

# **Labels in Education: The Role of Parents and Parental Cultural Capital in Acquiring Diagnoses and Educational Accommodations**

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## **Abstract**

This study provides a qualitative examination of the original tenets of Labelling Theory (LT) within the realm of education using a relatively new medical label, developmental coordination disorder. Labelling Theory, although initially proposed in the areas of crime and deviance, has been applied to mental illness and educational labels. However, recent social changes have prompted a renewal of its sustainability in these areas. This study empirically evaluates the original tenets of LT and explores the role of parents in the diagnostic process. Arguably, parents play an active role in their well-being and educational opportunities today; this study uses one case in exploring this role and in asking four research questions. It finds that parents, from beginning to end, played an active role in acquiring formal labels and services for their children throughout the diagnostic process and afterwards. Parents drew from the considerable resources and capital in this process. The findings of this article have profound implications for health care policies and educational policies, which are discussed in this article.

*Keywords:* labelling, stigma, parental role, cultural capital, special education

## Résumé

Cette étude fournit une analyse qualitative des principes de base de la théorie de l'étiquetage (TÉ) dans le cadre de l'éducation; elle recourt à une étiquette médicale relativement nouvelle, le trouble de l'acquisition de la coordination. Bien qu'elle ait été initialement proposée dans les domaines du crime et de la déviance, la théorie de l'étiquetage est également appliquée à la maladie mentale et à l'éducation. Des changements sociaux récents ont par ailleurs favorisé un renouvellement de sa viabilité dans ces domaines. L'étude évalue de manière empirique les principes fondamentaux de la TÉ et explore le rôle des parents dans le processus du diagnostic. Sans doute, les parents jouent-ils un rôle actif dans le bien-être de l'enfant et les possibilités de s'instruire qui lui sont offertes aujourd'hui; cette étude a recours à un cas pour explorer ce rôle et poser quatre questions. Elle dévoile que les parents, du début à la fin, ont joué un rôle actif dans l'acquisition des étiquettes formelles et des services pour leurs enfants tout au long du processus de diagnostic et par la suite. Les parents ont puisé dans des ressources et un capital considérables au cours de ce processus. Les observations recueillies dans le cadre de cette étude ont des incidences profondes pour les politiques en matière de santé et d'éducation, comme le démontre cet article.

*Mots-clés :* étiquetage, stigmatisation, rôle parental, capital culturel, éducation de l'enfance en difficulté

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## Introduction

Labelling individuals is negatively viewed in sociology because of the individual consequences (Becker, 1973; Goffman, 1963; Link & Phelan, 1999; Scheff, 1984; Shifrer, 2013) and because labels are imposed on individuals by moral entrepreneurs, to categorize them while exerting power (Becker, 1973). Few individuals within sociology have explored the intended benefits of labels for individuals. Some studies have explored this idea (Higgins, Raskind, Goldberg, & Herman, 2002; Rist, 1970; Rist & Harrell, 1982) and have found that individuals receive a variety of treatments and accommodations (Ho, 2004) and even garner increased sympathy from the general public (Higgins et al., 2002) and professionals (Hayward & Bright, 1997) because of being labelled.

Parents have been encouraged to be collaborative and active in the education process, but to what extent has not been determined (Nurmi & Salinskas, 2014). Parents as a group have played a particular role within the disability and education movement (Ong-Dean, 2009; Ong-Dean, Daly, & Park, 2011), advocating for educational opportunities and inclusionary accommodations; they have been termed “privileged advocates” (Ong-Dean, 2009). Ong-Dean (2009) argues that research focuses on the special education system as being dominated by those who are disadvantaged, while overemphasizing the effect the cumulative disadvantage has on children (Ong-Dean, Daly, & Park, 2011) rather than reviewing the evidence for this relationship. Ong-Dean, Daly, and Park (2011) have argued that parents who are privileged with wealth, education, income, and other sources of capital have long been involved in the special education movement. This idea has been echoed by others in studies of children who proliferate in private schools (Khan, 2010) and elite university campuses (Demerath, 2009). This article explores how labelling and parental advocacy are linked as parents draw from a pool of “capital” in making the decision to acquire a label for their child or refute one.

## Literature Review

### Labelling Theory: Review and Core Arguments

For several decades, theorists have believed that the labelling of individuals produced negative consequences such as lowered self-esteem and self-perception (Becker, 1973; Goffman, 1963; Link & Phelan, 1999; Scheff, 1984). Labelling Theory (LT) was further developed 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. Building on this work, theorists viewed labelling as a form of social control that can come 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 components together 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.

Rist (2001) applied LT within the educational context, arguing that teachers label students in various ways for various reasons, 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 (Shifrer, 2013) may lead to fewer educational opportunities (usually through lowered expectations, ability grouping, and/or downward streaming) (Rist & Harrell, 1982), stigma, and, along with lowered self-concepts, can contribute to a self-fulfilling prophecy (Ho, 2004).

However, since the time of Goffman, social contexts have changed. 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, and learning disability. Consequently, there has been a marked expansion of the fields of special education and

childhood disorders, in which special educators and other professionals readily draw on and apply formal labels to children's abilities and capacities within the classroom environment. The use of these terms has become common in our culture to the point of being normalized (Furedi, 2004), resulting in more awareness of ensuing stigma (Stuart, 2012). This normalization has resulted in accommodations and treatments to labelled individuals. Lastly, parents now play an active role in their child's educational outcomes (Demerath, 2009; Fylling & Sandvin, 1999; Khan, 2010; Ong-Dean, 2009) and health outcomes. All of these trends together may serve not only to increase the odds of children receiving formal labels for a variety of primary conditions but also to alter the ensuing social consequences of these labels. And while considering LT and the role of parents in label advocacy, more attention needs to be paid to how labels may be tied to socio-economic status and cultural capital. Ong-Dean (2009) found that parents access special education services and accommodations by their sheer advocacy skills.

### **Parental Cultural Capital and Health/Education Seeking Behaviours**

Parents draw on their cultural capital in order to create and sustain opportunities of educational advancement not otherwise provided without a diagnosis. The notion of cultural capital and health and educational outcomes is not a new one. The concept of cultural capital was first established by Bourdieu and Passeron (1990), where they elaborated on how social status was reproduced in society through a variety of mechanisms they termed under the concept of capital. According to some, capital refers to the highbrow explanations that Bourdieu may have alluded to in his original work (Lareau & Weininger, 2003; others have argued that there is more to understanding it: capital involves understanding a host of sources and processes (Lareau & Weininger, 2003). For example, a number of researchers have demonstrated how socio-economic status and wealth are intimately linked to health and educational outcomes (Adler et al., 1994; Allin & Stabile, 2012; Braverman, Egerter, & Williams, 2011; Lamont & Lareau, 1988).

Within the educational domain, lower SES levels predict lower levels of educational achievement, and higher levels of SES predict higher levels of educational achievement (Willms, 2002). This phenomenon has been termed the health/education gradient and there is an abundance of evidence demonstrating its presence and effects (Adler et al., 1994; Canadian Council on Learning, 2008, 2009; Phelan, Link, & Tehranifar, 2010;

Reinhold & Jürges, 2012). Exploring this gradient requires first exploring childhood socialization practices and family values (Allin & Stabile, 2012; Lareau, 2011). Specifically, Allin and Stabile (2012) found in their study that family income and the mother's education had a significant effect on children's overall health outcomes. Health disparities increase as age increases for those individuals who live at impoverished or lower levels of socio-economic status. Link, Phelan, and Tehranifar (2010) speculate that some of the underlying mechanisms in this relationship could be situated within the theory of fundamental causes: individuals deploy resources that are at their disposal when needed and necessary to avoid risk or in order to buffer it.

Lareau (2011) offers another understanding of this underlying mechanism of social class perpetuation with her concept of concerted cultivation. This concept links sources of income, wealth, and resources to educational outcomes, but Lareau argues that also included in the concept of capital are familial educational practices and extracurricular activity participation. This concept consisted of families, irrespective of race, imparting educational values in their children by engaging in various activities with them and enrolling them in various extracurricular activities; it also entailed intervening on children's behalf (Lareau, 2011).

Demerath (2009), similarly, found in his ethnographic study that children who went to exclusive and upper-class schools often had parents who, in the background, would negotiate their entrance. He argues that there are correlations that exist between cultural practices, the reproduction of inequality, and parental practices. He found that "these practices devoted to negotiating special circumstances for parents' own offspring are certainly a central component...they make up another key linkage that binds together this suburban cultural system to personal advancement" (Demerath, 2009, p. 48). Parents would often negotiate so that special education resources were acquired for their children as a means of creating and sustaining opportunities (Demerath, 2009; Ong-Dean, 2009). However, do these practices translate to the disparities in health outcomes, given that we already know that more capital is linked to better health outcomes? In order to examine this relationship in more detail, this study drew on a population of children who received a relatively new diagnosis in the area of child development.

## **Developmental Coordination Disorder: An Overview**

Developmental coordination disorder (DCD) is categorized as a neurodevelopmental disorder in the recent DSM-V, as emerging research has shown that DCD may have neurological correlates (Zwicker, Missiuna, Harris, & Boyd, 2010). DCD affects 4% to 6% of all school-aged children and is characterized by significant motor impairment, which leads to a disruption in academic performance (American Psychiatric Association, 2013, section 315.4). Symptoms of and criteria for DCD are marked by developmental delays in crawling and walking and displays of general clumsiness. Children can 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 (American Psychiatric Association, 2013, section 315.4). Symptoms include tripping, falling, and bumping into things, and a lack of organizational skills necessary for playing, drawing, and completing other routine school activities (Polatajko, 1999). DCD is often diagnosed with other disorders such as ADHD, speech language disorders, and learning disorders (Missiuna, Rivard, & Pollock, 2004).

Parents of these children with DCD voice frustrations when dealing with the education system and educators in seeking various ways to help their children (Missiuna, Gaines, Soucie, & McLean, 2006a). They often try to approach professionals; however, accessing these professionals has proven troublesome (Missiuna, Moll, Law, King, & King, 2006b). Parents also may not know the cause of their child's difficulty, but they are nonetheless aware that a difficulty exists (Peters & Henderson, 2008). With these facts in mind and using this relatively newer label, it became opportune to explore the following research questions:

1. What role do parents play in acquiring labels for children? And why do they seek or not seek labels?
2. What are their experiences in the diagnostic process?
3. What types of attitudes do they hold concerning labelling of children?

## **Methodology**

This case study was qualitative in design and included a sample of nine children, four of whom had no diagnosis (or label), one child who was in the midst of receiving an official

diagnosis, and four children who had official diagnoses of DCD from their respective pediatrician. This case study was part of a larger study which not only assessed the above research questions but also assessed if providing labels was beneficial for students. Given the goals of the larger study and the small sample of participants, qualitative methods were the most appropriate design to employ (Yin, 2009). In this regard, interviews were conducted with parents of all the children, and children were observed for a period of seven days in all environments: home, school, and extracurricular activities. Employing both interviews and observational techniques allowed for a triangulation of themes (Yin, 2009). Although the sample was relatively small, consisting of nine children and 16 parents, the qualitative nature of this study made the sample size large enough to explore ideas and themes, while also delving deep enough into participant responses during interviews to draw some preliminary conclusions and findings (Yin, 2009). These findings cannot be generalized, but provide an in-depth understanding of experiences suitable to this segment of the population (Shenton, 2004).

### **Recruitment, Characteristics of Participants, and Methodologies**

This study was conducted in northern Ontario and participants were recruited through various means because of the relatively unknown nature of DCD as a disorder. This recruitment strategy included brochures being provided to families from a local children's treatment centre and posters advertised at the local pediatric and general family physician offices. As a result, two groups of participants were recruited and provided for a comparison of sorts: pre-labelled children who have similar symptoms but have no label attached (as identified by occupational and physical therapists), and those with an official diagnosis (as provided by a pediatrician). As a result, the sample was purposive in nature and small, as it consisted of nine families and nine children, two of whom were siblings in the same family. Ages of this sample of children ranged from 3.5 to 17 years of age and consisted of eight boys and one girl. All of the names used in this study are pseudonyms and some details are masked or changed to protect the identities of these families and children.

Qualitative methods were used, such as interviews and observations for data collection. Interviews were completed with parents regarding their lived experiences during the process of diagnosis and to ascertain if they observed benefits and consequences as a



result of receiving or not receiving a label. 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. These interviews were completed at the Centre and volunteers were provided to mind children for the convenience of the parent.

Observations of the children, their families, and their school lives were completed in this study. This method was used to delve deeper into the issue of labelling and the variety of contexts in which it can occur. Each child was observed over a five-day period, and the observation took place in the child's home, school, and other locations relevant to their health, academic, and social activities. Observations were made by sitting in on the children's classes, homes, and extracurricular activities throughout the week, in some instances allowing for a few days for a child to adjust to my presence. 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. Although this part informed the larger research study, aspects of the observational component were also used in the analysis and reporting of results in this article.

## **Data Analysis**

Given the small sample and the nature of the questions, the data can be considered credible given the research methods used in this study, as they were well-established in previous studies of this nature (Shenton, 2004). After being completed, all interviews were transcribed and coded in NVivo (QSR, Version 10). Each participant was sent a copy of their interview transcript to provide comments and feedback for the researcher. The interview and observation data were rigorously analyzed for major themes and patterns using LT as the guiding analytical framework, but also for themes and processes not accounted for by LT. Returning to the theoretical framework is essential for analysis to be considerable reasonable (Yin, 2009). 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 larger study's

research questions, as well as for themes not accounted for in the LT literature (Reid & Gough, 2000).

## **Findings and Discussion**

This study split participants into two separate groups: undiagnosed but receiving treatment for gross and fine motor delays, and diagnosed with DCD. Interestingly, of all of the children, only one was female, and she was receiving services for delays but had not yet been diagnosed with any disorder. Table 1 depicts some details of the participants who were included in this study. The gender disparity 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, Davenport, Epps, & Nordquist, 2003). Family income ranged from \$35,000 to \$100,000 or more, and most of the participants made more than the top income stated (six out of the nine). This skew in income is not surprising, as 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 various professionals, and hiring private tutors (Ong-Dean, 2009).

**Table 1.** Demographics and Characteristics of Participant Families

Name of Child	Parents' Names	Parental Occupation	Age	Siblings?	Diagnosis?	Residential Information/ Parental Income	Parental Status	Parental Occupation	Extracurricular Activities
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
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
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
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
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,
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
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
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
Keith	Rebecca	City Worker and Administration	17	Older brother	Yes- DCD and Autism (questionable)	Single dwelling, within city, income not stated	Divorced, Single	City Worker and Administrator	None
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

## **Fears and Ambivalence of Labelling**

Most of the parents were “ambivalent” about the negative consequences of receiving a diagnosis, but they were also aware of the benefits. This ambivalence resulted in a range of contrasting attitudes expressed by parents. For example, Ken’s parents expressed a number of fears that began when teachers felt he might have ADHD:

Jill: We didn’t want him to, you know, to be known as a kid with ADHD, as opposed to “here comes Ken.”

Kevin: And then they pour 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!

These same parents also voiced concerns of stigma in having an individual education plan (IEP) for Ken as a result of being labelled:

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 of the parents expressed some fear of labelling. But some felt that it depended on the type of disability. Tanya felt that a visible disability could lead to more sympathy, not an invisible one like DCD, and her husband felt somewhat differently:

The world is more sympathetic when it is visible. 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. 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. He felt that our son would grow into his big body, into his big feet, and that he was born a big baby. That he would eventually catch up to the size of his body.

Other parents voiced their concerns as being different from one another, for example Owen's mother stated that her husband had a difficult time with the label in the beginning, given his background:

Tina: It was hard on him [her husband], '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, however; now he's much more accepting.

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

Basically, I don't want him to be labelled and then treated differently. 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.

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 their case.

### **Benefits of Labelling**

Many parents of both undiagnosed and diagnosed children voiced benefits of attaining labels for their children. For example:

Tina: I think it's hugely important for children to have the diagnosis because 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...but I think you have to do that to get the help that you need.

The majority of these parents voiced that there were benefits and that the justification for attaining a label revolved around getting accommodations for their child and providing their own personal answers to problems they saw as deficits:

Rebecca: 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, just even from standing.

## **Parental Advocacy**

Parents stated a range of experiences where advocacy was needed for their children within the educational and societal contexts. This advocacy was to ensure fair treatment and respect for their child that a typically developing child would receive. For example:

Elaine: 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. 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... somehow there was miscommunication between principal and teacher that he was coming in with delays. And eight days into JK, I get a phone call from the school, saying he's been suspended from school; and I thought OK, they were warned, so what is going on? So I got to the front desk, I said to the girl "I am here for Andrew?" and she 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 the file was, she went, "Oh my God, are we dealing with a child with special needs?" and I said, "Oh yea." 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, was what she said, and I told this teacher, you need to break it [instructions] down.

Parental resources illustrated a heterogeneous grouping of skills and materials that helped in advocating for their children; however, these skills were only put to use if the parents wanted a formal label or help for their child. Parents in this study played a very active

role in the labelling process. This was not the only example of parental advocacy in the sample; Rebecca mentioned in her interview how she often would discuss Keith's abilities and inabilities with the physical health education teachers. In one of Keith's education years, Rebecca recalled, his teacher would not do up his "ice skates because he didn't understand that Keith couldn't do them up. I walked in once and was shocked at what was happening. I explained to the teacher the situation and asked him to do them up. I found out later that the teacher still wasn't helping Keith."

## **Parental Resources or Capital**

***Financial and economic forms.*** Parents who had the economic means to provide more treatment and activities for their children did so. For example, many parents had enrolled their children in extracurricular activities they deemed interesting to the child or that would benefit the child, such as Owen's mother, who enrolled him in drumming, wakeboarding, and snowboarding, or Andrew's parents, who enrolled him in Cadets. Even Dylan's parents enrolled him in squash and cross-country skiing to encourage activity. Here they comment:

Kendra: 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.

Donald: 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.

***Cultural and social sources of capital.*** 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. For example, one couple (Elaine and Nathan) mentioned that their neighbour was one of the local pediatricians, and they went to see him about Andrew's condition. Additionally, they stated that their family helped found the centre where Andrew was receiving services. Both this couple and Tina and Ethan had taken their children to a hospital out of town for services and assessments, because of their social connections.

As another example, 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:

Kendra: 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.

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

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 economically affluent of the group, but displayed a good working knowledge of the medical system because of their training and educational backgrounds:

Felicia: So what had happened, even when I switched from one pediatrician to the next, the pediatrician 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. It wasn't easy; it was really hard. Most things you can self-refer, the only two things you can't are pediatricians and the infant program.

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



Felicia: 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. 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.

Kody: 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. Thus, social, cultural, and economic resources were important for these parents as they were used in leveraging a diagnosis and used at every opportunity to acquire opportunities and treatments for their children. Almost all the parents were left to negotiate the system blindly while advocating for their child, regardless of their position on labelling, something which is reiterated in previous research done by Missiuna et al. (2006b).

## **Implications and Final Remarks**

This article explored the role of parents in the diagnostic process and how involved they were in this process, what attitudes they had on labelling, and what their experiences were throughout the diagnostic process. All of these findings have implications for both LT and policy. For example, parents offered numerous justifications for pursuing a label or not pursuing one. And although parents pursued labels, most were ambivalent due to unclear social implications regarding the label. This decision was termed ambivalent because of the very divide that parents wrestled with: the benefits that labels could bring versus the social consequences that they faced as a result of having or not having a label. LT does not elaborate on this ambivalence. Few studies have highlighted the benefits and the struggle parents have in accepting the label for its benefits. Studies such as Higgins et al. (2002) have stressed the reactions of children but not of parents.

This labelling ambivalence did not hinder some of these parents from using every source of capital they could in acquiring treatments and labels; most of the participants

drew from their considerable educational and health care knowledge in acquiring treatments and services from their family physicians. Additionally, 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, something which resonates with other research and theories (Lareau, 2011; Ong-Dean, 2009). These resources 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.

Labelling Theory, to date, has not yet acknowledged the active pursuit of labels by parents both within the health care field or educational field. Some have commented on self-labelling (Rotenberg, 1974) as a missing link in the original societal reaction theory. This pursuit of labels and negotiation of the health care setting and professionals required these parents to draw on their capital resources; in this capacity, parents engaged in practices that contribute to what Lareau (2011) has termed concerted cultivation. For example, parents negotiated, advocated, and participated in the diagnostic process. However, this cultivation is also applicable to the health care setting, not just the educational setting. Children are being taught to request second opinions, question them, and they have the ability to reject diagnoses and medical claims or accept them, something which has been alluded to by Demerath (2009), Lareau (2011) and Lareau and McCrory Calarco (2012).

These findings also have profound policy implications. First, many parents are active in the process of seeking formal labels but vary in their experience and success, which shows 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 within the educational domain: 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 education requires the dissemination of solid information to educators and medical practitioners as well as the general public. Many parents were left to fend for themselves when researching strategies to help their children succeed in the classroom and external activities and social situations outside of the classroom suitable for their child's needs. This idea is something that Missiuna et al. (2006b) have already elaborated upon in their interviews with parents of children with DCD.

The unequal capacity for all 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. Health care systems and educational systems need to work in tandem to ensure equality in access and opportunities as more advantaged parents are finding new and innovative ways to ensure that their children remain ahead. This inequality in access, then, leads to inequality in academic opportunities and perpetuation of class structures.

Additional research needs to tease out the relationship between parental sources of capital and the ability to navigate the health care system well. This future research could be accomplished by interviewing other sources in addition to parents, such as educators, board members, and the children themselves, on the benefits and drawbacks to a label. Research should also determine which sources of capital contribute to more effective means of health care access and, perhaps, more effective means of attaining a diagnosis. This study was limited in exploring these relationships more fully because of its small sample size and confined study time period. More longitudinal research on these processes would help in uncovering these relationships and questions on the benefits of labels in the long term, both academically and psychologically.

This study was profound in uncovering the hidden mechanisms of health care and educational access inequality and its link to educational accommodations. Like Lareau's (2011) work on the link between parental practices, childhood socialization, and status attainment, this study found that parental practices and sources of capital were not only essential in attaining educational opportunities but also health care access and diagnoses. In a sense, parents just wanted to acquire opportunities for their children in any capacity and by any means possible.

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