of Study: Understanding Developmental Coordination Disorder and Its Effects on Children

Researcher's name: Christina DeRoche

Your parents are letting me to talk to you about a project that I am working on with a couple of other people. The project is on how you feel about yourself and your friends. I am going to spend a few minutes telling you about our project, and then I am going to ask you if you are interested in taking part in the project.

Who are we? My name is ***Christina*** and I am a student at the McMaster University. I work in the Department of ***Sociology.*** That means I like to study people and what they do.

Why are we meeting with you? I want to tell you about a study that involves children like yourself. I want to see if you would like to be in this study, too.

Why are we doing this study? I want to find out about how you feel about yourself, what kinds of things you do alone and with your friends, and about some of the times when you are in class or on the playground. I also want to know what you think of One Kids Place and the people who work with you there.

What will happen to you if you are in the study? If you decide to take part in this study, there are some different things we will ask you to do.

- First, I will ask you to look at a certain picture.
- Second, I will ask you what you think about the picture.
- Third, I will ask you to tell me about some of your own experience doing what's shown in the picture. While doing these things all you have to do is try your best. If you have tried your best and do not know what to say or do next, just say 'I do not know.'
- It will take you about 30 minutes to finish the pictures and questions. We will take a break in between so that you can have a snack or go to the washroom. If you need a break, you can always tell me.

Are there good things and bad things about the study? What I find in this study will be used to help other children like you, and their parents. As far as I know, being in this study will not hurt you and it will not make you feel bad.

Will you have to answer all questions and do everything you are asked to do? If I ask you questions that you do not want to answer, then tell me you do not want to answers those questions. If you find things get boring we can always stop.

Who will know that you are in the study? The things you say and anything I write about you will not have your name with it, so no one will know they are your answers or the things that you did except for me.

I will not let anyone other than me see your answers or any other information about you because I am the only one who gets to see these answers. Your teachers and therapists will never see the answers you gave.

Do you have to be in the study? You do not have to be in the study. No one will get angry or upset with you if you don't want to do this. Just tell me if you don't want to be in the study.

And remember, if you decide to be in the study but later you change your mind, then you can tell me you do not want to be in the study anymore.

Do you have any questions? You can ask questions at any time. You can ask now or you can ask later. You can talk to me at any time during the study. Here are the telephone numbers to reach me

(Christina DeRoche) (Sociology) (705-478-8558) or (705) 303-5261

IF YOU WANT TO BE IN THE STUDY, SIGN YOUR NAME ON THE LINE BELOW:

Child's name, (Print your name on this line): _____

Date: _____

Signature of the student researcher:

_____ Date: _____

McMaster University
Inspiring Innovation and Discovery

Assent Form for Minor to Participate (Ages 13 to 18)

Study Title: Understanding Developmental Coordination Disorder and Its Effects on Children

Researcher's name: Christina DeRoche

I would like to invite you to be part of my research study at One Kids Place. Before you decide if you would like to participate, I want you to know why I am doing the study. I also want you to know about any risks (anything unexpected that might happen) and what you will be expected to do in the study. You can only be in the study if your parent(s) agree(s).

This form gives you information about the study. I encourage you to discuss this study with your family before making your decision. I will ask you to sign this form to show that you understand the study and I will give you a copy of this form to keep. It is important that you know:

- You do not have to join the study;
- You may change your mind and stop being in the study any time you want and I will mind.

Who am I ? My name is ***Christina*** and I am a student at the McMaster University in the Department of Sociology and am studying to do my PhD. I also teach at Nipissing University in the Department of Sociology and have been a supply teacher in North Bay for a few years.

Why am I doing this study? I want to find out about how you feel about yourself, what kinds of things you like to do and not to do, and how you feel about your friends and family. How you feel about having or not having a certain disorder. I also want to know what you think of One Kids Place and the people who work with you there. Lastly, I want to know what kinds of experiences you have in school. This is important information for me because it helps me understand how students like you think and experience being diagnosed with a disorder. I am more interested in how you feel than anything else.

What will happen to you if you are in the study? If you decide to take part in this study then you and I will complete an interview together at One Kids Place. I will ask you to tell me about some of your own experiences with friends, family, and school. All I ask is that you do your best to answer. If you have tried your best and do not know what to say or do next, or say 'I do not know'. I really just want to have a conversation with you about your experiences because I think it is important that other people in my job know. It will take you about 30 minutes to finish the interview. We will take a break in between so that you can have a snack or go to the washroom. If you need a break, you can always tell me and we can take one.

Are there good things and bad things about the study? What I find in this study will be used to help other children like you and parents of those children. As far as I know, being in this study will not hurt you and it will not make you feel bad but if you do feel bad, embarrassed, or shy about anything in this interview, we can always stop. I have a counsellor who has agreed to help if you ever need any.

Will you have to answer all questions and do everything you are asked to do? If I ask you questions that you do not want to answer then you do not have to answer them. You don't have to answer all my questions if you don't want to.

Who will know that you are in the study? The things you say and anything I write about you will not have your name on it, so no one will know they are your answers or the things that you did. I will not let anyone other than me see your answers or any other information about you. Your teachers and therapists will never see the answers you give. And any information I discuss with my coworkers will also be confidential, meaning they will never know who you are. Only your parents know that you are participating and no one else. Anything you say to me is very much confidential.

Are there any risks? In this study, there are no physical risks to you participating; however, if you feel uncomfortable or embarrassed at any time during our conversation, just let me know and we can always stop the interview. Afterwards, if you feel like you need to talk to someone or if I feel like you might benefit from a counsellor, I have the name of someone who is willing to do this here in North Bay.

Do you have to be in the study? You do not have to be in the study, participating in this study is your decision. I will not be angry if you decide you don't want to do it. And remember, if you decide to be in the study but later you change your mind, then you can tell me you do not want to be in the study anymore and I won't be mad.

Do you have any questions? You can ask questions at any time. You can ask now or you can ask later. You can talk to me at any time during the study. Here are the telephone numbers and the email address you can reach me at.

(Christina DeRoche) (Sociology) (705-478-8558) (705) 303-5261

derocc2@mcmaster.ca or
christinad@nipissingu.ca

IF YOU WANT TO BE IN THE STUDY, SIGN YOUR NAME ON THE LINE BELOW:

By signing this form means you have read through all the information, discussed it with your parents and family, and agree to participate. You have also agreed that you understand the questions that are being asked of you any of the risks. If you do have questions, again, please feel free to call me or email me.

Student's name, (Print your name on this line): _____

Date: _____

Signature of the Researcher:

_____ Date: _____

Signature of Parent

_____ Date: _____

March 6, 2012

Labels, Stigma and Sick Roles in a Therapeutic Culture: The Case of Developmental Coordination Disorder

Principal Investigator: Christina DeRoche
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Purpose of the Study

The purpose of this study is to discover how children perceive their own abilities and self-esteem, whether they are in the process of being diagnosed with a particular disorder, or have already been diagnosed. In addition, this study aims to understand the role of parents in this process and to uncover any frustrations, obstacles or positive experiences they have had.

Research questions guiding this project include the following:

1. *How do peers and teachers treat children with DCD before and after being diagnosed? How are these children described by peers and teachers?*
2. *How did children feel about themselves, both before and after being given the label? What sorts of things do they mention?*
3. *In terms of opportunities, what was presented as a result of being diagnosed? Were there expanded or restricted opportunities in schools and in social relationships?*
4. *What is the role of parents in all of this?*

You are invited to take part in this study on self-esteem and self-perception of children who are and are not diagnosed with developmental coordination disorder (DCD). I hope to uncover the positive and negative opportunities of being diagnosed with this disorder and learn about the integral role parents and peers play in this process.

What will happen during the study?

- You will be asked to read over the consent form, sign this copy, and bring it to your appointment.
- As a parent/guardian, you will be asked to meet to participate in an interview (approximately 1 hour in length).
- During this interview you might be asked questions such as "What has this process been like for you? How did you know to have your child referred? Did you do any of your own research before coming to One Kids Place?"
- I will also ask you for some demographic information like your age and education level.
- Your child will also be asked to participate in an interview/discussion that will last approximately 1 hour.
- Prior to entering this interview, you will be asked to provide a list of all the individuals you have contacted or spoken with for the duration of time you have been seeking assistance both before being referred and after receiving treatments at OKP. Please bring this list to your scheduled interview for discussion.
- Your child will be asked, in his or her interview, to respond to various illustrations of tasks. Lastly, they will be asked to participate in a drawing exercise. This will take approximately 30 to 60 minutes.
- This discussion with your child can be conducted at One Kids Place in a room with a double-sided window for your comfort and viewing.
- During both of these interviews, a recorder will be used to help in the transcription of the interviews later on.
- Once transcribed, you have the option of reviewing your interview as well as your child's interview before I analyze it.
- As a last component, I will be following your child through his/her daily activities including school, playground, OKP, extra-curricular activities and home for a period of five days. I will be observing your child's behaviour, peer interactions and responses and I will be taking various hand-written notes about these topics.

Are there any risks to doing this study?

You should be aware that there are some risks in participating for both yourself and your child. These risks are minimal; the questions delve into experiences that may make you or your child feel anxious, uneasy, or worried. In this case, I will always give the option to not answer the question and provide assurance that your answers are confidential. You and your child can withdraw at any time during the interview. Upon withdrawal, you may also request that the information gathered from you, or your child's interview not be included in our study.

Are there any benefits to doing this study?

In participating in this study you are actively helping in understanding the consequences that diagnosing a child with any disorder has for that child and their family. It will add to the little

amount of research we have on the consequences for children. Lastly, it will add to the research being done on Developmental Coordination Disorder.

Who will know what I said or did in the study?

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified and, instead, will use only a pseudonym for your name and your child's name. Only I will know your real identity as the pseudonym will be used in all transcriptions and reports that emerge from this project. Any names of institutions will be also be kept confidential and given a pseudonym as well. Because there are only a small number of participants in this study, you may be identifiable by your circumstances, so please keep this in mind as the interview goes on. This does not mean I will report on all the small details.

The information I collect will be kept in a locked cabinet located in my office at the university and I will be the only one who has access. The information recorded during these interviews will also be kept on a password-encrypted computer which only I have access to. These encrypted files will be deleted after a period of two years.

b) Legally Required Disclosure

Although I will protect your privacy as outlined above, if the law requires it, I will have to reveal certain personal information in such cases as child abuse, self-harm, harm to others or suicide. If these cases do arise I have already made arrangements with One Kids Place to have a counsellor available to deal with such issues. In addition I will have to contact proper authorities if more extreme cases present themselves.

What if I change my mind about being in the study?

Your participation in this study is voluntary. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In the case of withdrawal, all information and data will be destroyed. If you do not want to answer some of the questions you do not have to, but you can still participate in the study. Your decision whether or not to be part of the study will not affect your continuing access to services at One Kids Place, nor will it affect the relationship you have with your therapists and paediatrician.

Information about the Study Results

I expect to have this study completed in approximately one year. If you would like a brief summary of the results, please let me know how you would like it sent to you. Provide your e-mailing address or home mailing address so that it may be sent.

Questions about the Study

If you have questions or require more information about the study itself, please contact me.

This study has been reviewed by the McMaster University Research Ethics Board, and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca

CONSENT

I have read the information presented in the information letter about a study being conducted by Christina DeRoche, of McMaster University. I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form. I agree to participate in the study.

Signature: _____

Name of Parent/Guardian Participant (Printed)

_____:

I would like a copy of this study's results sent to me

Home address: _____

_____

_____

E-mail address:

☐ I give my consent to share my email with other parents in order to form a support group or social network.

Child's Interview (To be Used with Children over the age of 10)

Read over assent form and have child sign or verbally assent to interview if willing to proceed.
Before we go any further, I just want to remind you that we can always stop when you don't feel comfortable or if there is a question you are not comfortable with (or don't like). If you need a break just let me know. Lastly, your name and any other people you mention to me will remain confidential, that is, I am the only person who will know about who you are in this study. Nobody else has access to your private information. Do you have any questions before we go ahead?

1. What sorts of activities do you enjoy doing?
2. What sorts of activities do you do at school? What about at home? Do you do any extra-curricular activities (say after school or on weekends)?
3. What sorts of activities do you avoid doing? Why?
4. Do you like to play any sports or active games? Why or why not? Do you find them difficult?
5. Is there anything that you have tried to learn how to do that was tough for you to learn?
6. Are there sports (or activities?) that you have tried before that you don't do any more?
7. Do you enjoy some kind of sport now?
8. Do you find it difficult or hard to do daily things like getting dressed? Doing up buttons or zippers? Eating? What other things do you find challenging at home or with everyday?
9. Do you enjoy school? Why or Why not? What are some of the easy things to do at school? What sorts of things are difficult or challenging for you at school?
10. Do you have difficulties getting things organized (for example, your homework, your desk, etc.)?
11. Can you complete tasks easily at school or at home?
12. Do you like writing? Or drawing? How about the computer?

    Can you tell me about the relationship with your parents or other family members?

13. Do you have friends that you hang out with at school? At home? Do you go out with them often? What sorts of things do you do with your friends?
14. Have you ever been teased or bullied? Do you know why it happened? How do you feel about that?
15. How do you feel about having the diagnosis DCD? Do you understand what it means?
16. Do you get to use special things at school to help you learn? What are they? And how do you feel about that?
17. How do you feel about yourself overall? Is there anything you like? Anything you would want to change?
18. Do you feel that I have forgotten anything about your experience with having DCD?

It may be difficult to remember all the people you have had contact with in your child's diagnosis but please try and list these individuals whom you have contacted or who have contacted you in this process of referral and diagnosis, beginning with the earliest recollection you have. If you can list dates of contact (these can be approximate dates) that would also be helpful. Once you are finished please answer the questions on the next page. Thank you again for volunteering your time to participate in this study.

Please circle the most appropriate response or fill in the blank.

1. Your age:

Under 18
19 to 25
26 to 30
31 to 35
36 to 40
41 to 45
45 to 50
51 and older

2. Your marital status:

Single Married Cohabiting Separated Divorced Remarried

3. How many children do you have? _____

4. What is your combined (if applicable) yearly income? (Please check the appropriate box and indicate whether this is a single or combined yearly income).

This reported income is:

☐ Combined ☐ Single

And I/We make approximately:

☐ $0 to $12,000
☐ $13,000 to $20,000
☐ $21,000 to $35,000
☐ $36,000 to $49,000
☐ $50,000 to $65,000
☐ $66,000 to $80,000
☐ $81,000 to $99,000
☐ $100,000 or more

Interview Guide—Parent (Approximately 1 hour in length)

Child's Name: _____

Good morning/afternoon/evening and thank you for agreeing to participate in this study

(Have parent go over consent form, if not already signed and completed)

This morning/afternoon/evening I am going to ask you a series of questions concerning your experience so far in having your child assessed, treated, and diagnosed for DCD/ Motor Coordination Delay. If at any time you feel uncomfortable or need a break, please let me know. You are not obligated to answer all the questions. I want to remind you that all your information will be kept confidential and only I have access to this information. Do you have any questions before we begin?

*(Allow appropriate amount of time and address any questions the participant may have) ***Allow for open-ended questions to be asked, including any prompting and probing questions****

Before beginning the rest of this discussion, I asked you to list the names of professionals that you contacted or had discussions with about your son/daughter's diagnosis. Can we take a look at this list and discuss it?

What were some of the initial steps you took in talking to these individuals?

What was this experience like? Can you provide any details about the time frame?

Is there anything that you think you might have left out in this list or anyone?

Let's begin the rest of the discussion:

1. What led you to therapy? Was *(insert child's name)* referred by a teacher or general practitioner or did you find out about therapy yourself? What was the importance of this referral for you?

2. What was your role in this referral? What were some of the new responsibilities given to you as a result of the diagnosis or in the process of diagnosis? How did this make you feel?

3. What sorts of concerns did you have about *(insert child's name)* initially? What sorts of symptoms did your child exhibit that may have caused some concern?

Did you always have concerns about your child's abilities and symptoms? What sources did you use (if any) to research these problems?

How has the diagnosis (if any) or the referral been a confirmation or surprise to you? How has it been important for you?

4. How did your child feel prior to receiving therapy? What were some of his/her experiences like in school? What were his/her behaviours like?

5. What has your child's classroom experience been like? What are some of their peer relationships like?

6. Is your child currently receiving therapy in school? What sorts of accommodations have been made for him/her in the classroom? What have teachers been like in this process?

7. What sorts of positive experiences have you had in this process of diagnosing?

8. What have been some of the negative experiences in this process of diagnosing?

9. How do you think the diagnosis will benefit your child? (*Ask participant to explain or elaborate if possible*)

10. What has your experience been like with therapy? *(ask participant to elaborate on experience with therapists, pediatricians, navigating the system, length, duration*).

11. What would you like to see as the outcome of all the therapy and diagnosis for both your child and yourself?

12. Is there anything else you would like to contribute to this interview and to my knowledge of your experience in having your child diagnosed?
    Do you feel I left anything out that might be important in understanding parents/guardians' roles in having their child diagnosed?

That brings us to the end of this interview and conversation. I want to thank you once again for participating and remind you that if at any time you have questions you can always contact me via e-mail or phone with the information outlined in the letter (point to it). Do you have any questions for me before we conclude? As a thank you for participating I have a $20 gift card from Creative Learning for you to use. Thank you once again.

Appendix B: Educator Scripts and LOIs

Date

Dear Educator (Put full name):

My name is Christina DeRoche and I am a PhD student at McMaster University's Department of Sociology. I am writing my dissertation on the experience of both children and parents receiving diagnoses and treatments for a particular disorder, Developmental Coordination Disorder (DCD). In addition I want to interview teachers and gain their perspective on these children and the effects it has on their classroom and the child. This project wants to outline the process of receiving that diagnosis and children's self-perceptions along the way. Your viewpoint is essential to understanding this matter.

I obtained your contact information through (insert child and parents' names) in an effort to address these concerns. I have attached a consent form outlining the details of this study that are pertinent to you. It is important that you read through all this information and please note that your participation is purely voluntary. If you are interested in participating in this study please contact me via e-mail or phone listed below. In addition if you have any questions, concerns, or comments please do not hesitate to contact me. I am more than flexible in accommodating your schedule and am willing to travel. I am very excited about working with you and having this opportunity to collaborate with both school boards and yourself.

Sincerely,

Christina DeRoche
(705) 478-8558
(705) 474-3450 Ext. 4194
derocc2@mcmaster.ca or christinad@nipissingu.ca

DATE: _____

Labels, Stigma and Sick Roles in a Therapeutic Culture: The Case of Developmental Coordination Disorder

Investigators:
Principal Investigator: Christina DeRoche
Department of Sociology
McMaster University
Hamilton, Ontario, Canada
(705) 474-3450 Ext. 4194 or (705) 303-5261
E-mail: derocc2@mcmaster.ca or christinad@nipissingu.ca

Faculty Supervisor: Dr. Scott Davies
Professor, Department of Sociology
McMaster University,
Hamilton, Ontario, Canada
(905) 525-9149 Ext.
E-Mail: daviesrs@mcmaster.ca

Purpose of the Study
The purpose of this study is to discover how children perceive their own abilities and self-esteem, whether in the process of being diagnosed with a particular disorder or already diagnosed. In addition, this study also aims to understand the role of parents in this process and uncover any frustrations, obstacles or positive experiences they have had in the process.

Research questions guiding this project include the following:

1. *How do peers and teachers treat children with DCD before and after being diagnosed? How are these children described by both?*
2. *How did children feel about themselves before and after the label? What sorts of attributes do they mention?*
3. *In terms of opportunities what was presented as a result of being diagnosed? Were there expanded or restricted opportunities in schools and in social relationships?*
4. *What is the role of parents in all of this?*

You are invited to take part in this study on self-esteem and self-perception of children who are and are not diagnosed with developmental coordination disorder (DCD). I hope to uncover the positive and negative opportunities of being diagnosed with this disorder and how parents and peers play an integral role in this process. In addition I really would like to know the perceptions and experiences of teachers in accommodating these students in their classrooms.

What will happen during the study?

- You will be asked to read over the consent form and sign this copy and have it ready for your interview.

- This interview will be scheduled at your convenience and can take place in your classroom or at another location such as a coffee shop.
- During this interview you might be asked questions various questions such as "What has it been like to accommodate this student? What do you know about the peer relationships of this student? Do they have many friends? What is the student's behaviour like?"
- I will also ask you to fill out a short, 1 page, form on some demographic questions concerning your age category, education level and experience in education.
- I will also be recording this interview using an audio recorder solely for purposes of transcribing the interview later on. I will also be making some notes but I am more interested in what you have to say.
- Lastly, I will be observing this child for a period of five days in your classroom and on the playground . I will be out of the way and my sole purpose is to simply observe the child and their interactions.
- As a thank you for participating I am giving a free workshop to all teachers, including yourself, on DCD and the effective strategies in accommodating these students in the classroom. In addition you will receive a $10 gift card from Creative Learning.

Are there any risks to doing this study?
You should be aware that there are some risks in participating. These risks are minimal; the questions delve into experiences that may make you feel uneasy or worried. In this case, I will always give the option to not answer the question and provide assurance that your answers are confidential. You participation in this study is purely voluntary, so if you ever feel uneasy you can always decide to stop and not participate any longer. If this is the case I will not use any of the information in my research.

Are there any benefits to doing this study?
In participating in this study you are actively helping in understanding the consequences that diagnosing a child with any disorder has for that child and their family. It will add to the little amount of research we have on the consequences for children. Lastly, it will add to the research being done on Developmental Coordination Disorder.

Who will know what I said or did in the study?
You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified and instead will use only a pseudonym for your name and your child's name. Only I will know your real identity as the pseudonym will be used in all transcriptions and reports that emerge from this project. Any names of institutions will be also be kept confidential and given a pseudonym. Because there are only a small number of participants in this study, you may be identifiable by your circumstances, so please keep this in mind as the interview goes on. This does not mean I will report on all the small details and does mean I will do my utmost to respect your identity and confidentiality.

The information I collect will be kept in a locked cabinet located in my office at the university and I will be the only one who has access to this. The information recorded during these interviews will also be kept on a password encrypted computer which I have access to only. These encrypted files will be deleted after a period of two years.

b) Legally Required Disclosure (If applicable)

Although I will protect your privacy as outlined above, if the law requires it, I will have to reveal certain personal information if such cases as child abuse, self-harm, harm to others or suicide arise. If these cases do arise I have already made arrangements with One Kids Place to have a counsellor available to deal with such issues. In addition I will have to contact proper authorities if more extreme cases present themselves.

What if I change my mind about being in the study?
Your participation in this study is voluntary. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In any case of withdrawal all information and data will be destroyed. If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your decision whether or not to be part of the study will not affect your job status or the relationship you have with the student.

Information about the Study Results
I expect to have this study completed by approximately June 2013. If you would like a brief summary of the results, please let me know how you would like it sent to you. Provide your e-mailing address or home mailing address so that it may be sent.

Questions about the Study
If you have questions or require more information about the study itself, please contact me. This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca

CONSENT

I have read the information presented in the information letter about a study being conducted by Christina DeRoche, of McMaster University. I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form. I agree to participate in the study.

Signature: _____

Name of Participant (Printed) _____

Signature of Researcher: _____

Date: _____

I wish to receive a copy of this study's results

Home Address: _____

_____

Email: _____

Interview Guide- Educator (Approximately 30mins to 1 hour in length)

Good morning/afternoon/evening and thank you for agreeing to participate in this study

(Have educator go over consent form, if not already signed and completed)

This morning/afternoon/evening I am going to ask you a series of questions concerning your experience so far in accommodating a child with DCD in your classroom and your perceptions on this child's progress and peer relationships. If at any time you feel uncomfortable or need a break please let me know. You are not obligated to answer all the questions. I want to remind you that all your information will be kept confidential and only I have access to this information. This will not affect your job status or quality. Do you have any questions before we begin?

*(Allow appropriate amount of time and address any questions the participant might have) ***Allow for open ended questions to be asked including any prompting and probing questions or more elaboration if needed***)*

1. How long have you been teaching for?

2. Tell about some of the courses you have taken in preparing to be a teacher (allow to answer). Did you find them useful?

3. Tell me about what you know about (child's name)?

4. How has (child's name) been in terms of behaviour in your classroom? Are there any noteworthy experiences you have had with his/her behaviour?

5. What sorts of things have you noticed in general about this child's attitude? How about their style of learning?

6. Does this child receive accommodations in your classroom? What sorts of accommodations?

7. How do you find this experience of accommodating?

8. Tell me about what you know of Developmental Coordination Disorder? Had you heard of it before? What do you know about (child's name)'s disorder? What has been told to you?

9. From your observations, what have his/her social skills been like?

10. Do they have many peers that you know of? What kinds of children do they affiliate themselves with? How do they interact within the classroom or recess setting that you know of?

11. How often do these children participate in active programs like Physical Education (this may not pertain)?

12. Do you think things would change if the child had a diagnosis? OR have things changed for the child as a result of having the diagnosis?

13. How do you think (child's name) feels about her/his self? What makes you say this? Can you think of an instance or example to help better explain why you think this way?

14. Do you think this child is best served in the general education classroom? What do you think the benefits are? What do you think the drawbacks might be?

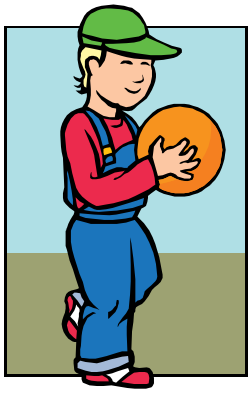
15. How do you think (child's name) needs could be better served in your classroom?

16. Is there anything else you would like to contribute to this interview? Is there anything that I have missed or you think is valuable in knowing about child?

17. Do you have any questions or comments that you want to ask or add?

That brings us to the end of this interview. I want to thank you once again for participating and remind you that if at any time you have questions you can always contact me via e-mail or phone with the information outlined in the letter (point to it). As a thank you for participating I have a $10 gift card for Creative Learning for to use. Thank you once again.

Appendix C: Parental and Children Recruitment Materials



Children with Motor Delays or with DCD

PARTICIPANTS NEEDED FOR RESEARCH IN Fine and Gross Motor Delay or with Developmental Coordination Disorder (DCD)

I am looking for volunteers to take part in a study of *children*

Who have fine and gross motor delays OR who have been diagnosed with developmental coordination disorder (DCD).
I am looking for 4 more participants in total.

Parents and children will be asked to take part in interviews.
I will also be observing your child in school and at extra-curricular activities. Each interview will take approximately 30 to 60 minutes. Ages of children can range from 6 to 19 years of age.

In appreciation for your time, you will receive a gift card for Creative learning

For more information about this study, or to volunteer for this study,
please contact:
Christina DeRoche
Department of Sociology
705-478-8558 or 705-303-5261
Email: christinad@nipissingu.ca or derocc2@mcmaster.ca

This study has been reviewed by, and received ethics clearance by the McMaster Research Ethics Board and Nipissing University Ethics Board

About the Researcher

I am a first-generation Canadian, whose family immigrated from Italy. I am a part-time Lecturer at Nipissing University and a full-time PhD student at McMaster University. I have a Bachelor of Education degree in Primary/Junior education and have been a supply teacher for some time. My past research has concerned how children with learning disabilities are included in everyday classroom activities.

Contact Information

If you have any questions about this study or would like to participate, please contact Christina DeRoche at my local tel: 705-474-3450 Ext. 4194 or 705-303-5261.

Or by email at:
derocc2@mcmaster.ca OR

christinad@nipissingu.ca

This study has been reviewed and approved by the McMaster Research Ethics Board.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact the McMaster Research Ethics Board Secretariat.
Phone:(905) 525-9140 Ext.23142
Email: ethicsoffice@mcmaster.ca
Mail :
c/o Office of Research Services
McMaster University
1280 Main St West
Hamilton, ON L8S 4L8

My faculty supervisor, Dr. Scott Davies and can be reached at (905) 525-9140 Ext. 23607 or by

McMaster University

McMaster University

To Label or Not to Label?

Research Investigator
Christina DeRoche

Doctoral Student
Department of Sociology
McMaster University
Hamilton, ON
Lecturer, Department of Sociology, Nipissing University, North Bay, ON

E-mail: derocc2@mcmaster.ca or christinad@nipissingu.ca
Phone: (705) 478-8558

About this Project

The purpose of this study is to discover how children perceive their own abilities and self-esteem, whether in the process of being diagnosed with a particular disorder or already diagnosed. In addition, this study also aims to understand the role of parents in this process and uncover any frustrations, obstacles or positive experiences they have had during this time.

During the months of April 2012 to June 2012. I will be interviewing parents and their children about their experiences at One Kids Place in North Bay, ON. Some of the questions I am asking are the following:

1. *How did children feel about themselves before orafter getting a diagnosis? What sorts of attributes do they mention?*
2. *What are the roles of parents in all of this?*

I am looking forward to hearing from both parents and children whether they are diagnosed or not.

.

Participant's Role

Parents and their children are invited to participate in one-on-one interviews totaling one hour in duration. Parents will be interviewed on their role in the diagnosing process, their experiences during such and on their overall understanding of the process. They will also be asked to write down all the individuals they contacted or spoke with in the process.

Children will be interviewed as well but in these interviews, children will be prompted with various illustrations. These are meant to help in eliciting conversations about their self-perception of their abilities and inabilities I will also be doing a drawing exercise to continue this conversation. These interviews will also last approximately an hour. Lastly, I would like to follow your child for approximately 5 days to observe their behaviours and peer relationships at home activities, school and in the playground.If you agree to participate you are asked to read through an information letter concerning the project and sign the consent form before the interview begins. With your permission both interviews will be audio-recorded using a small electronic device.

Confidentiality

This is solely for the purpose of transcribing the interviews later on and only I will have access to them. All records of my observations, tapes of individual interviews and conversations will be kept private and will only be available to myself. Records and basic demographic information of participants will be used only for research purposes and will be kept in secure storage. I will use pseudonyms in all publications, and no one will be identified by name in this study.

If there are any questions that participants feel uncomfortable answering or that they would prefer not to answer they may skip over that section or stop the interview. Participation in this research is completely voluntary and participants can decide to withdraw from this study at any time.