“YOU KNOW, KIDS DON’T COME OUT IN A COOKIE-CUTTER”: DISABILITY AND OTHER PROCESSES MOTHERS OF ‘LABELED’ CHILDREN NEGOTIATE IN THE EDUCATIONAL PLAYING FIELD.

by

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This thesis examines how mothers of children labeled ‘learning disabled’ negotiate with educational professionals as advocates for their children. Previous scholarship has not adequately addressed the role that parents, particularly mothers of children labeled ‘learning disabled’ play in the education of their children. Through analyzing the ways in which these educational practices shape people’s experiences and identities, we can gain a deeper understanding of the ways in which labeling processes are experienced, managed, constructed, negotiated and/or resisted. This subject was explored through in-depth interviews with six mothers, using interviewing practices informed by standpoint methodology.

My analysis follows two major themes. The first theme deals with the contradictory nature of psychoeducational assessments in the classrooms of the educational system. I demonstrate how psychoeducational assessments act as a set of rules, regulations and rights. I demonstrate how the mothers in my study used these as tools for empowerment and resistance to educational structures and discourses of normalcy. I also demonstrate the limitations of these texts to secure the educational interest and rights of children labeled ‘learning disabled’. The second theme deals with transformation processes. I ask, how do mothers of children labeled ‘learning disabled’ change as a result of negotiating their child or children’s ‘learning disability’. I demonstrate how being a parent of a child labeled ‘learning disabled’ is outside the sphere of ‘regular’ parenting and the sphere of the formal educational system and the economic, social and health-related consequences of such work.
# TABLE OF CONTENTS

Abstract........................................................................................................................................... ii
Table of Contents ............................................................................................................................ iii
Acknowledgements ......................................................................................................................... iv
Dedication......................................................................................................................................... v
Chapter One: Introduction and Overview ..................................................................................... 1
  Research Questions/Intellectual Puzzle....................................................................................... 10
  Review of the Literature ............................................................................................................... 11
  Chapter Outlines .......................................................................................................................... 22
  Notes for Chapter One .................................................................................................................. 23
Chapter Two: Theoretical and Methodological Foundations ....................................................... 25
  Defining Key Theoretical Concepts ............................................................................................ 25
  Methods of Data Generation ........................................................................................................ 33
  Sampling Strategy ....................................................................................................................... 36
  Ethics, Letter of Introduction and Consent Form ....................................................................... 37
  Ethical Issues and Limitations Due to Study Design .................................................................. 38
  Method of Data Analysis ............................................................................................................ 39
  Texts, Objectification and the Role of the Researcher ................................................................. 41
Chapter Three: When the Rules Don’t Apply: Disability in the Educational Playing Field ......... 44
  Introduction ................................................................................................................................. 44
  The ‘Field’ ................................................................................................................................. 45
  The ‘Rulebook’ ......................................................................................................................... 56
  The ‘Players’ ............................................................................................................................. 63
  Conclusion ................................................................................................................................. 76
  Notes for Chapter Three ............................................................................................................ 77
Chapter Four: What Game Are We Playing? Negotiating Disability on Multiple Playing Fields ... 78
  Playing on the Sideline ................................................................................................................. 79
  Profits and Deficits ..................................................................................................................... 83
  Persistent Players ......................................................................................................................... 92
  Parental Deficit Syndrome ....................................................................................................... 93
  Conclusion ................................................................................................................................. 96
  Notes for Chapter Four ............................................................................................................ 98
Chapter Five: Conclusion............................................................................................................... 99
  Limitations of Study .................................................................................................................. 103
  Directions for Future Research ............................................................................................... 105
Bibliography .................................................................................................................................. 106
  Online Sources ......................................................................................................................... 112
Appendix 1..................................................................................................................................... 113
Appendix 2..................................................................................................................................... 114
Appendix 3..................................................................................................................................... 115
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DEDICATION

…Disillusionment.
CHAPTER ONE: INTRODUCTION AND OVERVIEW

“when I was four years old they tried to test my I.Q. 
they showed me a picture of 3 oranges and a pear 
they said, which one is different? 
it does not belong 
they taught me different is wrong”

For every lie I unlearn 
I learn something new 
I sing sometimes for the war that I fight 
'cause every tool is a weapon – 
If you hold it right.”

-Ani Difranco, "My IQ"

The lyrics from the song, “My IQ” seem like a fitting place to begin. Most of us have been subjected to some form of test in the institutional setting and at one time or another most of us have learnt that ‘different is wrong’. The educational system is a generator of such lessons. It is where I learned such lessons; these were lessons hard learned, painful and forever written on my body. This particular type of knowledge accumulation is often referred to as ‘bad wisdom’. Bad wisdom is being confronted with the ways of the world when you are too young and too powerless too act on your own. For me, the school setting was a terrible and alienating place, this experience was exacerbated by my parents complete and undiscriminating faith in the teachers and professionals that made up my educational trajectory. In part, their trust was based simply on the fact that these individuals were more educated then my parents and, in part, because of the
stigma that was (and continues to be) attached to ‘difference’. Understanding how these stigmas are negotiated and resisted by parents is the purpose of this study.

New discussions on disability have challenged and disrupted the narrow and often pathologizing views of the health, caring and teaching professions of the past. However, there has been insufficient investigation of the ways that diagnostic practices of and interactions with these professionals impact the lives of people diagnosed with disabilities and of their families. These professionals continue to have a considerable impact on the ways that disabled people are socially, culturally and politically defined. It is only through their judgments that disability can be assessed, needs can be defined, and resources allocated. Given the currency of such judgments, it is surprising that educational practices such as psychoeducational assessments and the series of negotiations that precede these practices have remained largely unexamined.

The existence of such educational practices, as well as the many interactions parents of children labeled ‘learning disabled’ exchange with educational professionals, impact the identity, parental role and self-esteem of parents in multiple and often contradictory ways. First, parents may live what Goffman (1963) refers to as the “courtesy stigma,” or the process whereby the social stigma of disability generally and the condition of learning disabilities specifically is turned in on entire families (pg.30).

As Goffman (1963) explains:

The loyal spouse of the mental patient, the daughter of the ex-con, the parent of the cripple, the friend of the blind, or he family of the hangman, are all obliged to share some of the discredit of the stigmatized person to whom they are related. One response to this fate is to embrace it, and to live within the world of one’s stigmatized connection. It should be added that persons who acquire a degree of stigma in this way can themselves have connections who acquire a little of the disease twice-removed. The
problems faced by stigmatized persons spread out in waves, but of diminishing intensity (pg. 30).

Indeed, as Avery (1999) has asked, where does the tale of ‘peripheral prejudice’ appear, “with its insight into the shifts in a parent’s autobiographical cohesion when former notions of the body and ‘normalcy’ collide after learning one’s own child is disabled?” (pg. 117). In addition, parents may experience feel resigned to accept the judgments of professionals over their own instincts and knowledge, while at the same time, they may feel uninformed and unsupported by these same professionals. Indeed, as Swain, French and Cameron (2003) point out, “there is an unequal power relationship between professionals and their clients. Professionals have the power to assess and label people, to make moral evaluations about them and define their problems. Their knowledge is regarded as reliable, valid and ‘objective’ while that of their client is thought to be fanciful, dubious and ‘subjective’ ”(pg. 133). The different values applied to ‘knowledge’ can be explained, at least in part, by understanding them as located within the different realms of ‘the personal’ and ‘the public’

C. Wright Mills (2004) made an enduring contribution to sociology when he wrote about the dialectic of “the public issues of social structure” and the “personal troubles of milieu” (pg.4). Sociology is concerned with structure, context, and patterns. ‘Good Sociology’ locates individual’s personal troubles within the social structure and demonstrates how individual lives are shaped by these structures. Biology is not destiny; personal troubles do not reside with the individual alone. Emphasis on the deficiency of the individual as the root of the problem arises from the way that the medical metaphor operates within education. As Mehan, Hertweck, and Meihl’s (1986) suggest:
The medical metaphor has been extended from the physical to the mental domain within education. As a consequence, intelligence, aptitude or mental ability have become medicalized and subject to treatment. It is this medical metaphor that leads to the view that students have a “problem”. This problem is a disability, perceived as residing within students, as their private and personal possession (pg. 159).

One of Sociology’s biggest contribution to the production of knowledge is tracking how ‘troubles’ are a product of the specific, historical and political juncture that people (both adults and children) find themselves in. For my research, the locus of ‘trouble’ is in the various educational settings that make up the educational system. Bourdieu’s notion of the field is useful in this regard.

According to Bourdieu, the educational system is a ‘field’ made up of identifiable interconnecting structural relations. There are also fields within the educational system; these include preschool, primary school, secondary school and higher education. The educational field cannot exist in isolation from other fields. “These fields within fields connect with other fields outside of education: the health service, industry and media” (Grenfell and James, 1998, p.20). Moreover, as Grenfell and James (1998) suggest:

These are structural relationships, which constitute the nature and mechanism of each separate field. Each subfield will have its own orthodoxy, its own way of doing things, rules, assumptions and beliefs; in sum it’s own legitimate means (pg. 20).

From the construction of social problems⁴ to the sound bites and catchphrases of fairness and meritocracy, through to discourses of social justice the “legitimate means of each field” that Grenfell and James (1998) discuss are systemic and ideological. Individual deficiencies and character failings, these are the trappings of and residual effects of the inadequate and unequal power relations that characterize our society. They become excuses to divert attention away from the structural realities of the educational system.
Schools are microcosms of the social world. According to Althusser (1993), schools are part of the ideological state apparatuses; they are “a certain number of realities which present themselves to the immediate observer in the form of distinct and specialized institutions” (pg. 143). These apparatuses function to sort and rank the population hierarchically and in any other number of configurations where power is active in shaping social relations. Schools produce the ‘winners’ of society as surely as they produce the ‘losers’. Thus, failure is a function of school itself; it is written into the structural architecture of the school in much the same way that learning disabled is written into the genetic architecture of the child. Values such as democracy, capitalism, neo-liberalism, heterosexuality, euro-centricity and white anglo-supremacy, meritocracy, conformity or managed individuality, equality (within limits) competition, are drilled into a captivated audience.

Bourdieu has contributed tremendously to the fields of education and sociology. According to Bourdieu and Passeron (1990) educational institutions are not neutral. On the contrary, “the culture that is transmitted and rewarded by the educational system reflects the culture of the dominant class” (Bellamy 1994, pg. 122). Bourdieu's central concepts ‘cultural capital’ and ‘symbolic violence’ developed in his and scholar Passeron’s seminal work (1990) “Reproduction in Education, Society and Culture” have contributed immensely to our understanding of schooling as part of a larger universe of symbolic institutions that produce and reproduce existing power relationships. In this study Bourdieu and Passeron (1990) focus on the French educational system, secondary and tertiary, “as an ideological practice, which serves to produce what it claims to destroy” (Miller, 2003, pg. 86).
According to Bourdieu and Passeron (1990), symbolic violence is “every power which manages to impose meanings and to impose them as legitimate by concealing the power relations which are the basis of its force” (pg.4). This violence is manifested in the fields of the educational system. In fact, for Bourdieu and Passeron (1990) all pedagogic action is “objectively, symbolic violence insofar as it is the imposition of a cultural arbitrary by an arbitrary power” (pg.5). As will become clear in my study symbolic violence plays a fundamental role in the reproduction and naturalization of the social hierarchy. In the classrooms of the educational system, the imposition of categories of thought and perceptions reinforces and reproduces the legitimacy of the social order. This is achieved so thoroughly that the dominated collaborate and participate in the reproduction of this social reality, albeit to varying degrees, because these impositions appear to be part of the ‘natural order of things’. In regard to disability, we can see how the ‘natural order’ places the disabled child outside of or on the margins of the system. Through the transmission of knowledge “educational institutions doubly impose artificially constructed objectifications because both the abstracted knowledge that is taught and the institutions themselves within which it is taught are products of the basic inclination to achieve distinction by imposing dominant conceptualizations” (Robbins, 1998, pg. 35). Disability both challenges and resists these dominant conceptualizations.

Schooling, then, is part of a symbolic process of social and cultural production. Schools advantage the upper and middle-classes by privileging their symbolic projections. These projections are forms of capital. The upper and middle-classes, as Sadovnick (2007) explains, possess “cultural capital or symbolic representations of cultural domination, such as language, ideas and knowledge music, are and literature, all
of which have important exchange value in the educational and cultural marketplace” (pg.11). At the same time, schools reproduce cultural capital unevenly among all social classes. Reproduction is accomplished by the codification of symbolic projections in the curriculum and in the symbolic violence they affect. These projections not only limit accumulations of cultural capital but also enable and legitimize such violence as being treated as inferior and being denied educational resources.

When it comes to academic achievement, Bourdieu (2007) argues that learning is dependent on a student’s ability to receive and decode information. Schools do not teach the techniques required to receive and decode culture. This skill-set, what Bourdieu (2007) refers to as practices, is largely dependent on previously acquired and embodied capital accumulations. Bourdieu (1977) explains that the embodiment of these capital acquisitions produces habitus. Habitus, as he explains, is a system of dispositions that are produced and reproduced when objective structures and personal history converge. In other words, practices are “determined by past conditions which have produced the principle of their production” (Bourdieu 1977, pg.73).

Describing neither complete determination by social factors nor independent agency, the habitus mediates between the “objective” structures of social relations and the subjective experiences of agents. Disabled children, thus, must function within objective structures, and this functioning is more or less successful, based on how their personal histories inform their attempts to function. These personal histories are embedded in the parents’ own personal history and their ability to influence the histories of their children. As Bellamy (1994) suggests, “for those students who already possess
the requisite cultural resources adjustment to school is facilitated, and academic achievement is enhanced; children who lack first degree experiences are handicapped. Thus, comprehension of secondary significations, reflected in academic achievement, becomes difficult if not impossible” (pg. 122).

Bourdieu and Passeron’s (1990) theorizing on the production and reproduction of educational structures that privilege the ruling and intellectual classes is extremely applicable to discussions of ability. The processes they describe regarding the role of the family in the acquisition and reproduction of capital can easily be applied to ability. We can apply their theorizing in terms of learning ability for both the child and the parents. In other words, we can look at ability or degrees of learning ability as constituting capital. As previously stated, academic achievement is contingent on the capital the family has available to transmit. This transmission is central because, despite claims to equal opportunity, schools continue to reproduce indirect mechanisms for social reproduction. For instance, as Bellamy (1994) suggests, “Differential academic achievement is usually perceived to be the result of differential ability, rather than as a result of the volume and cultural capital transmitted by the family; thus domestic transmissions of cultural capital is recognized as legitimate competence and is unrecognized as capital” (pg. 123).

Children who are labeled ‘learning disabled’ are therefore even more vulnerable to the mechanisms of reproduction embedded in the educational context. They are far more dependent on their parents and the family’s accumulation.

An analysis of disability as a social phenomenon is long overdue in the discipline of sociology. Disability has a history of being made sense of through a social deviance or
medical model lens, if made sense of at all (Swain, French and Cameron, 2003, pg. 34). Indeed, with the exceptions of such scholars as Goffman (1963) who writes about disability in the asylum context and Zola’s many contributions to medical sociology\(^8\) and disability rights\(^9\), not a lot has been written about disability in the educational settings of the school system. Indeed, “mainstream sociology has not taken disability seriously as a category for sociological attention” (Oliver, 1999, pg. 190). This reality, suggests Oliver (1999), is “symptomatic of the crisis that sociology finds itself in, that despite recognizing for years the problematic nature of all knowledge, it has increasingly engaged in the production of its own sociological knowledge in ways that have excluded rather than included other interests, communities or individuals (pg. 190). Indeed, sociology has a history of overlooking the ways that social institutions shape the life chances of populations labeled disabled. Further, sociology has overlooked the role that parents, particularly mother’s of children labeled ‘disabled’ play in the educational process. This is unfortunate since as Linton (1998) points out, “a disability studies perspective adds a critical dimension to thinking about issues such as autonomy, competence, wholeness, independence/dependence, health, physical appearance, aesthetics, community and notions of progress and perfection – issues that pervade every aspect of the civic and pedagogic culture” (pg.118).

The purpose of my research, then, is to demonstrate how mothers of children labeled ‘learning disabled’ negotiate with educational professionals as advocates for their children and how the process of negotiation transforms them. By analyzing the ways in which these negotiations shape people’s experiences and identities, we can gain a deeper understanding of the ways in which the disability label is experienced, managed,
constructed, negotiated and/or resisted by mothers. Applying a Bourdieun framework, including his notion of ‘game,’ I demonstrate the power that operates through this process and how the notion of ‘normality’ is sustained through educational practices such as psychoeducational assessments. The management, construction, negotiation and resistance experienced by mothers, is seen in light of the cultural and social capital they possess, and further explicated to show how these forms of capitals inform both their and their child’s habitus.

**Research Questions/Intellectual Puzzle**

According to Wendell (1996), “disability activists and some scholars of disability have been asserting for at least two decades that disability is socially constructed” (pg. 35). In other words, disability is a social phenomenon; an invention or artifact of a particular culture or society. ‘Disability’ is built upon a series of discourses, including but not limited to medical discourses. The purpose of this study is to uncover the ways in which these discourses, through educational practices such as educational assessments, both objectify and interpellate the subject of the practice. According to Althusser (1993) ‘interpellation’ demonstrates that subjects are always and already the products of ideology. However, as Foucault (1978) contends, “Discourse transmits power and produces power; it reinforces it, but it also undermines and exposes it, renders it fragile and makes it possible to thwart it (pg.100-101 as cited in Yates, 2006, pg. 70). Therefore, it is also imperative to understand the ways in which these assessments are struggled against and resisted.

Towards this goal, this study attempts to answer the following questions:
1. How do discourses of normalcy, for instance academic successfulness, appropriate behaviour, or certain ways of doing things lead to educational interventions? How do parents negotiate these difficult interventions, prior to and leading up to testing, and subsequent ‘labeling’?

2. How do parents negotiate the labeling or construction of their child as ‘disabled’? In other words, how do parents ‘read’ the assessment of their child both generally and particularly in relation to re-forming the identity of their child or, alternatively, how do they resist these re-formations?

3. How are labels such as ‘learning disabled’ used as tools for empowerment as well as tools for resistance to educational structures? Conversely, how are these same labels used to reproduce educational structures?

Review of the Literature

The foundations for educational knowledge are based on the human science disciplines of sociology, psychology, history and philosophy. Historically, literature around educational theory and educational research has developed along two major trajectories: the positivist, empirical approach and the hermeneutic or interpretive/ethnographic approach (Grenfell and James, 1998, pg. 8). Both approaches reveal something about how educational knowledge has been produced, organized and represented. Further, both trajectories, as Grenfell and James (1998) explain, “imply a specific character to knowledge and ultimately theory, deriving from activity in each of them” (pg,8). The positivist, empirical approach “which is often referred to as nomothetic since the prefix ‘nomo’ means lawful, is concerned with the natural sciences; the search for universal laws and explanation through the objective study of the world” (pg.8). The hermeneutic approach on the other hand is named after the Greek god Hermes, “whose job it was to interpret and communicate the ideas of gods to mankind” (pg.8). Here, the
focus is on “individual understanding, subjective interpretation and the acceptance of multiple realities in the world” (pg.8).

According to Grenfell and James (1998) “two important ideal types in social sciences research express the extremes of this plurality of view; namely subjectivity and objectivity” (pg.10). Subjectivity, as the authors explain, refers to individual knowledge. “It is personal; partly intuitive; affective; and may not have any direct relevance outside of the person who holds it” (pg.10). Objectivity on the other hand “is ‘knowledge without a knowing subject’, to adopt a phrase coined by a modern founder of scientific theory, Karl Popper. It transcends the individual and has a general, if not universal, applicability. The natural, normative sciences aspire to this form of knowledge” (pg.10). These distinctions are important as they manifest in the types of questions researchers can and will ask about the educational system, and the methods that they will utilize to investigate the terrain.

In the sociology of education, these two trajectories and the ideal types that underpin them are further divided into three schools of thought. These schools, Structural Functionalism, Critical or Conflict Theory and Symbolic Interactionism, while representing very different concerns, are hardly exclusive. Nor do they exist in pure form. Sadovnik (2007) emphasizes that “contemporary theories in the sociology of education have attempted to synthesize the major theories in the field, Functionalism, Conflict theory, and Interactionism and have provided a rich theoretical foundation for empirical work” (pg.17). In some cases, in fact, the scholarship emerges as sub-disciplines; in other cases, from the fruitful spaces between disciplines. Contemporary educational research has such a pedigree.
According to Sadovnik (2007), Durkheim was the first sociologist to apply sociological theory to education (pg.4). For Durkheim “education was of critical importance in creating the moral unity necessary for social cohesion” (pg.4). Durkheim’s focus on moral values set the tone for how present day functionalists approach the study of education. Functionalists see the work of schools as operating in the interests of the majority of citizens. In this view, society consists of a “system of positions or statuses, which are roughly equivalent to occupations. These statuses are arranged in a hierarchical order in terms of their importance for the preservation and maintenance of society. The positions that are the most important and require special skills for their performance are bestowed with the most prestige and rewards” (Mehan, Hertweck and Meihls, 1986, pg.3).

The notion that success is primarily the result of “personal achievement, individual effort, and hard work” is known as the “School as a Channel of Social Mobility” perspective (Mehan, Hertweck and Meihls, 1986, pg. 3).

Equality of educational opportunity, then, is ensured through the operation of a “contest-mobility system” (Turner, 1960 as cited in Mehan, Hertweck and Meihls, 1986, pg. 4) “in which virtually everyone has a chance to compete for important positions” (pg. 4). Indeed, for functionalists, “meritocracy is a laudable goal, with education viewed as a necessary institutional component in guaranteeing a fair competition for unequal awards” (Sadovnik, 2007, pg. 5). Therefore, while people occupy different positions, they all received “equivalent training, cognitive skills and treatment” (Mehan, Hertweck and Meihls, 1986, pg. 4) to attain their position. Thus, the just society, as Sadovnik (2007) explains, “is one where individual merit and talent replace ascriptive and class variables as the most essential determinants of status” (pg. 5).
The ‘school as a channel-of-social-mobility’ perspective has received much critique. One major challenge comes from the nativists who “assign greater weight to hereditary than to environment in determining life chances” (pg. 6). They subscribe to a type of biological determinism. However, as Mehan, Hertweck and Meihls (1986) so rightly point out, the nativist critique is not really a challenge to the school as a channel-of-social-mobility perspective. As they suggest, “A faith in a natural predetermination is essential to the functionalist philosophy of education. It may be true that schools provide equal educational opportunity in preparation for future life outcomes; yet functionalists also hold that eventual outcome depends solely on the individual’s inherent propensities, a position that is essentially the same” (Mehan, Hertweck and Meihls, 1986, pg 6-7). We can see how both nativist and functionalist perspectives locate disability as intrinsic to the student and not as social construction, as I contend.

Other critiques come from outside of functionalism. Functionalist theory was the paradigm in the sociology of education until the 1960’s when conflict theory emerged as a position of significant critique. According to Sadovnik (2007)

not all sociologists of education believe that society is held together by shared values and collective agreement alone, but on the ability of dominant groups to impose their will on subordinate groups through force, cooption and manipulation. In this view the glue of society is economic, political, cultural and military power. Ideologies or intellectual justifications created by the powerful are designed to enhance their position by legitimizing inequality and the unequal distribution of goods. (pg.6)

Much of the scholarship that informs my research is rooted in this school of conflict theory. Educational policies and practices, including those that impact children labeled ‘disabled’ and their families, are very much influenced by politics and economics. An example of scholarship that focuses specifically on educational issues of this type
includes Maude Barlow and Heather-Jane Robertson’s (1994) “Class Warfare: The Assault on Canada’s Schools”. Barlow and Robertson (1994) demonstrate how Canadian schools have come under immense attack in recent years. Using a range of methods, such as policy analysis, newspaper analysis, case studies and interviews, they chronicle the restructuring of public education, discursively and on the ground. Through textual and media analysis, they show how education has been framed as an underutilized commodity and an industry to be deregulated. Through myth-making and a ‘politics of blame’ they show how numerous social problems, such as unemployment, are blamed on schools.

According to the authors, North American corporations have three fundamental goals for their preoccupation and interests with schools. The first goal is ideological allegiance. North American corporations want to secure “the ideological allegiance of young people to a free-market world view on issues of the environment, corporate rights and the role of government” (pg. 79). The second goal they outline is gaining access to new markets. According to the authors, school children are the “largest untapped resource in our society” (pg. 83). It follows then that corporations want access “to the hearts and minds of young consumers and to lucrative contracts in the education industry” (pg. 79). Lastly, corporations are interested in “transforming schools into training centers producing a workforce suited to the needs of transnational corporations” (pg. 79).

Although their study does not deal explicitly with disability, it does provide an important dimension for understanding how the economic climate and the transformation of values under neo-liberalism are changing Canadian schools. Such a frame is necessary to my own research. Even though my work is interested in the day-to-day negotiations of
mothers of children labeled ‘learning disabled’, it is important to be ever mindful of the fact that there are many collectivities affected by these trends. It is not only the ‘labeled’ and their families that are vulnerable to this restructuring. The professionals that work within schools are also impacted. Indeed, these professionals are caught between the mandates of education and teaching and the expectations of corporate ideologies of the right wing.

I also draw extensively from the Symbolic Interactionist school of thought. Symbolic interactionism theories about the relation of school and society are “critiques and extensions of the functionalist and conflict-perspectives” (Sadovnik, 2007, pg 8). According to Sadovnik (2007), “the critique arises from the observation that functionalism and conflict theory are very abstract and emphasize structure and process at a societal (macro-sociological) level of analysis” (pg.8). And while this analysis is helpful for understanding “education in the big picture,” macro-sociological theories hardly provide us with an interpretable snap-shot of what schools are like on an everyday level” (pg. 8).

Symbolic interactionism has much to contribute to the study of education, both theoretically and methodologically. Symbolic Interactionism is rooted in the social psychology of the early twentieth century and views the self as socially constructed “in relation to social forces and structures and the product of the ongoing negotiation of meanings” (Sadovnik, 2007 pg. 8). In many senses, symbolic interactionism is a response to the societal level of analysis of structural functionalism and conflict theory. In fact, as Sadovnik (2007) explains, “interactionist theory is usually combined with functionalism and/or conflict theory to produce a more comprehensive theory of society” (pg 9).
Labeling theory, social constructionism and social and cultural reproduction theories all arise from the school of symbolic interactionism but remain theoretically tied to the conflict theory school. A good example of scholarship that employs the various facets of symbolic interactionism and conflict theory are reproduction theorists Bourdieu and Passeron (1990) who argue that school processes and practices reflect the interests of the cultural and social elites (Sadovnik, 2007, pg 7). A more contemporary variation of such an approach can be seen in Hugh Mehan, Alma Hertweck, and J. Lee Mehl’s (1986) “Handicapping the Handicapped: Decision Making in Students’ Educational Careers” and Roger Slee’s (1996) “Disability, Class and Poverty: School Structures and Policing Identities”. Families of children labeled ‘disabled’ have been constructed in numerous configurations. For a historical and cultural look at how families experience these constructions I also refer to Lorain Wilgosh and Dick Sobsey’s (2003) “Cultural Constructions of Families of Children with Disabilities”.

In “Handicapping the Handicapped: Decision Making in Students’ Educational Careers”, Mehan, Hertweck, and Meihls (1986) attempt to explain the processes by which elementary school students are stratified into learner categories. Theirs is a study in educational classification and educational equity and based on the study of 140 first-time learning assessments referrals. They employed numerous strategies to follow student careers through the referral system, including “reviewing official records, observing daily educational practice, videotaping key decisions making events and interviewing a number of school personnel” (pg. 41).

According to the authors (1986) whether schools make a difference in contributing to peoples’ life chances ultimately depends upon whether one sees the school as a mediator-
of-social-mobility (functionalist) or a transmitter-of-status (conflict theorist). “Mediators and transmitters may differ in their opinions about the origins of a person’s success in later life but it is evident that they share a similar opinion about the social organization of schooling. Both perspectives seem to operate on the assumption that the internal workings of schools are not particularly influential on the status that people attain in later life” (pg. 13). Mehan, Hertweck, and Meihls (1986) conclude that from both perspectives the “school exercises very little control over peoples’ lives. It is the characteristics with which people enter school that determine their position in the social order after school” (pg. 14).

What schools do exercise control over however, are students’ educational lives. Schools determine access to or exclusion from particular educational programs. Schools structure opportunity on a daily basis. This is accomplished through “prescreening teachers’ referrals, changing administrative reporting procedures, and discouraging referrals from certain educational programs at certain times of the year” (pg. 158) and the structural importance of practical circumstances, as Mehan, Hertweck, and Meihls,(1986) explain:

The most general conclusion that we have reached from this study: student identities are constructed by the institutional practices of the school. This means that designations like “learning disabled student,” “mentally gifted minor,” or “average student,” are characteristics not exclusively of student’s conduct (e.g., their talent) or those characteristics associated with social class background (e.g. the possession and use of “cultural capital”). Nor are they a direct manifestation of educator’s beliefs or expectations. Instead, they are a consequence of institutional practice (pg. 158-159).

By focusing the gaze on institutional practices that build on and exacerbate socio-economic based differences the authors disrupt many of the discourses that disguise and conceal the causes of educational classification. In these ways, their work guides and informs my own.
Another relevant work that looks how “Disability, Class and Poverty: School Structures and Policing Identities”. Slee (1996) is able to transcend borders to demonstrate how the characteristics of schools and market discourses that proclaim choice, efficiency and quality actually exacerbate the divisions of class. Drawing on examples from Australia, Britain and the United States, Slee (1996) demonstrates the intersections of poverty and disability and argues that “poverty and disability is not an economic problem, nor is it a problem of deficient individuals (Mills 2004; Ryan 1971); it needs to be set as a political problematic” (pg. 97).

Much like Mehan, Hertweck, and Meihl’s (1986) work, Slee (1996) locates disability in the social structures and institutional contexts of schools. Whereas referral and assessment processes were the focus of “Handicapping the Handicapped: Decision Making in Students’ Educational Careers,” Slee’s (1996) focus is on the actual institutional responses to and provisions for disability in the educational context. As well, Slee (1996) is concerned with the role that policy plays in reconciling “incompatible discourses of social justice and equity with antithetical languages of special education based on a medical model of disability and corporate managerialism” (pg.105).

Slee’s (1996) research provides a comprehensive and materialist reading of past and current educational responses and policy interventions. Beginning with policy interventions for the excluded and disabled, such as Poor Law legislation and disability welfare entitlements through to educational integration programs in Australia, Slee (1996) demonstrates how “the complex interaction of material (political economy) and non-material (biological factors) conspired to disable people in ‘real social and historical contexts’ (pg. 98-99). Slee (1996) argues that the replacement of segregated educational
systems by integrative and inclusive policies has only served to maintain the existing structural relations of schooling. As he suggests, “Psychologists, special educators, academics, teachers, school administrators and bureaucrats discarded old segregative lexicons and used the discourse of inclusion, equity and social justice to ply old practices into new sites” (pg. 104).

Equally important to any sociological study is attention to both historical and contemporary issues surrounding disability. In “Cultural Constructions of Families of Children with Disabilities” an article by Wilgosh and Sobsey (2003) the authors demonstrate how parents make meaning and interpret their experiences through the cultural attitudes and beliefs of the larger society. Through historical analysis and cultural comparisons, the authors demonstrate that such beliefs and attitudes are subject to change and reconfiguration. Beginning with the ideas and attitudes of Pagan and Christian myths, Wilgosh and Sobsey (2003) describe how ‘disability’ was understood through the construct of religion. Even if mothers were not blamed “for their creation, parents who protected children with disabilities were often seen as doing the devil’s work” (pg. 193). The transformation of religion as the dominant process to that of science meant that attitudes about disabled populations and their families came to be understood through discourses of breeding, purification, hygiene and genetics. Thus, as the authors point out, “People with disabilities and their families were seen as threats to the society and ‘the race’. Notions of racial superiority were clearly and inextricably interwoven with notions of disability” (pg. 193).

During the prewar era these discourses mixed with ideas about race and citizenship to gain currency in Canada. Thus, as the authors suggest, parenting a child
labeled ‘learning disabled’ in the pre-war era “was portrayed, at worst, as a source of shame and degeneracy for families, and, at best, a tragedy that families could overcome by abandoning their child to death” (pg. 197). The ideas of the eugenic era did not die completely. However, the links that were established between such thinking the holocaust facilitated the development of a shift in thinking. As a result, more families gained the courage to speak out about their families. This shift can be traced to the seminal texts\textsuperscript{12} that were published in the post-war era about parents of children with various disabilities. Some of these accounts were admissions of guilt for denying the existence of such children. The authors also provide an inventory of more current fiction and non-fiction publications to track changes in beliefs and attitudes about family and ‘disability’. They also provide a useful discussion of cultural factors that can influence not only how families make meaning of disability but how they cope with it as well.

My own research strives to incorporate the strengths of the above-mentioned research. By examining ‘disability’ as a product of education, economics, culture and history, my work offers an approach that is conscious of the effects of such constructions on the mothers of children labeled ‘disabled’. Further, my research also strives to fill in the gaps that I see in the current literature. My work does not attempt to provide a critique of current policies or practices, but instead seeks to determine the ways that ability is constituted, categorized, represented and reproduced in the educational context and the enduring and disciplinary effects of these processes on parental esteem and identity.
Chapter Outlines

The remainder of this thesis is organized as follows. The second chapter addresses the theoretical and methodological foundations that underpin this research project. My theoretical considerations begin with an interrogation of the concept ‘normal’. I then discuss other theoretical concepts that inform my work such as discourse, discipline and moral regulation. Further, I then explore some of the ethical dilemmas that can arise from the research process as well as some of the tensions of being a woman researcher in the academy. Chapters Three and Four address the substantive analysis. Chapter Three, “When the Rules Don’t Apply: Disability in the Educational Playing Field” deals with the contradictory nature of psychoeducational assessments in the classrooms of the educational system. I demonstrate how psychoeducational assessments act as a set of rules, regulations and rights and demonstrate how these can be converted into tools for empowerment and resistance to educational structures and discourses of normalcy. I also demonstrate the limitations of these texts to secure the educational interest and rights of children labeled ‘learning disabled’. Chapter Four, “What Game are we Playing? Negotiating Disability on Multiple Playing Fields” analyzes how mothers are forced to negotiate the ‘disability’ of their children on multiple playing fields. I take up persistence as a special type of capital that mothers bring to the educational game and demonstrate how being a parent of a child labeled ‘learning disabled’ is both outside the sphere of ‘regular’ parenting and outside the sphere of the formal educational system and the economic, social and health-related consequences of such games. The final chapter of this thesis provides an overview of the analysis, limitations and recommendations for future research.
Notes for Chapter One

1 According to Swain, French and Sally (2003) “professionals have viewed disabled people as tragic, deficient, and inferior and have sought to eliminate them (through abortion), remove them from society (through institutionalization), and to cure or approximate them to ‘normal’ through surgery, drugs and rehabilitation” (pg. 134).

2 According to Wendell (1996), it is the judgments of doctors, researchers, and other medical professional in particular that “operate far beyond medical institutions—inside and in relation to government bureaucracies, insurance companies, courts, schools, charities, rehabilitative organizations, and institutions for long term care” (pg. 117).

3 For instance, parents of children with learning disabilities may need to consult various doctors, therapists, school counselors, learning specialists, teachers, teachers aides, pharmacists, social workers, and community workers.

4 According to Jensen and Gerber (1993) “although public concern may precede the state creation of social problems, the primary claims making activities are conducted by politicians who have a professional stake in the social construction process (pg. 454, as cited in Anisef and Andres, 1996, pg. 85).

5 By power I mean capital, social, academic, cultural, racialized power tied to the person (by which I mean all that is physical (matter) as well as all that is outside matter (ie. the mind, sentience being, and consciousness). My intention here is not to produce or reaffirm any dualisms of modernity but only to problematize an axis of oppression largely absent and under-theorized in discussions of power and power relations and speak to these constructions to the extent my discourse currently allows me.

6 Democracy is an especially loaded and value laden term. Unfortunately, further discussion is beyond the scope of this project.

7 By captivate I mean captured not held by enchantment.


10 Here, the subject is extended beyond the disabled child to those who also inhabit the stigma of disability, in particular mothers of the child.
Indeed, as Swain, French and Cameron (2003) point out, there are ‘certain ways of doing things’ that “is presented to us as facts, beyond dispute; whereas they are really reflections of looking at the world in a particular way” (pg. 21).


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CHAPTER TWO: THEORETICAL AND METHODOLOGICAL FOUNDATIONS

In this chapter I discuss the theoretical and methodological foundation upon which my research stands. The relationship between theory and method is a nuanced one. Where theory ends and practice begins has been a source of much debate. What remains clear is that this discussion always proves productive and useful. While neither precise or definitive, this chapter has been organized to outline the contours and thinking that informed my research practice and standpoint at some very specific junctures.

The first section of this chapter takes up some of the larger theoretical concepts that inform my work. Here I explore the concepts of ‘normal,’ including the process of ‘making normal’, habitus, cultural capital, discourse, discipline and moral regulation. Following this discussion is a section on my method of data generation and analysis. The last section of this chapter deals with some of the ethical dilemmas that can arise from the research process as well as some of the tensions of being a woman researcher in the academy.

Defining Key Theoretical Concepts

Concepts of what constitutes ‘normal,’ including the process of ‘making normal’, habitus, cultural and social capital, discourse, discipline and moral regulation all inform this research project. However, it is important to note that none of these concepts exists in isolation from the other; they all function in a dialectical relationship. The first concept that informs my research is the concept of ‘making normal’. What constitutes normal is hardly stable, nor is it certain; it is a historical, social and discursive process. As Fawcett (2000) contends, “The positions of women and disabled women and men have varied over recorded time relating to prevailing economic
circumstances, hierarchical status, personal characteristics, the orientations of particular societies, the cultural dictates of the time and the direction of the religious teachings or belief systems” (pg. 15). Additionally, normality, or what is considered normal, rests on definitions of abnormality in complex and multiple ways.

Shakespeare (1994) asserts that, “when boundaries are breached, and identities seem threatened, behavior is devoted to re-establishing the fixates, reinforcing categories and power relations” (as cited in Fawcett 2000, pg. 15). We can see then, how normal is a social construction which must be shored up by reinforced structural boundaries in order that it does not threaten existing power relations. The process of making normal, while appearing as fixed, requires the constant re-invocation of professional knowledges in order to maintain its otherwise fragile boundaries (Wendell, 1996; Shakespeare 1994; Overall, 1998; Nicki 2001).

Just as what constitutes normal is subject to interrogation, so too must the concept of abnormal be examined. The ‘abnormal,’ more readily (and comfortably) recognized as ‘disability,’ is a social process that ‘reinforces’ and ‘fixates’ notions of normal, “not a condition about which we can unproblematically amass absolute knowledge” (Yates, 2006, pg. 68). In other words, disability is a function of social categorization. Like conceptions of normal, disability is a product of history, culture and discourse.

Disability has a long history of being understood as a problem of the individual and, as such, a problem for intervention and mediation. However, the medical model, according to Oliver (1999) “was rapidly followed by the formulation of a number of other models variously termed ‘medical,’ ‘psychological, ‘charity’ and ‘administrative’ models” (as cited in Fawcett, 2000, pg.17). As Fawcett (2000) further explains, “all of these models can be seen to have been influenced by notions of biological determinism and all focus on medically orientated ‘cure and
care’ agendas” (pg. 7). Efforts to change this understanding of ‘disability’ have been challenged on political, juridical and discursive dimensions.

Example of such challenges are critiques of the terms and definitions applied to disability. For instance, ‘impairment’, ‘handicap’ and ‘disability’, terms introduced in the 1980’s by the World Health Organization, were challenged as highly problematic. However, as Abberly (1998) suggests, the term “disability” represents a complex system of social restrictions imposed on people with impairments by a highly discriminatory society” (pg. 79). Barton (1998) adds to the discussion by making a very important distinction:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairment by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.

Thus, we define impairment as lacking part or all of a limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participating in the mainstream of social activities (pg. 56).

The word handicap as a descriptor of dependency and charity has also been rethought. There has been a shift from understanding handicaps as deficits in the individual to an understanding of handicaps as related to deficits within the wider social structure. According to Miller & Sammons (1999), examples of handicaps include:

*Social Obstacles*, Such as other people’s negative attitudes and behaviors.

*Personal Obstacles*, such as lack of information about one’s own disability and resources.

*Physical Obstacles*, such as inaccessible buildings, parks, or transportation.

*Resources Obstacles*, such as insufficient money, insurance, personal care assistants, employment, training, housing, or recreation (p.27).
As becomes clear, ‘ability’ and ‘disability’ are concepts which require both structural processes and category; they are both practice and subject position. Habitus, the second concept that informs my research, is the key to social reproduction.

‘Ability’ and ‘disability’ could not be reproduced without the work of the habitus. For Bourdieu and Passeron (1990) the habitus is so central to social reproduction that they theorize “habitus [to be] is the equivalent, in the cultural order, of the transmission of genetic capital in the biological order” (1990, pg. 32). Furthermore, as Harker (1992) explains

habitus ensures the active presence of past experiences, which deposited in each organism in the forms of schemes of perception, thought and action, tend to guarantee the ‘correctness’ of practices and their constancy over time more reliably than all formal rules and explicit norms…habitus makes possible the free production of all the thoughts, perceptions and actions inherent in the particular conditions of its production – and only those (Harker 1984, pg. 44).

At the heart of the concept of habitus is the idea of structure, embodiment of structure and reproductions of structure. According to Grenfell and James (1998) “Structure remains the final methodological unit of analysis but not structure in the traditional structuralism intent of uncovering transcultural patterns, but structures as a dynamic cause and effect; as a structured structure and a structuring structure. Habitus is best understood as the operational site of this dual sense of structure” (pg. 14). As they further explain, “habitus brings into focus the subjective end of the equation, field focuses on the objective” (pg. 15-16).

According to Bourdieu all social activity resembles the market place. The idea of market is a telling one. Here concepts of supply and demand, the laws of attraction, and competition have a place. In it, there is also a sense of purchasing power. As Grenfell and James (1998) suggest, “there is a sense of ‘purchasing power’, on the basis of personal resources, of gains and loss, of winners and losers. There is a price to pay, inflation, and a constant ‘renegotiation’ of the
values of the market products” (pg,20). But, as in the case of education, we do not enter the market with equal amounts of capital, or identical configurations. The amount that we hold is based on accumulations not only of economic wealth which we inherit and which becomes incorporated into the habitus. Because the habitus obscures the passage of social privileges within the family and in the classrooms people mistake these inheritances for natural differences.

Bourdieu’s approach expands the traditional and familiar definitions of capital beyond objectified forms which emphasizes material exchanges, to include "immaterial" and "non-economic" forms of capital, specifically cultural and symbolic capital. Cultural and social capital is the third theoretical frame that informs my work. In the “Forms of Capital,” Bourdieu (2007) explains how these different types of capital can be acquired, exchanged, and converted into other forms.

For Bourdieu (2007), cultural capital is the collection of non-economic resources that a family possesses, such as lineage and social class. Bourdieu distinguishes between three forms of cultural capital: embodied, objectified, and institutionalized. Embodied capital is directly linked to and incorporated within the individual and therefore cannot be transmitted automatically. This form, as Bourdieu (2007) explains, “implies a labor of inculcation and assimilation, costs time, time which must be invested personally by the investor” (pg.85). The objectified state of cultural capital is represented by cultural goods, material objects. They can be appropriated both materially with economic capital and symbolically via embodied capital. Finally, cultural capital in its institutionalized state provides academic credentials and qualifications which create a "certificate of cultural competence which confers on its holder a conventional, constant, legally guaranteed value with respect to power" (50).
Bourdieu (2007) defines social capital as "the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition" (89). Social capital is determined by the size of an individual’s relationship network, the sum of its cumulated collectively owned resources (both cultural and economic), and how effectively the individual mobilizes the network. According to Bourdieu (2007), social networks must be continuously maintained and fostered over time in order for them to be called upon quickly in the future (pg. 89).

The fourth concept that informs this work is the concept of ‘discourse’. Foucault treated “discourses sometimes as the general domain of all statements, sometimes as an individualized group of statements, and sometimes as a regulated practice that accounts for a certain number of statements” (pg. 80, as cited in Yates, 2002, pg. 70). Thus, discourse can be understood as both a practice of power and a knowledge system or systems (such as professional knowledges). As previously discussed, notions of ‘normal’ or ‘normality’ fall apart upon interrogation. The concept of discourse is an analytical tool that can help us to understand how such concepts are constructed and fixated in the first place, and to track what coercive or normalizing forces are at play. According to Foucault, power and knowledge are so intricately linked that they are therefore “best captured in the expression knowledge/power” (Thomas, 2007, pg. 37). For Foucault (1994) “What makes power hold good, what makes it accepted, is simply the fact that it doesn’t only weigh on us as a force that says no; it also traverses and produces things, it induces pleasure, forms knowledge, produces discourse” (pg. 307). Understanding the knowledge/power equation is central to understanding the various operations and achievements of discipline, however and in whatever form they occur.
The fifth concept that informs my research is the concept of ‘discipline’. In “The Means of Correct Training” Foucault (1999) explains that:

> discipline ‘makes’ individuals; it is the specific technique of power that regards individuals both as objects and as instruments of its exercise. It is not a triumphant power, which because if its own excess can pride itself on its own omnipotence; it is a modest suspicious, power, which functions as a calculated, but permanent economy (pg. 97).

The economy that Foucault refers to is embedded in various disciplinary sites such as prisons. However, this economy is not bounded to these sites. Instead, this economy stretches the bounds of physical locations altogether and interacts, acts and is constituted by professional knowledge(s). This is also evident in professional knowledge in fields such as medicine. A Thomas (2007) explains,

> Medicine has secured its influence in the education system, the media, in all Departments of State – in short, in every social domain. So pervasive and saturating are ‘public health’ concerns in contemporary society that people are charged with the self-regulation of their every movement – what to eat, how and whom to have sex, how to bring up children and so on (Bunton et al., 1995; Lupton, 1995). Rose (1990) refers to the associated development of therapies of self-help as methods for ‘governing the soul’ (pg. 38).

The application of ‘science’ to human problems legitimates discipline, such that walls are not essential to contain, restrain and retrain individuals. “Indeed, one of the most original features of Foucault’s analysis is the idea that power functions best when it is exercised through productive constraints, that is, when it enables subjects to act in order to constrain them” (Tremain, 2002, pg. 4). In other words, the infliction of corporal discipline necessary in order to punish, correct, regulate, and transform behavior is simply not needed. Instead, moralistic surveillance, control and regulation, both moral and physical, become the province of scientific, medical rationality; crystallized in the helping and teaching professions, through for instance the ‘management’ of children and adults with ‘disabilities’ (Zola, 1972; Swain, French and Sally
Indeed, as Swain, French and Sally (2003) explain, “professionals have viewed disabled people as tragic, deficient, and inferior and have sought to eliminate them (through abortion), remove them from society (through institutionalization), and to cure or approximate them to ‘normal’ through surgery, drugs and rehabilitation” (pg. 134).

Such interventions are often referred to as ‘moral regulation’. Moral regulation is the sixth concept that informs this research. As a technique of discipline, moral regulation constitutes a number of moral practices and processes. According to Kinsman (2003), moral regulation “is made up of a broad range of social discourses, institutions, ideologies, and practices” (pg. 123). Further, a key part of moral regulation is normalization, which “leads to the making normal of only some practices and ways of living and the marking of others as pathological, abnormal and deviant” (pg.125). The enforcement of normality, through “special needs classes” and the medication of learning disabilities for instance, is often informed by and through educational administrators and medical practitioners.

Moral regulation is a technique of discipline. It involves the deployment of moral discourses. According to Hunt (1999) “moral discourses seek to act on conduct that is deemed to be intrinsically bad or wrong” (pg. 7). To illustrate the point, Hunt (1999) raises the example of childrearing. As he explains, “When parents are advised by experts on child-rearing this is never simply a technical question, but always to a greater or lesser extent, includes a moral component that invests the parent with responsibility for conduct, present and future, of their children” (pg.7). In order to make this operation more concrete, Hunt isolates the following elements of moral regulation by reference to child rearing.

- a moralized subject (the parents);
- a moralized object or target (the child);
• knowledge (informal or expert);
• a discourse within which the knowledge is given a normative content (parents should monitor the television watching of their children);
• a set of practices (potty training; school attendance);
• a ‘harm’ to be avoided or overcome (poorly socialized children, undisciplined workers, etc.). (pg. 7)

Moral regulation scholarship is thus useful in rendering unnatural the “on-going processes by which the state and social agencies organize social life” (Little, 1994, pg. 235). This body of scholarship includes, for instance, the work of Foucault (1978), Valverde (1991), Little (1994, 1998, 2003), Sangster (1994), Kinsman, (2003) and Ross (2003). It can also inform our understanding of the ways in which morally-informed discourses impose notions of the ‘natural’ or ‘normal’ onto the lives and bodies of those deemed unnatural or abnormal. It is important to note, however, that these “moral rules and regulations can and will be challenged” (Little, 2003, pg. 239). In short, moral regulation is extremely useful to my work as parenting, especially mothering children with learning disabilities, continues to be one area of social life that is extremely vulnerable to public scrutiny, surveillance and judgment.

**Methods of Data Generation**

The methodology that most informs my research is standpoint. Standpoint methodology offers insight into how research is conducted and how our epistemology informs our research. Smith (1987) provides strategies for placing participants, as subjects, into sociology. An important point, raised by Smith, is that the subject must be conceived of as both knower and actor, as an "active and experiencing subject" (105). Rather than objectifying the subject, the point is to enable the subject to be both author and authority of his/her own lived experience. This "creates the space for an absent subject, and an absent experience that is to be filled with the presence and spoken experience of actual women speaking and in the actualities of their
everyday worlds” (Smith, 1987, p. 107). Feminist strategies for interviewing are especially useful for such research endeavors. I therefore looked to feminist strategies for my primary method of data generation, interviewing.

The use of interviews allows my participants to relay their lived experiences from a place of knowledge, and hopefully, of power. This is not to suggest that interviewing is always the perfect strategy for data generation. I am in agreement with Yates (2006) who states that “what people say about their situation implicitly contains a particular picture of the social world to which they relate” (pg. 70). Furthermore, interviewing, especially feminist interviewing informed by standpoint methodology, has the potential to create exchanges that are more natural and less censored than may be the case with other strategies because standpoint recognizes how difficult it can be for women (and other marginalized collectivities) to speak up and to speak out. As DeVault (1999) reminds us “It is quite difficult for most women to be speaking subjects—harder than for men— and that is true both for women as our research subjects and for us as researchers when we write and talk about our work” (pg. 83). Part of the reason why it is so difficult for women “is that language itself reflects male experiences, and that its categories are often incongruent with women’s lives” (pg.59). As a feminist researcher, I am ever mindful of my potential to reproduce such relations by the texts I pen. Disrupting such practices requires that I not only reflect on generating “data,” but also on what I do with the data once I have recoded them. Transcribing and analyzing data also requires serious consideration.

Memory cannot always be relied on. So much can occur during an interview, and what is spoken is only part of the exchange. Oftentimes, what is not spoken is just as illuminating and the pauses and hesitations, the sighs and the groans, are aspects of communication, and thus consequential. People speak with their hands and through their bodies. Posture, for instance, is a
statement about self-esteem. We need only pay attention. Tape-recording captures much of this and what it fails to record memory can accommodate. One of my strategies was to use field notes to remind me of body language or other non-auditory language that may have been missed by the tape recording. Tape-recording provides an auditory opportunity to engage with the interview material while transforming it into text.

The process of transcribing, that is turning recorded talk into text, requires considerable attention. Transcription techniques, decisions regarding interpreting, coding, editing, excerpting, condensing or polishing can all impact the integrity of the interview data. It is in this process that people’s words can be distorted or misunderstood and their lives misrepresented. Therefore, I have elected to transcribe my participants words as they were expressed. Following DeVault (1999), I “developed the rudiments of a system for preserving some of the ‘messiness’ of everyday talk. I inserted ungrammatical commas to indicate hesitations mid-sentence. I included many (though not all) of my respondents ‘ums’s’ and ‘you know’s’; I indicated outright laughter…” (pg. 78).

Some of the questions that informed data generation are the questions outlined in Appendix I. These questions were suggested starting points for understanding not only broader discourses of disability/ability, but also a parent’s role in negotiating their child or children’s learning disability. At the beginning of the interview session, I started by asking participants about themselves and to describe their families in order to break the ice. I then directed the discussion into the following three areas. First, I asked questions regarding how they, as parents, came to learn that their child or children had a learning disability. Second, I asked questions regarding their interactions with health, caring and teaching professionals and their impressions of the documentation process. Third, I asked about strategies that they, as parents, have used to
adjust to their new roles. Following these questions, I allowed for some discussion of what issues my participants found most relevant. Based on my commitment to standpoint methodology, I wanted my participants’ needs and interests to inform the direction of my research. My interviews were therefore only loosely structured to allow for the participants’ issues to more readily come to light.

After completion of each interview, a debriefing session took place, at which time I was available to answer any questions that arose during the interview process. During this time, the participants were also given full disclosure regarding what I was looking for. At the end of the debriefing, I arranged for one-on-one interviews with those parents wishing to follow up or to expand on any of the issues arising from the interview.

**Sampling Strategy**

I chose a study population of parents with children labeled as learning disabled. There were six participants in total. I recruited participants on a strictly voluntary basis. Posters, which outlined the general subject of study, were placed on bulletin boards at community centers, libraries and post-secondary institutions throughout Vancouver. All initial contact was made via e-mail, except for one participant whom I was referred to by another participant. Additionally, I used snowball sampling to facilitate recruitment of other potential participants. Although I am aware that those who volunteered to take part in this study are not representative of the general population, it is important that the participants were recruited on a voluntary basis, and I was compelled to work within that bias. Since I am a student, I anticipated only minimal power or inconsequential resource differential between myself and my research subjects. I addressed any power differentials by reassuring all participants that they could withdraw from
the interview at any time without negative impact. Four of the interviews were conducted in a room booked at one of the Vancouver Public Library (VPL) branches, one interview was conducted at the home of one of the participants, and one was conducted at a participant’s workplace. Follow-up interviews were also conducted at the VPL or in the homes of the participants when they preferred that setting.

**Ethics, Letter of Introduction and Consent Form**

Participation in this research was completely voluntary. All participants were assured that they could withdraw from the interview at any time without a negative impact. They were also informed that they could, at any time, ask for clarification throughout their participation. The issues that were discussed were very sensitive in nature. Guarantees of confidentiality were of utmost importance. All participants were given the choice to use their own names or to choose a pseudonym. All tape recordings and field notes were stored in a locked filing cabinet and computer data were password protected. Any identifying data were disposed of upon completion of this research. Tapes will be erased, and any identifying computer data will be erased. All physical copies of the same nature will be shredded with a paper shredder. After the transcription the participants were also given the opportunity to review the content of the interview and to withdraw comments that they made. All participants’ names and other identifying information were kept completely confidential and any identifying materials will be destroyed as stated above, once the data have been written up. Please see the attached Letter of Introduction and Consent Form, which ensured that ethical considerations were managed within the context of this study.
Ethical Issues and Limitations due to Study Design

An understanding of the ways that processes of assessment and being labeled as disabled shape the subjectivity and identity of individuals cannot be obtained through an analysis of psychoeducational assessment documents alone. However, interviewing those with learning disabilities, especially young children, can present its own ethical and methodological dilemmas. First, young children may not be able to articulate the ways in which being ‘labeled’ has impacted their own sense of identity. Further, interviewing children, who are in their early processes of identity formation, may be traumatic to the child’s sense of self and impact their future development. Issues of disability are often shrouded in secrecy and shame, especially for children who may already experience stigmatization in their school or home relationships.

Considering these issues, working with mothers of ‘labeled’ children can tell us much about not only the impact of labeling on their children, but their interactions with the ‘structures’ and institutions that children are subject to, but seldom active in. However, this course of research is also not without limitations, especially when understanding the nature of subjectivities. While a parent cannot be expected to provide a ‘true’ interpretation of the ways in which documents have shaped the identity of their child or children, they can talk about their experiences of the process. Additionally, parents can provide a unique perspective which is both inside and outside of the ‘processes of assessment.’ As a parent, the subject can report on not only changes in behaviour, attitude or academic success and/or failures, but also articulate their own negotiations and identity shifts that arise out of having a child or children with disabilities. Additionally, I recognize the role that the social sciences as an institution play in the ruling, managing and administering of ‘our kind of society’ (Smith, 2004) and therefore my very real participation in this ruling. As Smith (2004) so rightly points out:
Although sociological inquiry is necessarily a social relation, we have learned to
disattend our own part in it. We recover only the object of its knowledge as if that
stood all by itself and of itself. Sociology does not provide for seeing that there
are always two terms to this relation. (pg. 29)

Therefore, although the lived experiences of my subjects must be central to my research, my own
reflexivity must also be present in this research, as I am invested and can never inhabit a place
truly outside of this research project.

Uncovering my own experiences as an adult recently diagnosed with a learning
disability has led me to understand the power of assessment documents and interactions with
health and caring professional in shaping my own life. Thus, I truly cannot inhabit a place
outside this research. My desire to continue to research this area was, in some ways, a desire to
test my own perceptions against the ‘reality’ of others. I acknowledge that I therefore ran the risk
of desiring reflections that mimicked my own experiences, a longing for familiarity and
validation and confirmation. However, I expect that my experiences diverge in many ways from
those lives I study.

Method of Data Analysis

My analysis was informed by the methodological approaches of both Dorothy Smith and
Michel Foucault. From Foucault I recognize the reach of discourse (knowledge/power) to tie
certain human acts, practices, behaviors or characteristics to certain subject positions and
identity. Through discourse analysis, the objective is to “uncover evidence of the forms of
knowledge by which people are objectified, the interventions that operate upon them, the
judgments, decisions, and forms of authority to which they are subject, and the types of
relationships with others in which they are situated.” (Yate, 2002, pg.71).
Similarly, from Smith (1990) I recognize that texts (including psychoeducational assessments, memos and correspondences between offices and professionals memos, correspondences) indeed influence people’s lives and shape their realities. Texts are more than passive receptacles of neutral words. They are active in shaping both perceptions and social action. According to Smith (1990) “might be thought of as more like a crystal which bends the light as it passes through. The text itself is to be seen as organizing a course of concerted social action. As an operative part of a social relation it is activated by the reader but its structuring effect is its own” (pg. 121). Although writing about the case file, Maynard (1998) also advises “thinking of discourses as practices rather then solely as texts— or to put it another way, thinking of discourses as texts that work— is one way to capture something of the materiality of discourses” (pg. 81). Therefore, I must be cognizant of the ways in which psychoeducational assessment documents serve to shape perceptions and social action at every level of contact between parent and teaching, helping or medical professional.

In “The Active Text: A Textual Analysis of the Social Relations of Public Textual Discourse” (1990), and then again in “Texts and Repressions: Hazards for Feminists in the Academy” (1993), Smith demonstrates the organizing capacity of texts to operate as constituents of social relations. According to Smith (1990) “the simple properties of the documentary or textually-mediated forms of social organization involve their dependence upon, and exploitation of the textual capacity to crystallize and preserve a definite form of words detached from their local historicity” (pg. 211). Texts are neither neutral nor ordinary. As Smith (1990) suggests “our lives are, to a more extensive degree than we care to think, infused with a process of inscription, producing printed or written traces or working from them” (pg. 209). It is my intention to view the experiences of the parents in my study not only as embedded in values and meaning, but also
as in a historical located-ness which also serves to produce these values and meanings. In this way, I hope to ensure that contextual specificity is not stranded, obscured, or marginalized.

Thus, the framework for my method of data analysis arises from four important factors. First, I recognize that texts are active in shaping the everyday actualities of social organization and actions. Second, texts subsume, erase or replace the context that shapes them. Third, texts serve to “coordinate subjectivities or consciousness” (Smith, 1999, 195). Last, texts both universalize and objectify those who are contained within them.

When at all possible, the participants voices will speak for themselves as the acknowledgement of participants as sites of knowledge is crucial within a sociology for women (Smith, 1987). When necessary, I will bring common themes and issues to light.

Texts, Objectification and the Role of the Researcher
The academy is a generator of texts, but it generates much more than texts. I am increasingly aware that the texts and documents that I produce must avoid as much as possible the objectification of research subjects. I am ever mindful of my own positioning as a researcher in the academy. The academy, like all educational institutions, is a central apparatus to and vendor of, the relations of ruling and thus, identity formation, orchestration, and objectification itself. Research, therefore, must always be understood as an activity with the potential towards domination and objectification. Indeed, as DeVault (1999) points out, “Social scientists have become increasingly aware that writing is not a transparent medium with which researchers simply convey “truths” discovered in the field, but itself constructs and controls meanings and interpretation” (pg. 79). It is from this place, under these circumstances, and with this
knowledge that I sought out a feminist practice that destabilized these objectification processes. Such an ethic necessitates adherence to transparency and participant-centered research.

Transparency is one of the most important principles in feminist research. My work here is a project in transparency and reflexivity. Research can often begin at the entry point, the interview. Many times, the researcher/subject relationship that evolves does so through a one-way dialogue, whereby the subject is asked to disclose all, while the researcher remains opaque. I am committed to transparency in not only my written work, but in my verbal communications. The subject must be made aware of my own personal and academic investment in this research project. However, although I believe that a certain level of solidarity and co-commitment to the project is important, certain boundaries are necessary for the integrity of the project.

Cotterill (1992) makes an important distinction between ‘friendship and friendliness’ that is central to the integrity of a feminist research practice. As she states “close friends do not usually arrive with a tape-recorder, listen carefully and sympathetically to what you have to say and then disappear” (Cotterill, 1992, pg. 599, as cited in Kirsch, 1999, pg.30). Thus, while transparency is vital to a feminist project, so too is personal responsibility to the researcher/subject relationship.

Personal responsibility to the subject begins by placing the subject at the centre of the research in two regards. First, the knowledge and subjectivities of the subject must be regarded with the utmost respect. Second, responsibility to the subject must be a central component of any feminist research. By placing the subject’s knowledge and subjectivities at the centre of the research, I retained not only subjectivities, but also the biographical context as well. Further, it means a commitment to hearing what participants say, outside of my own preconceived ideas or
notions. However, it is imperative to remember that placing a high value on the subject as the source of knowledge does not safeguard against the possibility of misinterpretation. As Kirsch (1999) contends, “the politics of interpretation are never unproblematic” (pg. 58).

“One way to face the responsibility of representing others is to include them actively in the analytical and interpretive stages of research” (Kirsch, 1999, pg.59). Thus, our subjects do not simply become data, but instead continue to function in the interpretation of their own stories. In this way, not only is the researcher forced to be reflexive, but so too are the subjects encouraged in this regard. This makes the danger of objectification far less likely. While I was aware that not all subjects would be committed to involvement in the interpretation process, my commitment to my participants meant providing such opportunities for participation. At the end of each interview I conducted, I asked the participant if she would be interested in involvement in the interpretation process of my research. I proposed e-mailing the interview transcripts as a starting point for dialogue and collaboration. Only Violet expressed interest in this process. Later, she declined participation. Family and work obligations meant that she did not have the time to participate.
CHAPTER THREE: WHEN THE RULES DON’T APPLY: DISABILITY IN 
THE EDUCATIONAL PLAYING FIELD

Introduction

The educational system in Canada is often framed as a site of neutrality. Various forms of 
evaluation claim to provide an objective and fair gauge of students’ understanding, 
comprehension and mastery of a provincially mandated age-appropriate curriculum. The 
‘system’ is a product of standardization, science and rationality. Every child is imagined to begin 
in the same place, with the same chances. He or she works through the system and is able to 
secure a place in society that reflects his or her competencies and rewards his or her efforts. 
Thus, the field is often assumed to be a level one.

On the other hand, a number of researchers have shown that the educational system is 
hardly neutral; from form to content, the educational system is laden with bias (See for instance 
Willis, 1977; Curtis, Livingstone and Smaller, 1992, Lenskyj, 1994, Gaskell and Willinsky, 
1995; Dei 1996; Reynolds, 2001). Researchers have shown how myths of meritocracy, 
neutrality, equality, inclusion, and multiculturalism all mask real and persistent barriers inherent 
in the educational system. Numerous metaphors can illuminate the terrain parents of children 
with learning disabilities are forced to navigate. However, the metaphor of ‘game,’ one I borrow 
from Bourdieu (2000) is perhaps best suited.

The following chapter is organized in such a way as to illuminate what this game looks 
like, how this game operates, and who the ‘players’ are. There are two separate sets of players in 
this game; the parents and the practitioners of the educational system and granting agencies, or, 
in other words those that work for the ‘house’. The first section of this chapter examines ‘the
field’ or, in other words, the ‘system’ or network of education in which this game takes place and introduces the ‘players’. This section also provides an overview of some of the ways in which the educational system functions for the ‘normal’ child but does not function for a child labeled ‘learning disabled’. The second section, ‘Rulebook,’ provides an analysis of psycho-educational assessments as a set of rules, regulations and rights. Holding the rulebook can provide both power and restrictions, it can be converted to advantage in the game and thus can be a valuable form of capital. The last section, ‘The Professionals’ examines the second set of players, the practitioners of the educational system such as teachers, principles and psychoeducational assessors. It also examines how parents experience and negotiate these various relationships based on the capital they possess.

The ‘Field’

The Canadian educational system exceeds the classroom or even the school, school district or what we might first imagine to be a national education system. At the national level there are 13 systems of education or ministries, including one for each of the territories (Northwest, Yukon and Nunavut) which, until recently, were controlled by the federal Department of Indian Affairs. (Barakett and Clegorn, 2000, pg. 9). Unlike the provinces, these three ministries are still federally funded. At the local level, public education including curriculum comes under the authority of the provinces and territories. Generally consistent throughout Canada, the powers and duties of these school authorities are defined and mandated in provincial or territorial statutes and operate under the Ministry of Education. As Barakett and Clegorn (2000) note “there is a remarkable similarity across the country from one system to another…there is a considerable degree of consensus in Canada about what children ought to be
taught at which grade level, as well as about how they should be taught” (pg. 13). The
governing body of these school authorities consists of school trustees who are elected to office in
public elections.

The school year normally runs from September to June. Six or seven years is generally
allocated for primary school and five or six years for secondary schooling (pg. Barakett and
Clegorn, 2000, 9). In general, Canadian children attend kindergarten at the age of four or five on
a voluntary basis. Children begin Grade 1 at about six years of age. Secondary schools go up to
Grades 11, 12 or 13, depending on the province or territory. Education is compulsory up to the
age of 15 or 16, depending upon the province or territory and is required by law. From there,
students may attend university, college or Cégep studies.

From the above description, it is clear that the Canadian educational system is expansive.
However, what is not as clear are the boundaries between the educational system and other social
institutions. Upon examination, one finds that the educational system is tied to other socio-
politico systems in quite complex ways. For instance, “medical discourses and their associated
practices have extended medicine’s reach in a systematic fashion over time: medicine has
secured its influence in the education system” (Thomas, 2007, pg. 38). Indeed, the judgments of
doctors, researchers, and other medical professional in particular “operate[s] far beyond medical
institutions—inside and in relation to government bureaucracies, insurance companies, courts,
schools, charities, rehabilitative organizations, and institutions for long term care” (Wendell,
1996, pg. 117). This influence can be seen in effect through, for instance, standardization tests
and IQ testing as well as age-based curricula.

Another way that this influence is felt is through the development of Individualized
documented plan developed for a student with special needs that describes individualized goals, adaptations, modifications, the services to be provided, and includes measures for tracking achievement. It also documents the special education services being provided as these relate to the student’s identified needs” (pg. 16). These learning plans can be developed as a formal response to educational assessments such as those that are administered by school-based resource personnel or introduced as a pre-referral activity. However, for most students, as the BC Ministry of Education (2006) suggest:

> the identification/assessment phase begins in the classroom, as the teacher observes exceptionalities in learning and behaviour. The teacher responds by entering the first phase of the process, initiating in-depth, systematic classroom observation and evaluation. Further, while beginning a comprehensive assessment of learning needs, the teacher should also introduce variations in instructional approaches, evaluating the success of using such teaching techniques and instructional materials with the student (pg. 13).

If these efforts do not prove sufficient to meet the student's educational needs, the teacher then embarks on a process of consultation and collaboration with the parent and, when appropriate, the student, and consultation with a medical professional may then be suggested. School-based resource personnel will also be consulted. Further efforts may take the form of “classroom observation, additional assessment, the consideration of additional classroom intervention strategies, and implementation of those strategies” (the BC Ministry of Education, 2006, pg.13-14). While this may be the official protocol it is often not the reality. Although the route from unmet need to met need may seem straightforward, there are a number of factors which can lead the players in this game off course.

> The ‘fields’ of the educational system can be understood as a game where chance, luck, class positioning, racialized identity, sexuality, and ability all factor into the way the game is played. Simply playing your hand well and working ‘hard’ are not always the most direct routes
to success. According to Bourdieu (2000) people are not structurally constrained by predetermined life scripts; “actions (or practices) are neither mechanically determined nor the result of the creative free will” (Bellamy, 1994, pg. 126). Rather, social actors improvise, strategize and make decisions in much the same way that people play games. However, the ways in which people ‘can’ or ‘will’ act can be limited, contingent upon ‘habitus’ and where they, as the actors, are situated in the field. As, Bourdieu (2000) explains:

Habitus, is that which one has acquired, but which has become durably incorporated in the body in the form of permanent dispositions is a product of conditionings which tends to reproduce the objective logic of those conditionings while transforming it. It’s a kind of transforming machine that leads us to reproduce the social conditions of our own production, but in a relatively unpredictable way (pg. 377).

In other words, habitus is a strategy-generating principle that generates aspirations and practices that are compatible with those requirements that have already become durably incorporated. In this way, as Bellamy (1994) suggests:

the most improbable aspirations and practices are excluded from one’s repertoire of choice. Exclusion results because practices are perceived as unthinkable, and therefore not examined or as a result of double negation which “inclines agents to make virtue of necessity; that is, refuse what is anyway refused and love the inevitable” (Bourdieu 1977b, 77). (pg. 127).

Habitus is a game plan, of sorts, determined in part by individual strategy, but always informed by both the rules of the game and the player’s position on the game board.

Given the internalization of these dispositions, actions appear persuasively natural and spontaneous, making it difficult to recognize actions (or lack of actions) as a product of the habitus, of “history turned into nature” (Bourdieu, 2007). In the classroom and in terms of academic achievement, what is assumed to be an expression of ability is, in fact, intricately tied to the cultural and economic capital held and embodied by the family to
ensure its cultivation\textsuperscript{13}. For instance, children from economically disadvantaged families may not be able to expect the attendance and participation of their parents in various school and extracurricular activities. Parent’s absences from these activities may, in turn, compromise their ability to learn the rules for interacting with teachers and other professionals. This involvement, while seemingly benign, provides numerous and diverse opportunities for the child or children’s capital accumulation.

The educational system favors the values, interests and knowledge of the dominant class. Class counts. In other words “the culture that is transmitted and rewarded by the educational system reflects the culture of the dominant class” (Bellamy, 1994, pg. 122). Hegemony is produced and reinforced through the schooling process. Schools, as Wotherspoon (1998) suggests,

\begin{quote}
Are not necessarily organized to favor explicitly the interests of the wealthy and powerful over the poor and disenfranchised, but when social inequality is not discussed as a central part of the curricula and when the world is seen as a collection of individuals rather than as a system based on distinct social positions, one consequence is that prevailing patterns of domination and subordination come to be understood and experienced as natural and inevitable rather than as something to be questioned (pg. 95).
\end{quote}

Favoritism and support of dominant interests are expressed in numerous ways are well documented in the sociology of education scholarship (See for instance Ng, 1991; Wotherspoon, 1998). The ‘hidden curriculum,’ the transmission of cultural values and attitudes through the structure of teaching and organization of schools, affects all students, but it is those most economically disadvantaged who are the most adversely affected. According to Curtis, Livingston and Smaller (1992) this population is most vulnerable to tracking, to occupying the lowest streams, labeling and being disqualified from higher education opportunities, while children of privileged families tend to

49
predominate the academic streams and are more likely to be enrolled in schools better equipped to produce success. Embodied capital as a frame for analysis is insufficient. Bourdieu’s theorizing does not go far enough in addressing the problematic therefore of gender, race, sexuality, ability or other social characteristics limiting or suppressing the embodiment of capital.

Understanding education as a gendered and racialized endeavor is equally important to this project, but the central problematic that provides the framework for this thesis is that of ‘disability’. Ability, how it is framed, how it is established and how it is accommodated, has been given little attention in sociological investigations. The educational system privileges the ‘normal’ child. ‘Normal’ must be understood as a silent currency much like whiteness, heterosexuality, masculinity, or wealth. For instance, white is oftentimes “deracialized and rendered invisible in the eyes of the dominant groups” (Castagna and Dei, 2000, pg. 30). As Castagna and Dei (2000) explain, white not only represents itself “as a universal marker for being civilized” (Giroux, 1994, pg. 75) but also as being “raceless” (Fordham, 1988)” (as cited in Castagna and Dei, 2000). Further as Higginbotham (1992) suggests:

Race must be seen as a social construction predicated upon the recognition of difference and signifying the simultaneous distinguishing and positioning of groups vis-a-vie one another. More than this, race is a highly contested representation of relations of power between social categories by which individuals are identified and identify themselves. The recognition of racial distinctions emanates from and adapts to multiple uses of power in society. Perceived as “natural” and “appropriate,” such racial categories are strategically necessary for the functioning of power in countless institutional and ideological forms, both explicit and subtle (pg. 253- 254).

The notion of ‘ability’ can also be understood as strategically necessary for the functioning of power within the educational system and can thus be argued to be one of the most valuable currencies within the educational system.
The educational system is one of the primary generators of what constitutes ‘normal.’ The logic underpinning a host of decisions regarding teaching, learning, and evaluation is based on this idea of ‘normal’. Therefore, if a pupil does not fall within a predetermined range of what constitutes ‘normal’, the inability of the student to adapt or fit in is questioned rather than the parameters or organization of the system. As Wotherspoon (1998) points out, “we tend to view successful educational social outcomes, essentially, as the product of initiative, aptitude, intelligence, and other attributes associated with qualities of the individual, while factors that contribute to failure are commonly psychologized and persistent problems are regarded as ailments in need of treatment” (pg. 83). Indeed, little allowance is made for differences between students, demonstrating that inclusion is more rhetoric than reality.

We have seen thus far how, despite educational protocols, the cards are stacked against some students. The players’ positions on the game board, the currency they carry and the assumptions of fair game play all work to privilege some players over others. The exclusions that result became clear in my own research. The mothers I spoke with were quite clear about the ways that the educational system favored “normal” children over their own. The women ranged in age from 39 to 51. Their children, (those labeled learning disabled) ranged in age from 10-30 years of age. Each of the mothers had two children, with the exception of one mother, Leanne, who had one child. Some of the mothers had more than one child who had been labeled ‘learning disabled’. For instance, Violet, Simone and Abby had all of their children labeled as learning disabled. Interestingly, two of the mothers, Dalia and Denise, had children who were considered or labeled learning ‘gifted’ by the educational system.

The labels amongst the children varied. Dalia’s son Ryan had been diagnosed with a Language-based Nonverbal Learning Disability (NVLD), as well as Learning Disability Math
and Attention Deficit Hyperactive Disorder (ADHD). Violet’s son Aaron and daughter Jade were both diagnosed with Attention Deficit Disorder-Inattentive. Leanne’s son, Neil, was diagnosed with Math and General Cognitive Learning Disabilities and, according to his mom, he also suffers from anxiety issues. Simone’s son Daniel was diagnosed with Supraventricular Tachycardia (SVT), Dysgraphic, ADHD, Developmental Co-ordination Delay and a Speech disorder. Denise’s son Nathan was diagnosed with a language comprehension delay and, like Daniel, Nathan suffers from anxiety as well as clinical depression. Abby’s son Jacob was diagnosed with . However, his mom adds that Jacob also has some other issues that have yet to be assessed. He also suffers from anxiety as a result of “feeling stupid”.

All of the mothers I spoke with lived in Vancouver or the surrounding areas. Dalia, Violet and Abby had all resided in other areas of British Colombia at some point. Abby also spent some time in the Yukon with her family. Of the children, three were schooled in the public school system while five were schooled is private systems. Out of all eight of the children ‘labeled’ four were withdrawn from the school system at some point during their elementary education. One child was withdrawn to be homeschooled because of concern over educational and esteem issues; one child was withdrawn due to a school phobia; and two were withdrawn for ‘stress-management’ purposes. Two of these children were eventually enrolled in new schools by their parents.

The educational system is based on a number of assumptions. One such assumption is that children will arrive in the classroom on time with little assistance or need for accompaniment. For some children in my study, even this small assumption became a huge hurdle. One of the mothers, Leanne, recalls the anxiety her son experienced upon entering the
classroom. Leanne wanted to work with the teacher on accommodations which would lessen the anxiety her son Neil faced, but this was not possible. As she explains,

Neil has *major troubles* with transitions so to get him going, to get him moving, to get him out the door was really hard. I was also exhausted, so, it was harder for me. So to get him there, even a few minutes late, and then he had the major trouble with transitions and he had to have me walk into his classroom. And the teacher decided at one point that she had an issue with this and she came to the door and she said to me “I don’t want you walking into the classroom anymore”. That was it, no discussion, no sitting down, you know, and I just said, “Well, he won’t, you don’t understand, he won’t come in there with out me”.

Already before class begins, Neil is ‘handicapped,’ not by his ‘disability’ but by the teacher’s inability to allow for the flexibility necessary for his comfortable transition into the classroom. The enforcement of such ‘norms’ does little to enhance the well-being of children requiring assistance with transitions, and is far more disruptive to the other children in the classroom than the possible alternatives. Furthermore, the enforcement of these kinds of ‘norms’ sets the child up for future failure. Consequently, the child is faced with yet more hurdles; an uneven playing field becomes much more uneven.

Another such point of such inflexibility is that children should not wear outdoor clothing in the classroom. Initially, one might consider such an expectation to be legitimate and reasonable. On what basis does it make sense for a child to wear clothing intended for the outside in the classroom? After all, it can be argued that the classroom is a sheltered place, temperature controlled and protected. Logically then, one might argue that wearing a jacket in such a place would only serve to make the wearer uncomfortable and hot. Such thinking, however, is not neutral. It favors those students for whom the classroom climate is agreeable, both in terms of temperature and, more importantly, in terms of feelings of safety. The forced removal of
outerwear for some can be an extremely humiliating and traumatizing event. Thus, the
cclimate of a classroom cannot be defined by temperature alone; classroom climate is far more
nuanced.

Abby recalls a school incident during a period when it was clear that her son was
beginning to shut down due to the pressures of the classroom. She explains that he began to feel
stupid because of a mismatch between reading level and writing skill. While his reading was
advanced for his age and grade level, his writing was all "scrawly and backwards" and "he just
didn't feel safe”. The child had a hooded jacket that brought him much comfort, making it
reasonably easy to understand why he might not want to remove it upon entry to the classroom.
As she explains,

This was wintertime. So he would just cocoon himself in this jacket. I'd call him
spaceman. He would have his jacket on with the hood all done up, sitting there,
and I would just watch him through the door. He’d practically be in fetal position,
sitting in his class, being crushed, kind of. And then one day the principal asked
him to take his jacket off. He didn’t want to. And the principal picked him up and
shook him as hard as he could and slammed him into a chair, and he didn’t phone
me. He used to phone me about homework and this time he didn’t phone me. He
was really shaken and uhh so I had to pull him out of that school because I was
very upset with them and uhh I went to the superintendent and I went to child
protection. He had bruises on his shoulders and uhh, they basically, they, what I
realized was how vulnerable my child was. He wasn’t the sort to act up or act
smart, but he would question, “Why do I have to do this? Why do I have to take
off my jacket? Why?” And that was enough for them and he had enough going on
in his personal life. We pulled out of the town…and had a very good year there.

Here, insecurities were stigmatized and amplified. Rather than reading the child's clinging to the
ccoat as an expression of dislocation, the principal read the child's actions as defiant opposition
warranting correction. What might such a child learn from being stripped of such simple
comfort? The message is that children do not have a right to feelings of safety. Here too the
lessons are many. Mom also learns a lesson; she learns how incredibly vulnerable her child is.
Another assumption is that academic weaknesses can be simply and easily remedied by the efforts of the student. The formula for success is simply the assignment of remedial work; extra work plus extra effort equals progress. Thus, it is not uncommon for a parent to be told that their child is simply not working hard enough. However, for some children this assumption could not be further from the mark. Such charges do little but exacerbate the situation and hurt the child. Denise explains the anxieties that her son Nick experienced as a result of not being able to do the work he is assigned and the difficulties she herself faced (and continues to face) in trying to get one of her son’s teachers to agree that there is actually a problem that needs to be addressed.

And usually what it is, what happens, is the anxiety happens, is that before you notice that he is really falling down and not able to do the work he is assigned is that he becomes very anxious. He, he stops sleeping, he has stomach problems, he withdraws from the other children and stuff. And then when you really investigate it’s like “Oh, he’s not getting, you know understanding, he is not able to write to the level he is supposed to” or “He is not able to read to the level he is supposed to or something, and so”… well I remember one teacher, “Well, if you just go home and work harder, you know do some homework it would work”. And it’s like, “He is. He’s studying, he’s doing everything that he thinks he needs to be doing”.

Here the child is working to capacity but still needs support. The child is obviously trying, studying, demonstrating motivation and commitment, but his best is simply not enough. The curriculum is set and ordered, learning objectives and timelines are outlined but not with this child in mind who cannot work within such restraints. There is little flexibility but it is his inability that he experiences, not a deficit in curriculum management. Thus, not only is the curriculum developing at a rate he cannot yet meet, but as his anxiety levels rise and his sleep is disturbed, his ability to catch up, let alone move forward and learn new concepts, is compromised.
Much like ‘white’ and what constitutes ‘white’ has historically been at the centre, so too can we understand ability, functioning within a certain range, as constituting a type of cultural capital that is privileged in the school system and yet normalized so that it appears benign, if not invisible. Children with learning disabilities are constructed ambivalently in the school system. On the one hand, they are integrated into the classroom and given the ‘opportunity’ to have the same education as everyone else. On the other hand, their ‘problems’ are pushed outside of the classroom, both spatially, and socially. This is done in order to avoid disturbing a fixed system. Accommodations take place outside of the classroom, diagnoses are outside of the classroom, (although the child is allowed to be in the classroom, his/her disability is not). Conversations with teachers, therefore, are always outside of the spaces of ‘normality’ and mediated by doctors, social workers, administrators and ‘special education’ professionals.

**The ‘Rulebook’**

Psychoeducational assessment is a tool that is used to assess a student’s level of functioning based on a variety of measures. Instruments such as the Vineland Adaptive Behaviour Scale and the Adaptive Behaviour Scale are used to assess a student’s adaptive behaviour. Intellectual ability is often tested using the most current revisions of the Stanford-Binet and Wechsler Intelligence Scales. According to the BC Ministry of Education (2006) “Special Education Services: A Manual of Policies, Procedures and Guidelines”, “formal psycho-educational assessment must determine the student's level of functioning and must include information regarding academic and life skills; communication skills; sensory disorders; social-emotional development; and specific aptitudes”

(http://www.bced.gov.bc.ca/specialed/ppandg/planning_2.htm).
The assessment document refers to the results of many measures and scales. It covers many components of an individual’s functioning within the classroom and outside it. It draws on information from teachers, educational administrators, the family and, where available, other service providers. Such a document is arguably comprehensive. It can define a person and has the scientific authority to do so. However, the document does not speak about itself or refer to itself. It does not point out the rules and regulations of the educational system that it outlines. Nor does it speak about the many ways that these rules and regulations are tied to the rights of the bearer. The document is silent about the game of education; silent about the role it has to play, however contradictory. The assessment is a trump card; it permits or denies the bearer movement, access, advancement.

In this game, the ‘rulebook’ acts as a set of rules, regulations and rights. In many ways, rules and regulations can be used interchangeably. Rules are defined as a “prescribed guide for conduct or action” while regulations are defined by a set of rules or orders that are “issued by an executive authority or regulatory agency of a government and having the force of law” (Merriam-Webster Online). An important and useful distinction that should be pointed out is that regulations are always located formally whereas rules may not be.

The psychoeducational assessment defines difference by measuring and quantifying cognitive functioning. This functioning is established through the Wechsler Intelligence Scale and the results are commonly called an Intelligence Quotient or IQ. The performance of the child is then compared to other children of the same age or grade level. “One way of determining whether a child has a learning disability is to look for differences between their ability and their achievement. A child with average or higher than average intelligence but below average achievement (i.e., WIAT-II) may have a specific learning disability”
(http://www.drshred.ca/psychoeducational-assessment.php). However, psychoeducational assessments do not only define difference; they outline the rules and expectations that will govern the child’s education. In psychoeducational assessments, rules are generally referred to as expectations. Such rules, as Violet explains, are not always reasonable.

In terms of the way uhhm, this is developed, it’s developed not just as a tool for relaying this kind of information and making a plan from this information. At the bottom of it is the expectations of the student which I think is really interesting in terms of you know the educational plan. Uhhm, it says “Jade will be expected to one, develop proper use of school agenda.” So again this is kind of unsupported by the document in terms of, you know, she needs help in that area. That is something that the teacher should be kind of enforcing, right? “Arrive at every class on time, come to class with all essential materials prepared to work.” Again, that’s very difficult for a child with Attention Deficit, right. So, oftentimes one of the things that is recommended is that teachers check, do a check when they come in: “Do you have your calculator? Do you have your textbook, Do you have your paper?”

Such expectations are contradictory. The document does not assign the teacher, learning strategies assistant, or school counselor with the task of ensuring that all this skill development takes place. Unlike other children, the child with the learning disability is expected to bare the responsibility of her own skill development. As Violet explains:

You know, “begin an assignment promptly”. That’s one of the things she has challenges with, so again, it’s kind of, it’s very interesting. It’s like we will do all this but you have to do this, but it doesn’t even reflect what’s in here [points to the assessment]. “Initiate own involvement in work, seek help when required,” demonstrate an ability to assigned task”. How is she supposed to demonstrate this ability when this document says she has this disability. You know, so, I just found this really interesting in terms of the ways in which this document [the IEP] really draws on this document [the psychoeducational assessment] but also ignores it in a lot of ways and of course places the responsibility on the child. Like the teachers are responsible for the daily homework check and personal organization but she is responsible for being organized. You know there’s some contradictions there.

These rules place the majority of responsibility on the child with the learning disability.

However, these are not the only rules that are established as a result of the psychoeducational
assessment process. Some of these ‘rules’ are far less overt and pertain more to the parents’ conduct.

Parents are compelled to follow many ‘rules’ of conduct in their interactions with their children’s teachers and other educators. However, processes of assessment can transform these rules. As Violet recalls:

I could say “I told you so” without, I mean obviously I didn’t go up to the teacher and say [holds up the assessment] “Look. I was right” because I knew that I was right. You know, I don’t really think I had any doubt that, I just knew. But, it was just it was hard, you keep being told that you know, that maybe you’re wrong and you just, I don’t know I think that you it’s not that I ever doubted it, but it’s hard to keep saying “This is the way it is”. Because it does, it wears you down. Not that you don’t believe it, just that you don’t want to say it anymore, you get tired of it. So I think that reading this really made me kind of go, “Hey! Somebody recognizes this besides me”. You know, so I think that was the kind of vindication for me. You know, everybody’s going to see this now and I don’t have to say it anymore. Uhmmm because it’s here. In a way it is really a powerful tool because it means that I don’t have to fight back, you know. Like, as sad as it is, this authority [holds up the assessment] can speak to it with an authority that I can never speak to it, even though I know. You know, even though I knew these things.

For Violet, the assessment meant that she could finally substantiate her concerns when it came to her daughter’s learning situation and lay her doubts to rest.

Regulations can be understood as the element that governs access to rights for educational accommodation and adaptations. Regulations mete out rights. Regulations are built into the bureaucracy of the educational system. These regulations outline when a child can be assessed and/or whether they can be assessed. For instance, Simone is quick to make a distinction between getting an assessment and requesting an assessment:

The difference is the teacher throws out the piece of paper, which goes into the office, the office takes a look at this and then it goes to the resource team, and the resource team has to do an assessment to see if he needs to be assessed. I’m not joking. That takes, the, and, and they’ve got a tight schedule. So, we finally get the assessment to see if he needs to be assessed at the beginning of grade 3.
The regulations embedded in these assessments also outline specific strategies and recommendations. These strategies and recommendations are used to create Individualized Education Plans. This type of plan, as previously discussed, “formalizes planning decisions and processes, linking assessment with programming” (BC Ministry of Education, 2006, pg. 16) However, these plans are not always followed; parents often shoulder the responsibility of making sure that IEPs are being implemented. As Violet explains:

I don’t know, I think that it was difficult in some ways in terms of I felt like I really had to manage the situation in some ways, to not be perceived as checking up on the teacher but to be perceived as checking up on my children, so in that way you’re seen as sort of maybe an over-attentive mother, but not as critical of the teachers. When in fact I really felt like that was exactly what I was doing—was checking up on the teachers to make sure that they were doing what they were supposed to be doing. You know, in terms of ‘Did Aaron stay after class today because I know he needs extra time for math’? You know. So asking about whether he did it rather than whether they ensured that he stayed.

Denise echoed this concern.

We usually, we met every couple of months, depending on whether there was something happening that was really affecting him, usually it’d come out in social problems. He wasn’t, he’d be on his own all through recess and lunch hour, wouldn’t do any activities with kids in the class. You know or he would sort of become disruptive in the class or wouldn’t join uhm usually it was physical education or something like that, only because he didn’t understand the games. He uhh, uhm the oral instructions that were given to him were, and then he would do something wrong and he wouldn’t know why, and then he wouldn’t want to play. Well, and you can understand that. Well, so my interaction was actually, fairly, just a couple of times a year, and you always got the feeling that they were very wanting to help and wanting to set something up but outside that meeting nothing would get done because there was always other meetings, other students or whatever. And so you know we would have documents that we would write up about what was going to happen with him and in the classroom to a large extent things were done. But some of the larger overall kind of watching, overseeing what was supposed to happen I never really got the feeling that it ever happened and that was part of the reason, I think, that his IEP lapsed.
Despite the rules and regulations embedded in the psychoeducational assessment parents had many difficulties accessing the rights promised by these documents.

The psychoeducational assessment outlines rights for individuals; these must be understood in relation to the rules and the regulations however. Some regulations, like those covered in the IEP are clear. Others are not so clear. For instance, what a parent can know and what a parent cannot know about their child’s ‘disability’ is dependent upon whether they themselves have applicable credentials. The personal experience, knowledge and intuition of parents have little value in the educational system. This reality was illustrated by Violet when she stated that “this authority [holds up the assessment] can speak to it with an authority that I can never speak to it, even though I know. You know, even though I knew these things”. Simone confirmed this reality. She too was aware of the authority of the assessment document. As she explains:

This document reflects what he can’t do, this says here are boundaries, this tells me what he can’t do. Nobody has said, “Jeepers, David can do anything he wants if he is so inclined to put in the effort and the interest to retain the information required”. This document says, “David can’t read because he’s dyslexic”. It doesn’t say “Jeepers with a year of tutoring Daniel can read at the grade level”. This doesn’t say that. This says “Daniel can’t read, oh well”. This is what Daniel can’t do [holds up document]. We’ve already spent how many years listening to the school say “Daniel can’t” how about something that says “Jeepers, Daniel can do this”. This does not reflect Daniel responding to tutoring, this doesn’t say “Daniel would respond well to a positive environment where he is rewarded or praised verbally for his efforts and achievements”. This doesn’t say that Daniel can learn to function in a group setting given time, effort and patience”.

Q. And it doesn’t say Daniel’s mom and Dad know what Daniel can do.

Simone. No because they don’t care what Daniel’s mom and Dad have to say. Daniel’s mom and Dad’s opinion don’t matter to the school, they have their pieces of paper.
The assessments do not always guarantee rights either. What they do provide is potential access to rights. For instance, Ryan did not receive the accommodations necessary to be successful. As Dalia explains:

He didn’t receive the support, he didn’t receive the accommodations necessary for him to be successful. I know now I would have advocated for him to be given a calculator so he could move forward with the class, that is provide him with the adaptive equipment necessary to be successful, no different then a pair of eyeglasses. But I didn’t know that and it wasn’t suggested by the educational professionals. And at that point, that’s when life started being more and more difficult for everybody. Up until grade 2 he was able to learn how to read, still had letter reversals, he hadn’t developed handedness, he was still ambidextrous. He would do er, uhhm, certain things like make weird sounds, pakaw, paakawaa repetitive sounds and stuff which we now know is very common with Aspergers and/or Nonverbal Learning Disability, which in my mind nobody had defined the difference between the two [laughs].

According to Dalia, Ryan received a little bit of learning assistance from the Learning Assistance Centre to help him with some of the areas that he was lagging in such as math but he was not given any accommodations or adaptations. Dalia remembers being especially concerned about the fact that he could not remember his multiplication table. Dalia was not able to get her son the help he needed to advance despite the security of the ‘rulebook’. As a result, Ryan was held back. Violet’s daughter Jade was also not able to access appropriate accommodations and support, despite her psychoeducational assessment. As a result, Violet chose to home school her daughter.

She was diagnosed in second grade and at that time I didn’t feel like she was getting the support she needed in terms of rebuilding like Aaron had. Uhhm she needed that affirmation and I felt like the more we went to see her teacher the more resistant the teacher was to offering her any kind of accommodation. So, I made the decision and I pulled her out of school and homeschooled her in order to build her confidence, uhhm because I really felt like that was a crucial time where if she did not realize at that point that she was smart she would never really get it. So I took her out, and I schooled her at home. She worked through her yearly school math book within a month-and-a-half. And she finished her math before she, you know, before, the term had ended by about 3 months so she was certainly
capable but she needed the time to focus, she needed the encouragement, she needed that constant “Jade” do two questions” and she would do three questions. She needed to have it broken down because she had no confidence, so if you said “do this page of math” she would just stare off into space even if she was on Ritalin just because she didn’t believe she could do it, I mean that was one of the, that was the reason that we homeschooled her.

These assessments are trump cards: they have utility and value. They are useful but they are not foolproof. The bearers need to know how to work them. These rights are bound up in the bureaucracy of the educational system. They are at once proof that the educational system is changing and that the educational system has stayed the same. The journey to access is long and timely and not without expense.

The ‘Players’

Within the schools, parents can expect to interact with teachers, school counselors, special educators and principals, amongst other professionals. However, there is a world outside of the classrooms too, consisting of a network of professionals consulted and enlisted by the schools (and in some cases, the parents) to assist in the integration of students into the school system as well as in the processes of assessment. These professionals include special educators, general practitioners, child psychologists and social workers. The mothers I spoke with had been in contact with many of these professionals at various points in the assessment process.

When Nathan was two and a half, Denise consulted a speech pathologist. It was three years before it was determined that Nathan had a Language Comprehension Delay. Nathan had a privately paid fulltime aid to help him three days a week when he was in pre-school. The expense was shared by the pre-school and the family. In kindergarten, Nathan had an aid, but only for the first six weeks of the school year. In kindergarten, grade one and grade two his teachers were very aware of his condition, and Nathan had an individual education plan. During
those years, Deborah met regularly with the teacher and school counselor. At the end of grade two these meetings stopped. It was determined that these accommodations were no longer needed. Nathan had two psychoeducational assessments done by the school. The last one was done through a private psychologist outside of the school. Denise and her husband were able to pay for this assessment themselves.

Due to a number of health concerns, Leanne began consulting professionals early on in her son Neil’s life. Like other parents, she consulted a GP and a pediatrician. She also consulted Infant Development at Children’s Hospital, a physiotherapist, a nutritionist and an occupational therapist. Being on income assistance, Leanne also interacted with a social worker and a family worker. When Neil was in daycare he had a special needs support person. When he was six years old, halfway through kindergarten he had an assessment done. When Neil was in grade one he began to experience anxiety due to classroom expectations. As a result, Leanne was investigated by the Ministry of Children and Family Development for allegedly causing her son’s anxiety and health concerns. Later she and her son consulted a therapist to work through the ordeal and Neil’s depression. In grade three, Neil had another educational assessment, this time confirming a learning disability in math. This assessment was carried out by the school. Leanne has also been in constant contact with the principal and teachers as well as the Vancouver School Board mainly through e-mails advocating for her son. At the end of grade three, Leanne was no longer able to negotiate her son’s education with the principal and the teacher due to her own deteriorating health. She pulled Neil out of his old school and registered him in a new one. She is now in regular contact with the principal and the teacher. She describes these relationships as being far more positive for her and for Neil. However, she still feels that she and Neil would
benefit from more counseling. Unfortunately, she has not been able to afford the costs associated with seeing a counselor or psychologist.

Abby noticed that Jacob was having learning challenges when he began grade school. Abby approached Jacob’s teacher with her concerns, but she was told that it was far too early for testing. During this time it was not uncommon for Abby to receive calls that she needed to pick Jacob up from school due to his misbehaving. Frustrated, Abby pulled Jacob out of school and the family moved to the Yukon. At the new school, Abby was better able to negotiate her son’s education and had an individualized education plan put into place for him. This situation did not last very long. In grade three, Jacob was having some serious difficulties and Abby found it difficult to work with her son’s grade three teachers and the principal. At one point, she had a counselor attend a school meeting with her. She was no longer able to deal with what she describes as “hostility” leveled at her. At this point, Abby pulled her son out of school for “stress management”. A year later, Abby moved to Vancouver. After many attempts, and much frustration, Abby was able to negotiate another assessment for her son when Jacob was in grade five. Despite the assessment, Jacob was not getting the help he needed. Abby approached the principal and was able to negotiate more assistance for her son. As a result, Abby’s interactions with this teacher were far better than her previous encounters. Unfortunately, Abby was evicted from her home this year, which forced her to withdraw Jacob from school. She had to enroll her son in a school closer to her new home. Currently, Abby has little contact with her son’s teachers and principal.

Both of Violet’s children have Attention Deficit-Inattentive Disorder. It was not until the children reached school that she began to suspect a problem. With Aaron, the eldest, Violet’s mother, who was a teacher, first brought the issue to her attention. As Violet recalls, he seemed
to have trouble paying attention, but it was not until second grade that they noticed that
Aaron’s grades were slipping and he wasn’t doing as well. His teacher did not believe that he had
Attention Deficit Disorder. As a result, Aaron was not able to get an assessment through the
school. Violet and Aaron’s father consulted a child psychologist privately. Jade was diagnosed
much earlier. They had this diagnosis confirmed by the family doctor who was instrumental in
getting the psychoeducational assessment administered. Jade’s psychoeducational assessment
was carried out through the school and at her father’s request.

From the very beginning, Simone knew that her son Daniel would have some serious
issues. At thirty weeks into the pregnancy Daniel’s heart rate increased to the dangerous rate of
288 beats per minute and Simone was rushed to Children’s Hospital, where she remained for the
remainder of the pregnancy. Since Daniel was born five to six weeks premature, Simone and her
husband were warned that Daniel could very well be born blind, with Cerebral Palsy or with
Downs Syndrome. Daniel was born with none of these. Daniel’s development was delayed,
however, and Simone became increasingly worried. Simone consulted her pediatrician on many
occasions, but he assured her that her son was fine. When Daniel began kindergarten Simone
brought her concerns to her son’s kindergarten teacher. The teacher disagreed. In grades one and
two Simone consulted Daniel’s principal, his teacher and the school counselor about her
concerns, to no avail. When Daniel was in grade two the family’s GP diagnosed him with
ADHD. However, it wasn’t until grade four (and with the assistance of Daniel’s grades two and
three teacher) that Simone managed to get her son assessed and diagnosed with Supraventricular
Tachycardia SVT, Dysgraphic, Developmental Co-ordination Delay and Speech disorder.

At the beginning of grade three, Dalia’s son Ryan asked if he could return to grade two
because he couldn’t remember his multiplication table. At the time, Dalia was studying about
learning disabilities. She began noticing that Ryan presented some common characteristics of a child with a learning disability. From an early age she did notice that Ryan was a little different than other children and beginning in kindergarten it was not uncommon for Dalia to be called into school to discuss Ryan’s behavioral issues with his teachers and the principal. These interactions were often uncomfortable for Dalia. When her son was in grade three, Dalia requested a learning assessment for him. Through the assessment, Dalia discovered that her son had an above average IQ and a severe language-based learning disability. Ryan received little assistance from the Learning Assistance Centre and was not given any accommodations for his learning disabilities. Ryan continued to be a ‘challenge’ for his teachers, who complained about his extreme behaviour often. Dalia consulted her pediatrician about Ryan’s behaviour when he was in fifth grade and Ryan was subsequently diagnosed with ADHD. Dalia spent the next few years constantly struggling with her son’s teacher, the principal and eventually the superintendent of the school district to get her son the accommodations he required.

From the above, it becomes clear that the educational system is a complex system made up of many professionals. For children who are not easily able to integrate into the system, a network of professionals, many outside of the fields of education, may be enlisted to intervene. Oftentimes, these interventions are extended over long periods. Parents of such children can expect to spend a lot of time meeting with teachers, counselors and schools before interventions take place. Sometimes the parents initiate contact with these professionals over their concerns; at other times it was the schools who consulted with the parents. However, what was common to all the parents’ experiences is the time frame and the tone of these many interactions. For all these mothers the process was experienced as unnecessarily long and the interactions with professionals experienced as power laden.
Simone recalls the lengthy process she and Daniel went through to get an assessment. She recounts how she chose to behave in order to have a policy changed in the meantime.

In the meantime with the transition through grade two to grade three, I pulled strings which is, I believe also called having a hissy fit in the, in the principal’s office because his grade two teacher who was the only one that responded to Daniel and that Daniel responded to adequately, was teaching a split class in grade three. They have a policy [waives finger] you do not have the same teacher two years in a row [smiles]. I changed that policy.

Q. Hmm. You call it a “hissy fit” though, is it a hissy fit?

Simone. It’s a temper tantrum, because reasoning, going in there and saying “I have a problem, this is what it is, my child is going into grade three next year, Mr. Michaels is teaching grade three and although we know that the policy is that Daniel should have another teacher, for him it doesn’t work. The issues of him changing over creates such a level of anxiety that the first three months of schooling he doesn’t learn. He’s dealing with such a high level of anxiety and he is already at least one year and a half to two years behind, we can’t afford for him to miss more school. We would like Daniel to stay with his grade two teacher”.

“No” The only thing that got it, is me, screaming, literally screaming, crying, having a hissy-fit, threatening to phone the newspaper. When I go in there and I make demands, it wasn’t even a demand, it was a request, it was well-laid out, here is my reasoning, you have dealt with Daniel now, you know, through kindergarten, grade one, grade two, you know?

According to Simone, transitions are almost impossible for Daniel. She presented this request reasonably, explaining that allowing Daniel to stay with the same teacher would bypass a number of issues and allow him to enter a familiar, thus far more productive, learning environment. However, the school administration was not prepared to listen to her. It literally took her having to temper-tantrum. When asked if that meant she ‘behaved badly’ she stated that she didn’t think she was ‘behaving badly’ at all. “It’s the only way to get things done” she explains. As she explains:

I believe it was, they did their pushing and shoving to me in a very subtle way, “No, Daniel can’t have this, No, Daniel can’t have that, this is the way we do it, we run this fine, the road is narrow and straight and we can’t be flexible for
Daniel.” And although it is very subtle and it is very quiet, it’s very much pushing and eventually you push back. But I don’t push back subtly, I am many things—subtle I am not. I can’t, I can’t be. Because subtle doesn’t get you anywhere.

Q. So when you (and not necessarily you) are being pushed to a point where you have to respond in a certain way, all of a sudden teachers—and new teachers may start to see you in a certain light as having “behaved badly”.

Simone. [Laughs] Well we can talk about grade 4 then.

Q. Being, I don’t know, an example of a bad parent.

Simone. Yes, yes, the overemotional problem parent that “can’t let us just walk our path because that is what we want to do. And this is our school and we are going to run it our way.”

Q. Right, and everyone else falls into line, why doesn’t she.

Simone. Everybody else sits back and says “Hmm, yes, sure, okay” but everybody else doesn’t have Daniel for a child.

Q. That’s right.

Simone. You know [begins to cry] kids don’t come out in a cookie-cutter.

Q. Yes, you’re right.

Simone. You know, we’re not all gingerbread men you know, that you can decorate, you know and some will have little blue m&ms for eyes and some will have green m&ms for eyes, it don’t work that way, I can’t treat him that way and I don’t expect any child to be treated that way.

Simone was not the only mom who admitted to behaving in a certain way in order to get her child the accommodations required. In fact, this tendency was echoed numerous times, and illustrates one of the strategies moms consciously employ on a daily basis. The various strategies parents used in negotiating with teachers, counselors and principals are all forms of capital. For instance, the capital that Simone employed in the example above was based on the ‘hissy-fit’. Denise on the other hand, relies on a totally different technique in her interactions. Denise relies on what I refer to as diplomacy. She recognizes the dangers of undermining or challenging an
educator, or even the system itself. As a result, Denise is cautious about how she represents herself:

Denise. You have to be really careful about shaking up the system too, I mean, I know parents that have left the school that we’re at, for that exact reason. They have shook things up so much they’re not welcome. Teachers don’t want to see them, principals don’t want to see them, because they’re difficult parents, with difficult children. And it’s like, no they’re not.

Q. Uhhm, difficult parents, with difficult children, can you expand on that.

Denise. Well basically, they’re squeaky wheels (laughs). The administration would like them to go away and part of it is that the administration is taught that there is only so much they can do. They don’t have the resources to shake things up.

Denise went on to explain that parents have to be careful about how they talk to educators. She explains that teachers will not appreciate being told how to do their jobs. She says that parents need to learn to allow the educator to believe that they know the most about education even when you disagree. As she explains,

You have to make your case, in and around to make them recognize, er, or find their own language for what’s wrong. I can speak diplomatically, and I can speak as a parent, but I can’t say as an educator this is what you need to be doing, I have to change my language of how I am speaking. I can’t presume to know more about education [pause] even if I feel I do, which after a lot of studying sometimes you do feel like you know more, but it’s like, I respect that you’re a teacher but you haven’t studied anything for 20 years and I have done a lot of studying more recently.

From the above examples it is clear that both moms, despite using different strategies are well equipped to deal with their situations. Simone’s strategy is based on dealing with situations head-on, improvisation and creativeness. Denise’s strategy, on the other hand, is far more cautious. Her approach is calculated, intentional. Other moms who I spoke with didn’t fare as well, however, and when communication and support break down, moving schools and even cities becomes the strategy employed. Choosing another
playing field is a strategy of preservation and of last resort. It is one that Abby has used more than once. As she explains

I feel like an educational gypsy. I feel like a ghost, because of. When we just. He had a teacher, he did special ed stuff. He’s retired now, he said “You know, with a kid like him”, and he knew he was brilliant, they were doing higher math, he just said, “It’s a year to year thing, it’s a job. You can’t put up with that kind of a boss, you’ve got to move on” and that was good advice. Also, it set the precedent for bullying. When the teacher was a bully and put the kid in that position they get picked on in the playground and it was the teacher that created that whole atmosphere. His little friends stuck by him with the good teachers. Then it affected me with my peers. They were like “Why can’t you do this? It’s simple stuff,. It’s so easy, come on.”

Q. So it’s in the school where these differences come up, otherwise?

Abby. You’re just fine.

Q. The teacher has considerable power, sets the tone for how the child is going to function. It sounds like you are afraid to get involved, right?

Abby. I am a target for them. I am a total target. My file is so thick and so nasty. It is really like, “Mother did this. Mother said this.”

Another common experience among the mothers I spoke with was the disjuncture between what they expected from the various professionals they interacted with and what they actually received from these professional in terms of supports and services. In fact, the disjunctures were wide and multiple. For instance, parents expected their children’s teachers and principals to understand the difference between behaviour that expressed excitement and behaviour that expressed disobedience. Part of this expectation was that these educational professionals would actually know something about the disabilities of their students and allow for variation amongst students. However, these differences were not always accommodated and the realities of the disabilities not always understood. For
Dalia, this became most evident when her son was not allowed to go on a skiing trip. As she explains:

You see me moving in this seat right now because I can’t sit still with ADHD it is really difficult to not be moving, it’s hard to explain to someone who doesn’t have it. But we have to move. Something’s moving. And, and, and we doodle uhhm, when somebody’s giving a lecture because it helps our brain stay on, in focus, okay. There are different things that a person with a disability does to, we have learned to accommodate our disability, and we know that it helps. Ricki doodles all the time, and was reprimanded for it. And one of the most heartbreaking things as a parent was, many times, I was called from work to deal with a situation, many times I was phoning from work trying to make somebody understand the disability. I paid, as a single parent I have no money, I was scraping by, I scraped up some money so he could go to a uhhm skiing with the school, with his class. So, he’s going to go up skiing, they are going to rent the equipment, he is going to learn to ski.

According to Dalia, Ryan was so excited about the school ski trip that he was counting the days and marking them off the calendar. The day of the trip, Ryan was so excited as Dalia recalls, that he was up earlier then usual and could barely contain himself. A couple hours into the school day, Dalia received a call from the principal to come pick up her son from school. When Dalia asked “Why?” she was told that the school doesn’t have the time or the staff to deal with a child like hers who cannot control his behaviour. The principal told Dalia that if Ryan could not control his behaviour in class then there was no way that he was going to be allowed on the bus. He also told Dalia that there was no way that he would expect a teacher to have to deal with her son on a bus filled with children. Dalia explained how disappointing this would be to her son, how he had been “waiting and wanting to go so badly.” She was told that “We are not responsible for that type of behaviour and it is not our job to deal with that type of situation.” Dalia picked up her son from school. As she recalls:
He was sitting on the sidewalk, leaning against the wall, his head on his knee, he is crying his eyes out. No one should ever, ever, ever have to go through that type of experience because the professionals don’t find themselves mentally, physically, emotionally or educationally equipped to deal with a child with a disability. To me, it was the same thing as him telling me Ryan was not allowed to participate in an activity because he was blonde, because he was in a wheelchair and there was no way they were going to carry him into the bus. There is no difference in my mind. None. But they couldn’t see that, they couldn’t see that. It destroyed him, he went through so much.

Leanne echoed this experience. Neil’s teacher was not prepared to deal with children with learning disabilities or to allow for difference. Like Dalia, Leanne felt that all teaching professionals should be prepared to deal with children with learning disabilities and to be willing to work with parents to make all children’s classroom experiences positive.

His first grade teacher, was known to be a good teacher and she is so good in some ways, she is very good with kind of, I felt with regular students who did well. You could tell, just by reading, I read a report card for this, one neighbor’s daughter who did very well. It was just wonderful. “Just a joy to have in the class; da, da, da”. Neil’s was all ughh. You know, just not, no some teachers, all teachers should be able to deal with special needs children and not all teachers are good enough. And they don’t have that compassion and they don’t respect the parents. We know what is best for our kids. I mean, hello, she was also, very, very inflexible, right, it’s like this thing about, it was more important that we not disrupt the class. Well, and my suggestion, if they would have talked with me, the principal refused to help too, which, was (pauses) bizarre.

Q. What do you mean refused?

Leanne. I went to him at the beginning of the April so that I wouldn’t have to deal with the teachers and he said “You have to deal with it yourself.” I just said to him “I can’t, nothing else works.” He finally apologized, 2 years, this, a year ago, last summer, that for all the problems he felt partly responsible. But I had been fighting the school district, I just about had a nervous breakdown. And uhhm, they just wanted me to shut up and go away. A couple of other parents just pulled their kids out of school, so part of it was the principal and part of it was the teacher. And uhhm, so, yeah, so there was no where to go. Because, they have this supposedly, if you have a problem, you try to settle it with the teacher first.

Q. Right. Step 1
Leanne. Step 1, a lot of teachers, they don’t treat you like equals, peers, so, it’s uhhm, it’s uhh, their way, they’re the teachers, they’re the professionals, you know, some of them are already, uh, anyways, it was pretty awful, really awful. Neil, wasn’t wanting to, he was crying in the morning not wanting to school, it was just, so. Grade 2, grade 3 and 4 but there was, I was still fighting with them to try and get some stuff and so it made being at that school very hard. I mean I was traumatized, I couldn’t, I mean, I couldn’t even stand seeing his teacher. He is at a different school now.

Another expectation or imagined norm that these parents had shattered in their interactions with professionals was that professionals are expected to support and help parents. Instead, these parents experienced professionals as judgmental and disparaging. For instance, Simone recalls how her son’s teachers attacked her parenting skills and questioned her home life.

When you going to people you think are supposed to support you, which is your community, your doctors, who sit there and say “It’s okay dear. He’s just a little behind. Give him some time.” And you go to the teachers and they say “Well, where’s your husband. Is your husband active? Well, he needs more discipline. He needs more structure. Is he getting enough sleep. Oh I see you have packed a fruit roll-up in his lunch maybe he is getting too much sugar. Have you thought of putting him on a macro-diet, a macro-biotic diet? Have you thought about uhhm, the effects of red dye number god knows what, you know. Have you thought of taking him off preservatives?” In today’s lifestyle that’s a very hard thing to ask a family to do.

Q. That’s not cheap.

Simone. No it’s not. And I tell you at 45,000 dollars a year, for a family of 4, and you are paying for the ADHD medication, you know we were paying for the Ritalin, we’re paying for the Prozac for his anxiety. You know, it’s not cheap.

Instructed to change diet, medicate, structure and discipline, questioned about marital status and father’s involvement in the parenting of Daniel, it is clear that Simone’s interactions with health, caring, and educational professionals were intrusive and invasive. Further, these queries and instructions were steeped in classed, capitalistic and heteronormative discourses. Such examples go a long way in illuminating the virtual reach of the educational system through practitioners
who decide what’s wrong and define what is normal. Thus, for these families, “advocating,” as Dalia reflects is “a nice word for fighting.”

Once the issue the child is facing is established to be legitimate and not the fault of the family or the parents, processes of assessment are started. Because of such processes, relationships between parents and professionals can change. However, this is not to suggest that the need to advocate ends. Rather, the dynamic changes and the nature of the interactions change. In some instances the parents find that they have gained some advantage for their child through the process. A paper trail of the child also develops and, in some cases, it is the parents who are left to manage, translate, and decode the documents. As a parent’s ability to decode these documents increases, so too might the parent’s ability to ensure that professional recommendations are actually implemented and followed through. Indeed, the codification of children’s educational issues can increase the parent’s capital in numerous ways. For instance, this process can provide the parent with a vocabulary with which to negotiate. With this literacy, a parent is also better equipped to coach and prepare their children for the daily challenges of the classroom environment.

Psychoeducational assessments do not simply level the field as might be commonly believed. Thus, while this advantage is highly prized, it is important to note that such advantages cannot undo past damages. The system does not change because of this assessment; the classroom, the instruction, the curriculum all maintain their previous shape. What changes is the status of the individual within the educational system. The assessment repositions them for the possibility of success. But at the same time these assessments define and discipline their difference.
Conclusion

The educational system, expansive as it is, is much like a game. In the game of disability, parents often mothers play a peculiar role. In such a game, the psychoeducational assessment acts as a trump card, it can enable movement. However, the psychoeducational assessment, as useful as it is, is not a guarantor of rights. How assessments are used, and what they can do for the child labeled learning disabled, depends on the capital of the bearer. Even with a great deal of capital, such territory is difficult to navigate, exhausting and transformative. These mothers change as a result of their experiences negotiating this game. How they change and why they change is the subject of Chapter Three: Professionalizing Mom: Agents and Agency.
As Bourdieu (2007) explains “the length of time for which a given individual can prolong his (sic) family can provide his (sic) acquisition process depends on the length of time for which his (sic) family can provide him (sic) time free from economic necessity, which is the precondition for the initial accumulation” (pg. 52-53).
As discussed in “Chapter Three: When the Rules Don’t Apply: Disability in the Educational Playing Field” assessments and disability designations do not guarantee educational rights, nor do they level the playing fields of the educational system. The “game” that parents, particularly mothers, find themselves in, can provide a route to success when there was no such route available before. However, the fact remains that these processes are mechanisms whereby differences amongst children are defined and disciplined. Arbitrary curricula, as Bourdieu argues are ‘naturalized’ so that social classifications are transformed into academic ones and “social classifications become ‘total’ hierarchies experienced as if they were grounded in nature” (Grenfell and James, 1998, pg. 24). The same is true for mothers of ‘labeled’ children. They too are subject to classification. They too experience the symbolic violence of the fields of the educational system, albeit in different ways. This disciplining can take numerous forms and provides us with insights into the role that mothers play in cultural and social reproduction.

One cannot truly comprehend how educational structures are reproduced without understanding the terms by which parents are involved in the fields of the educational system. Metaphors are often quite useful when trying to conceptualize the reality of people’s lives. Metaphors may act as short hand terms of reference; however, this is not to oversimplify the utility of metaphors. Indeed, as Dolmage (2003) suggests “metaphors are involved in the organization of thought. Metaphors are primary in relation to our existence, as we know it” (pg.153). Metaphors borrowed from Bourdieu anchor this analysis in multiple ways and are useful to the discussion at hand. In this chapter, I look at capital in all of its configurations. Such
conceptual exercises are necessary to fill the gaps where language and concepts are deficient and under explored.

For the parents of children with learning disabilities, the group of health and teaching professionals that they encounter are experienced as gatekeepers to the help and assistance their children need. Due to these circumstances, the way mothers in my study saw themselves, as well as how others received them, changed. In other words, the mothers to whom I spoke were transformed as a result of having to play the game, to draw upon their capital resources, and to negotiate their children’s learning disability. Their roles as parents were stretched in uncomfortable configurations and sometimes even to the point of breakage. But what generally emerged was a professional, one who approximated a teacher or a guide, and who sometimes acted at cross-purposes.

This chapter captures these professionalization processes by analyzing the various aspects of the role of being a parent of a ‘labeled’ child. I locate the mothers I spoke with at the intersection where public and private fields collide, and discuss how mothers are forced to negotiate the ‘disability’ of their children on multiple playing fields. In the next section, I take up persistence as a special type of capital that mothers bring to their game. In the last section, I take up the economic and social profits and deficits of this game. I ask what are the economic and social costs of acting as an agent in the field of the educational system and discuss what I call Parental Deficit Syndrome.

**Playing on the Sideline**

Parenting is a job in every sense of the word; women turn into mothers and men into fathers. Such is the character of parenthood, at least at this particular, historical moment. Being
a parent of a child with a learning disability is also transformative. Given the skill set that the mothers I spoke with required, the work they do appears to be more vocation-like than parental. Advocating, teaching, translating, decoding— theirs is a complex skill set. Having a child who does not fit the parameters of the educational system can pose a number of challenges. Similarly, the process of securing a psychoeducational assessment can be extremely frustrating. These assessments while valuable currency in the educational system cannot always be converted into educational assistance. What they do provide is leverage for mothers to act and to continue to act on behalf of children, in other words, to stay in the game. However, it is through the many interactions and negotiations that mothers are transformed into professionals.

The work that mothers are responsible for is diverse and varied. What is clear is that much of the work they do accrues capital. However, what mothers can generate for their children is limited to the amount of the capital they have in their own right. Here cultural capital can be understood in terms of experience, instruction and training. Much like a profession, various types of skills are required. Some of the skills may build on past work experience, When work-related activities are used strategically, they become skills for negotiating the ‘game’. The arsenal of skills that these mothers in my study have available to them are quite impressive.

Violet’s skill set included making appointments and acting as a liaison between health and teaching professionals. Intervening with teachers, advocating with teachers, and translating recommendations from her child’s assessment are not typical aspects of parenting. They are learned as a result of being a parent of a child labeled learning disabled. However, this is only a snapshot of her skill set. Violet felt that her daughter really required “one-on-one intervention”
support that she was not receiving in the classroom. As a result, Violet removed Jade from
the game “in order to build her confidence”.

Mothers also play the role of coach, acting as guide, teacher, role model and
administrator of the team. Simone is equally equipped with a skill set for teaching. This comes
out in the way she has arranged her family’s living environment. Simone’s home is designed for
teaching and for learning. As she explains:

My china cabinet has no china in it. It is packed with learning tools, you know. My bread maker and my canister set up there are packed with play-doe, my flour is shoved into my kitchen somewhere beneath the cupboard and I have my play-doe up here, and my foamies and my beads so we can work on our fine motor skills and you know, whether my kids know it or not. 90% of their waking hours I am working on their motor skills one way or another.

Learning tools are everywhere on Simone’s walls: letters, numbers, colors and shapes. These are
the first things one notices when visiting her home. Simone has played a pivotal role in her son
Daniel’s development, teaching him how to read, write and spell verbally through phonetics.
When asked “Who teaches you how to teach him?”. Simone responded, “Nobody. How do I do it? It’s called the internet and you know what? There is a yahoo group for everything including parents with special needs.”

Like Violet and Simone, Denise is also very involved in her son Nathan’s education. As a
result, she also has developed an impressive skill set. For instance, Denise experimented with
various approaches to learning. She also worked through trial and error to make sense of her
son’s needs. In the process, Denise became quite knowledgeable about Nathan’s learning
disabilities as well. As she explains:

You take on a, a new, uhhm, a new course of study. You spend hours and hours reading and researching and trying things out and you become educated in your child’s learning. You really do. Ah, so I would say that a lot of parents know more about their specific child’s learning development than any of the teachers
they contact because, because you work with that specific subject on a daily basis, you know it better than anybody else does.

It is clear from the passage above that Denise has spent a lot of time becoming an expert on how to educate her son. Denise is also aware of the fact that the way she speaks to her son’s teachers and other professionals is as important as what she has to say. As she explains:

If you are not educated as an educator and you’re talking to someone in education they won’t appreciate you telling them how to do their job. So you have to be respectful of who you are talking to and what language you use and it’s very diplomatic. To allow an educator to believe that they know the most about education and make your case, in and around to make them recognize, er, or find their own language for what’s wrong is uhhm.

Here it is apparent that experience, past training, and necessity have come together to make Denise an impressive politician and negotiator. Such skills are extremely useful to playing on the sideline.

Dalia advocated for her son up the educational hierarchy, all the way to the superintendent. Dalia’s skill-set is quite impressive indeed. However, one skill she discussed was unexpected, but should not be underestimated. Dalia “baked cookies to buy friends for my son.” The ability to make meaningful connections and maintain them is central to personal development. Recognizing the importance of such connections demonstrates not only her knowledge of healthy development but also her networking skills.

The many demands of being a mother of a child labeled ‘learning disabled’ left many of the mothers in my study feeling stressed and in need of guidance and support. Much like a job, training and instruction are required. However, because of the precarious nature of the work that these women do, there is no infrastructure for training and professional development. They are
required to be skillful, improvisational and inventive. They simply ‘make do’. For instance,

Violet found support and guidance from her mother and sister. As she states:

If anything it was my mom, you know I talked to her a lot and my sister just said, you know “As a mother you know best, you have to trust that, you have to trust that instinct, you have to advocate for them because they can’t advocate for themselves.” So she really encouraged me to move up the system.

Other mothers, such as Denise, relied on relationships with other mothers to “share strategies” and support. Simone, on the other hand, sought information and support through the internet. Her search resulted in her becoming involved in a support group. Mothers who seemed to handle their jobs best had more advisers available to them.

Despite the inventiveness and creativity these mothers demonstrate, it is apparent that the job of being a parent of a child labeled ‘learning disabled’ is a difficult one. Unlike other jobs, this one provides little training and instruction. It is a game where you are forced to learn the rules as you go. Everything is learned on the job. Like parenthood, there is a sense that you are never fully prepared for the position. As Denise suggests:

You go into it completely cold without any training for it. There’s, you know, you always say there’s no parenting manual, well that’s for the basic, average child that doesn’t have any problems, but there’s no appendixes for educational problems, or behavioral problems or physical problems or illnesses. You know those are all, you know if your child has any one of those you start all over and, you know find what help you can.

**Profits and Deficits**

The work of being a mother of a ‘labeled’ child is a difficult one. These skills cannot be taught nor can they be learned in a classroom, they are the product of the habitus and all its capital accumulations. There is no workplace for these mothers to go to, no place to escape from. They are at once in the system and completely outside of it. They work in the spaces where
public and private worlds collide. They have no colleagues and no superiors. Supports are not always in place. There is no training, instruction or feedback for the position they find themselves in. There are no manuals and no guidebooks to prepare them. Laboring under such conditions is trying. In economic terms, their work does not pay and yet the costs to these mothers are many: they are economic, social and health-related.

There are numerous economic costs associated with the work these mothers do. Some of the mothers I spoke with indicated that they experienced a financial burden as a result of the problems their children encountered in the classrooms of the educational system. These were not regular expenses. Rather, they were expenses that came from the advice they had received from teaching and health professionals. Simone’s family was surviving on her husband’s modest income. Despite their limited income, they paid for their son to experiment with numerous therapies. As she explains:

We went macro-diet, we took the preservatives out of our diet. We went 100% natural, now, number one on our income do you know how hard that is? It made absolutely no difference. And you know, “Well, maybe you didn’t do it long enough?” Well You know what? I did it for three months, it was hell, for me, for my children, for my budget, if they would like me to go on a no preserve, no artificial, 100% organic diet they can pay for it. It makes no difference. I tried it, you know, we tried it, you know, Tomatis Auditory Training, another joke, 3000.00 dollar investment, but it was, you know, it was something we did out of pocket because one of the resource teachers at school had said too, you know it’s a hokey thing, it’s like acupuncture, which by the way we’ve tried too.

Simone put her complete trust, as well as her bankbook, in the hands of the professionals. However, there was no return on the investment.

Abby also felt the economic costs. Unlike Simone, who invested in alternative therapies, Abby’s expenses came as a last resort on the advice of a counselor who suggested that she move her son to a new school. Her relationships with her son’s teachers and the school principal
became so strained that she felt she had no choice but to relocate from the small town where

she and her family resided. As she explains:

When I brought the counselor in as witness to what was going on she quit her job shortly after that, after a few other incidents in that little town. And she was shaking her head just telling me to bite my tongue, “Don’t say anything, let’s just listen, let him put his foot in his mouth, let’s just see where he takes this”, she was so mad at the end of it. She just, she realized that I wasn’t the one that was off. She was like “Get out of town this isn’t going to work for you, this isn’t working for either of you”. And my son said “Mom, I want democracy” So I had to leave.

Abby left everything behind for this new start for her and her two sons. She wanted to give her sons “democracy” through a new start. The move was expensive. As she states, “So many treasures, you leave empty-handed. These included “good jobs, a nice house, and beautiful furniture”.

Maintenance of scholastic gains also translates into financial expenses for these mothers. For Simone, it translated into tutoring at the Disability Resource Centre for Daniel in addition to all the work she does with him on a regular basis. However, for Denise maintenance has been far more expensive. Denise did not feel Nathan could wait until the middle of fifth grade for an updated assessment. This meant that Denise and her husband had to pay out of pocket for his latest assessment. As she explains:

The only reason he had this last fall is because we decided to uhhm pay for it privately to have it done. Because last spring it was well the psychologist that does it is monitoring three different schools and she is not going to be able to get to it at the earliest, until December. And I was like that’s halfway through grade 5 we need to get it done at the beginning of grade 5 so we know how to structure the year. What intervention does he need to make it through grade 5. If not, He, he would haven been lucky to start the testing right now, he wouldn’t have his IEP back in place this year, he would uhhm, he was uhhm, basically the psychologist said he was clinically depressed (she begins to cry) by the end of grade 4. (pause) Hmmm, and so (tries to compose herself) he would be losing most of the grade 5 year. (begins to cry again).
It is clear that Denise could not afford not to pay for this updated assessment. She had serious causes for concern. Not only would the year be compromised but so would Nathan’s mental health. For Nathan, an updated psychoeducational assessment has made all the difference.

The intensity of the game requires a serious time commitment and this is not a paid position. While it was not a possibility for all of the mothers I spoke with to stay home, some did lament over not returning to work. Violet, Simone, Leanne and Denise were all fortunate enough to stay at home. However, their situations were very different. Leanne struggled below the poverty line, due to her inability to work. Violet and Denise, on the other hand, had partners who were able to support the household on their wages. For Simone in particular, staying at home meant a severe loss to the household income. Abby and Dalia were in a similar situation. Being single parents, they had no choice but to work in the paid labor market.

Of course, not being able to return to work was only the tip of the iceberg for the mothers who participated in my study. The social costs of playing multiple roles are many. These costs far exceed any financial expenses associated with being a parent of a child labeled ‘learning disabled’. Even the loss of income and status cannot compare to the social costs paid out by these mothers. The social consequences of such work compromised the self-esteem and parental identity of these women in diverse and varied ways.

Mothers who fell outside of the ‘norms’ were themselves framed as less normal than, or inferior, to other parents. They therefore fell short of the criteria that frame them as effective parents. Moralizing discourses were not always explicitly expressed to the mothers I spoke with. However, the sentiment was clear enough for them to decode. Many of the mothers I spoke with were told that they were bad parents in one way or another. For Dalia, the message was implicit, and manifested in the guilt that she oftentimes felt. As she explains:
As a parent, you carry guilt. As a mom could I have eaten something different, could I have done something different, why do I have this child who’s not perfect, if there is such a thing. But that’s, I mean that’s how your mind is working, well, you’re trying to think “Wow, what did I do wrong, what could I have done different?” Then because of our ignorance of the disability we look to the professional, and if the professional is sort of putting it back on us that it is something we are doing wrong then that guilt is increased, and our stress is increased. We don’t want to share with other people because, I don’t want to tell you “I am so imperfect, I’m not a great mom because, look what I’ve raised”. And now the professional is telling me that you know, I should have maybe done something else, and why don’t I do this and then I go back to them and I tell them “I am” but they don’t believe me, and it goes back and forth. So it’s this guilt thing, it increases and you feel, inadequate as a parent, if I knew then what I know now, it wouldn’t have been as big an issue, but I was very ignorant then about disability, and didn’t know “Ahhh, it wasn’t me”.

Simone’s parenting skills were challenged in numerous ways, but the messages were far more explicit. For instance, she was questioned about the structure of her home life, how she disciplined her children and whether her husband was active in son Daniel’s life. As she explains:

I was being told “You’re not a good parent. You need to change things at home, his behaviour is your making”. It was made very clear to me. You know, especially in kindergarten, “He needs more structure. It’s your family life” [pauses]. “Well, it, does your husband, you’re married? Does your husband spend a lot of time with the children? Oh, well, maybe he needs more recreational activity. Have you thought about having him join a sports program?” We can’t put him in a program like that because of his disabilities. “Well are you sure? Have you tried?” It’s like, you know, yeah, I’ve tried, you know, would you like to spend the next two hundred dollars on his equipment, when he can’t attend because it is frustrating for him? You know, we would be happy to try again if you pick up the pieces of his little broken heart when he can’t cope and he’s kicked off the field. Yeah, they look at the parents. “Well, is your husband active with him? Well, does your husband participate”. Honey, before you start asking why don’t you come over for supper and take a look at my house.

The type of questions Simone faced illustrate how that her ability to be a good parent was challenged by the teachers and other professionals. From the passage above it is clear that all facets of Simone’s life came under the microscope and that she was blamed for her
son’s challenges. What is not particularly surprising however, are the insinuations regarding the families’ home life and her husband’s involvement in her son Daniel’s life.

The private lives of parents of children with learning disabilities and that of their children became open to public scrutiny, surveillance, and assessment. The standards by which these lives were scrutinized and assessed, while framed as value-free, neutral, objective and enlightened were subject to narrow, eurocentric, capitalistic, patriarchal, bourgeoisie values and ideals that are informed by the normalization and naturalization of capitalism, hierarchy, inequality, heterosexuality, gender and nuclear family forms.

Mothers’ marital statuses were actually an important factor in the equation when it came to how expensive the social cost to the game. It was not uncommon to hear single parents blamed for their children’s challenges in the classroom. For instance, Violet’s separation from her husband meant that the professionals she interacted with as well as others believed the issues her children experienced were due to the separation. As she explains:

I just kind of, I felt like everybody thought I was in denial because I kept saying “No, it’s not that they’re not bright enough, it’s not that they’re not trying hard enough” you know. But, the frustration for me before Aaron was diagnosed was that he would come home, you know, in tears everyday, you know saying, “I’m stupid. I’m stupid you know I can’t do it.” And he would just get frustrated we would do his homework and he would be sitting there just paralyzed. You know and so that was the frustration and that was what really broke me to push and to continue to push to find out what was wrong even through people kept saying “There’s nothing wrong. He just needs to get some confidence”. And a lot of it was attributed to the fact that their father and I split up uhhm during some of this time. So a lot of that was you know kind of attributed to their, like, not when my son was being diagnosed but when my daughter was, so, there was this kind of you know, “She’s just not doing well because there is trouble in the home” you know, so there was kind of a lot of blame, you know.
For Leanne, poverty and a general lack of support combined to make her especially vulnerable to the social microscope. As she explains:

I found out that I had actually been investigated before and no one told me. I had to fight and fight and fight for an apology. They sort of gave me a general apology but not much. It was really quite awful and totally traumatizing, traumatizing. Because if I could be, if I could be investigated, if anybody could think that I was causing my son’s problems, that’s sick. But if I had money enough, if I hadn’t been on welfare and I you know didn’t need their support, because I didn’t have enough money, then I would never have been investigated.

It is clear that, for Leanne, the costs were even more because the accusations more extreme.

For many of the mothers I spoke with, experiences accumulated into poor self-esteem and compromised parental identity. For instance, Abby got to the point where she would no longer enter the school. Even though, as a parent and as a taxpayer, she was entitled to enter the school, the humiliation and institutional assaults she suffered beat her down and made her doubt herself. As she states: “Well, I had to back off and not go to the schools again. I don’t go there. I don’t go in, I mean I go in to say ‘Hello’ but before I had to be there quite a bit and I don’t know I don’t want to go to the schools. The confidence, it’s really been knocked out of me because when I start talking about something, I wonder am I ranting, do I sound sane?” For Dalia, the many pressures of being a parent of a child labeled ‘learning disabled’ and having to do it alone made her feel considerable guilt. As she explains:

I had such horrible, horrible guilt. I used to imagine in my mind if I had a child that wasn’t so disabled what life would have been like and then I would, and then I would get sick to my stomach about it. And I’d be upset because he may not be somebody else’s idea of a wonderful child but he’s mine, and I loved him to death and I wouldn’t want him any other way. But honestly, some days I really didn’t know how I was going to get through.
It is clear that both Abby and Dalia’s parental identity suffered tremendously.

Another social cost to the mothers I spoke with was the consequences of advocating for their children. These mothers become the parent to be avoided. They become “the bitch in red lipstick,” as Dalia explains:

So what do I do? I go to the school, I argue with the teachers, I argue with the principal and I am the bitch in red lipstick. I am that person that they can’t stand, they are sick of seeing me they are sick of listening to me. They don’t understand and I don’t understand because maybe I am not advocating correctly. But what is not being communicated between these two parties is that this child needs some supports and needs somebody to be there for him. The only person that is there for him is his mom.

Simone is also familiar with feeling like the parent to be avoided. Simone has become a “problem”. As she explains, “I’m a problem, I’m a nuisance, I’m a flea. Fleas you swallow. You take some bug spray, you spray it, getcha outta here”. Leanne echoes Simone’s feelings.

However, unlike Dalia and Simone, Leanne uses language that indicates personal transformation. She uses the word “have become” to describe her current state. As she explains,

I have become a pest, and I am stressed out to the point of behaving in ways I normally wouldn’t. Okay, now I understand all that, at the same time I understand all that but these guys are supposed to be the professionals dealing with this and I can see what they’re supposed to be doing and they’re not doing it and they’re blaming me.

It is clear that these interactions are costly. What is also clear is that these interactions are transformative for the women. The mothers I spoke with were transformed, albeit in different ways, by the game of being a parent of a child labeled ‘learning disabled’ and by the conditions that they laboured in.

The social and economic costs certainly impact how mothers are able to play the game, both within the educational system as well as outside of it. Further, sometimes the costs are even more debilitating, resulting in loss of health and therefore ‘sidelining’ the parent or
‘handicapping’ them even further. All of the mothers I spoke with indicated that they had suffered some physical, psychological or emotional expense. For instance, Leanne’s struggles with her son’s teachers and other educational professionals, in addition to her struggles with the Ministry, compromised her health. As she explains,

So we’re just now starting to really pick up the tools. So he’s in grade four, I’m getting some, as long as I have some time, this is my time where I hope to relax to put things in perspective and heal, uhhm because there has just been, I have just been getting, I have been getting [pauses] okay.

Dalia’s health was also compromised. For her, the combination of poverty, stress and lack of support resulted in Chronic Fatigue Syndrome. As she explains:

At one point I found myself standing, hovering over top of the superintendent of the entire school district, with finger wagging in his face. And it was as though I had woken up from a dream, I was in such a high state of stress that I was advocating for my child at all levels of authority trying to get him the services that he needed, fighting with the superintendent, saying “He’s not a bad person, you’ve just got to understand that he is dealing with a problem”. And uhhm I was not as well versed as I am now on the disability. I was not able to present my case as well I could do now. So here I am wagging my finger in his face and I sat back down in the chair and I thought I’m at a breaking point. So, I went home and took a leave of absence from work. It was very stressful. I, actually ended up getting pretty sick. They diagnosed it as Chronic Fatigue Syndrome, so I was really sick for about two years, my immune system was impacted. I think it was, number one stress.

Faced with many of the same challenges as Dalia, Simone recalls reaching an “emotional low”. As she states:

I reached an emotional low, you know. I had it. My budget was broke, my, you know, at that point we had David on medication for ADHD, Concerta, a totally expensive medication. Okay, you know, my budget is broke. I’m looking for a job I can work somewhere between 9am when I drop my kids off and 3pm when I pick my kids up so that I can pay the, help my husband pay the bills, but still be available to Children’s Hospital, to the pediatrician, to the dentist. My children have lives outside of school and so do I and still manage to maintain it, but it’s impossible. And I hit an emotional low.
Persistent players

Despite the many costs associated with this game, the mothers I spoke with demonstrated extraordinary tenacity and personal strength. They were persistent, relentless, and unapologetic in their pursuits. The fact that many of them were so poorly prepared for the work of being a mother of a child labeled ‘learning disabled’ and so precariously positioned in the educational hierarchy did not deter most of them. As previously mentioned, these mothers are positioned at the intersection of the public and private sphere. Their activities are both outside the sphere of “regular” parenting and outside the sphere of the formal educational system. Unable to rely on credentials or professional associations as can other professionals made their work that much more difficult. For instance, Leanne had to do much of her game-playing through e-mails. Over a three and a half year period, she sent over 1500 e-mails. This may seem a bit excessive; however, she was clearly unwilling to stay quiet when it came to representing her son’s best educational interests. As she states:

I am not going to shut up! Because you never dealt with what you were supposed to deal with, okay. I am not just going to go away because you’re the guys with the power and the control. So, I’m kind of [pauses] the thing is too, there is a point though, you know, where, probably, so you need to but at the same time don’t you guys understand the psychological, emotional, but no, of course not because they’re the bureaucrats right, we’re the parents.

Simone also employed some unusual tactics: she staged a sit-in in the school office. She did this for a week. It is clear that she was also not willing to take “no” for an answer. As she explains:

I am Daniel’s first line of defense and his last line of retreat. If I’m not there nothing happens… you can’t take no for an answer. It’s the only answer they’ve got, I can’t accept it. I can’t. I can’t. So I sat there till 3 o’clock I never did see the
principal the first day. When I went to the bathroom they moved the seat outside into the hallway, so I said “Excuse me and went back into the office”. They got mad at me and asked me to leave and I said, “Well. Where’s the principal? I need to have my chat”. I never did get my chat the first day so I went home and I started phoning Mr. Smith. And I started phoning him 3 times a day. I came home and cried, came home had a couple drinks, came home smoked my lungs out. But went back to school in the morning. I put my face on put my smile on and went in there.

Taking ‘no’ for an answer was simply not an option for either Leanne or Dalia. These women managed to keep both worlds from collapsing in on them and their families. For some of the mothers, being the sole provider of the household meant straddling yet another world, the world of paid work. As Dalia explains:

Everyday you get up in the morning and you do it again because what are you going to do? You can’t curl up, how was I going to feed them? I was so poor, I counted the slices of bread to make sure there was enough to get through the week. We were so poor that if you came over for a cup of coffee then I knew that I wasn’t going to have enough coffee for each morning for that month, right? So, there’s, you just get up. You have no choice, you get up, you do what you do and you know that your child is going to benefit because of your strength and you know your children are going to benefit because of your ability to say, “I’m going to go to school, I am going to further my education so that I can get a better job so I can have more money and at least have milk”. Because he had ridges in his nails from lactosium the doctor told me and I wasn’t able to afford milk, right? I fed them powdered milk but they needed more than I was giving them. They needed more fruit from what they were getting and I wasn’t able to provide that unless I had a job. So you know, as a parent you are looking at raising your children, getting them shoes that fit their feet and all those sorts of things that parents worry about, you worry about every little thing, and when you have a disabled child it, it’s overwhelming.

**Parental Deficit Syndrome**

Given the many expectations, stated and implied, that the mothers in my study faced with it is not surprising that, at one time or another they should experience a sense of failure. The ‘game’ that these mothers play is not always winnable. Much like the ways that the educational system has set up certain types of learners as disabled, so too are these mothers set up to experience their selves and their efforts as somehow deficient. What drove all these mothers was
the high value they attached to the importance of education. The classrooms of the educational system can be places of brutality and humiliation for those who do not neatly fit the mold. For those students and moms situated outside the mold, positive self-esteem and mental health were at risk of deterioration.

All the mothers in my study could speak to these expenses and to the absolute necessity of protecting their children from such systemic realities. Denise’s son Nathan suffered depression as a result of an outdated individualized learning plan and lack of educational concessions. If Denise and her husband had not been able to pay for an updated educational assessment, Nathan would have not made it through grade five. As she explains,

He wouldn’t have his IEP back in place this year and he would uhhm, he was uhhm, basically the psychologist said he was clinically depressed (she begins to cry) by the end of grade four. (pause) Hmmm, and so (tries to compose herself) he would be losing most of the grade five year. (begins to cry again).

Abby’s child Jacob also suffered mental duress and poor self-esteem as the result of the educational system. As she explains, “He would wake up screaming. It was awful. He would be screaming out in his sleep and grinding his teeth. I am watching him kind of get more spacey, he is kind of going into his head a little bit.” Like Abby’s son Jacob, Dalia’s son Ryan also suffered tremendously. He suffered right through to adulthood and spent years doing drugs and “basically living on the streets.”

Mothers’ abilities to navigate the terrain of the educational system are an expression of their accumulation of capital in much the same way that their children’s ability to navigate the classrooms of the educational system is based on their own capital. Sometimes this capital was class-related. At other times, it was education-related, and in some cases it was a combination of both. Whatever the measure, capital played a role in the success or ‘failure’ rates of these
mothers. For Simone, success was facilitated by a teacher who believed in her son’s abilities and set a bar for his success. As she explains:

> We’ve got a teacher that says “Okay”. David was on a modified school-plan, she sat down with him and at the end of September she sat down “You know when it is a full class room we have trouble, but when I’ve got 2 minutes and we go to the back of the classroom where it’s quiet, and we go over it, he gets it, he can understand it, David can do this.” Do you know how that makes me feel? Just to have a teacher that’s on my side, she says “Yes, he is on 100% modified program, my goal is to get him on a 100% adapted program and we’re almost there”. Because, I’ve got a teacher that will show up a half-hour early for all of her students. She is in her classroom at 8:30 for all of her students. All of them. Not just David every one of those students. She does her job well. She’s not a lovey-dovey cuddly teacher, she teaches grade 5, she’s teaching these children social responsibility. You know she’s teaching them to be responsible for their own actions. David’s behaviour has changed dramatically because she sets standards but she understands these children and she says “David we’re having a group meeting, you have to act age appropriate.”

I’ve got a different kid this year. I have a teacher that cares. A teacher that has an understanding of the learning disability. Maybe it’s due to her own private experiences, yes, but she’s informed, she speaks to me with respect and demands the respect back which I have no problem giving her. And she has an aid in the classroom to help David half the day. She is on her own the other half and it’s not always easy, it’s not, she’s up to the challenge. She discusses these challenges with David, the goals, together they say “This is my goal.” She expects him to reach them. She says “David, you’re 10 years old. You can do it. You can do it.” And she tells me too. “He can do it.” She doesn’t tell me, “Well, we’ll see what we can do this year.” She tells me, “This year, this is what I’m teaching your son. It’s the same stuff I’m teaching the other kids.” He’s now adaptive in math, actually he’s adaptive in everything except Language Arts.

The definition of success was not as clear for Dalia. Dalia believed that graduation would signal success for her son Ryan. Dalia had faith in the dominant ideology of the educational system and its measures of success. In hindsight, Dalia recognizes that such a definition was misguided. As she explains:

> I felt that Ryan would be very happy as an adult to say that he graduated from high school; no one has ever asked him if he graduated. [But] it’s never been an issue. His disability is so severe he will not be able to go to university without major support and a lot of build up, he would have to take a lot of courses.
Q. So what did he need graduation for?

Dalia. He needed it for, because I thought he needed it, I should have saved him the grief. I should have allowed him to leave school and study a trade or skill that he enjoyed but that he could have success at instead of making him suffer the way that he did. He didn’t, it’s not as though he was going to all these social things and had these relationships. He didn’t have any of that.

He has come along way. He has come a very long way. We are really happy that he’s managed to be in a place where I think that mentally and emotionally he is calmer than he was when he was younger. We say that Ryan survived, but I think he survived but not unscathed, he was pretty beat up, his self-esteem was pretty fragile.

Dalia could have never known that the costs of such “success” would be at the expense of her son’s self-esteem nor could she know that the price would be so high.

**Conclusion**

The game of being a mother of a child labeled ‘learning disabled’ is a complex and transformative one. Such work is both outside the sphere of ‘regular’ parenting and outside the sphere of the formal educational system. The mothers in my study changed because of the work that they had to do to protect their children’s educational interests. They struggled, taught, advocated and negotiated on behalf of their children. In short, they became professionals. However, not only were these mothers professionalized by the work of being a parent of a child labeled ‘learning disabled.’ They were disciplined by it; they were transformed in a number of configurations. For instance, Dalia became a ‘bitch in red lipstick’ and the ‘parent to be avoided’. Abby came to see herself as ‘a target’ and as a result questioned the very words that came out of her mouth. Leanne became stressed out to the point of becoming a ‘pest’. Simone became the ‘problem parent’. She also described herself as a ‘problem, a nuisance, a flea’. Violet became an ‘over-attentive’ and ‘in-denial’ parent, while Denise described herself as ‘trying to play that
very fine line,’ constantly negotiating between getting her child’s needs met and ensuring that she doesn’t “turn the teachers at the school against” her.

Mothers who were well positioned economically, socially or in terms of networks, had a better chance of playing and winning the game than mothers who were not as well positioned. It was on this distinction that social class played a role. However, those who successfully negotiated and navigated the educational system on behalf of their children were not safe from the disciplinary gaze of the institution; they too had to stay within the boundaries of the ‘normal’. In the end, what the mothers in my study shared was that they all paid a price for being a parent of a ‘labeled’ child. They paid economically, socially and sometimes with their emotional and physical health. In the end, some of mothers were better equipped than others to navigate the ‘disability’ of the child or children. What remains clear is that they all did the best they could with the cards they were dealt.
Notes for Chapter Four

14 When I refer to the character of parenthood, I refer to a process of transformation that oftentimes accompanies parenthood not as an actual fact of parenthood.
CHAPTER FIVE: CONCLUSION

There is no such thing as neutrality in the production or dissemination of knowledge. In the introduction to *Pedagogy of the Oppressed*, Shaull writes that:

Education either functions as an instrument that is used to facilitate the integration of the younger generation into the logic of the present system and bring about conformity to it, or it becomes the ‘the practice of freedom,’ the means by which men and women deal critically and creatively with reality and discover how to participate in the transformation of their world (Shaull, 1981, pg. 16).

The questions I ask about disability, education and maternal identity in this thesis are questions that surfaced at the borders of discourses about ‘normal’ and about ‘ability’. This research comes out of knowing a socially constructed world first-hand. Indeed, the only way to know such a world is from within it. “We can never [be] outside of it” (Smith, 2004, pg. 28). To gain such a vantage point, I followed Irigaray’s (1985) lead, I “ma[de] an effort – for one cannot simply leap outside…discourse – to situate myself at its borders and to move continuously from the inside to the outside” (Irigaray, pg. 122).

This research began as an attempt to see the material effects of pedagogical practices, what Bourdieu and Passeron (1990) term ‘pedagogic work’ such as the psychoeducational assessment which constructs disability. This practice itself can be seen as organizing a course of concerted social action and as a key to social reproduction. For me, the psychoeducational assessment was a perfect but scholastically under-examined example of such a process. Nuanced and contradictory as they are, psychoeducational assessment processes have the power to not only shape experience but also serve to “coordinate subjectivities or consciousness” (Smith, 1993, pg. 195) or in Bourdieu and Passeron’s (1990) conceptualization to become actualized through individuals. According to Thomas (1999) “self-identity is a key element in … the
psycho-emotional consequences of disablism. By these I mean the ‘personally or inter-subjectively felt’ effects of social forces and processes which operate (not in a direct, mechanical or uni-dimensional way) in shaping the subjectivities of people with impairments” (pg.48).

However, these social forces and processes not only shaped (and impacted) those labeled ‘learning disabled,’ but, as I have shown, also affected the self-identities and subjectivities of the mothers who cared for them.

Bringing mothers more fully into the analysis provided an interesting vantage point to discussions of the inner workings of the educational system and to the generation of disability in general. Mothers could not always provide an exact interpretation of what these educational assessment and designation processes looked like. However, what they could provide were critical perspectives and commentary of these processes, which were both inside and outside of the ‘processes of assessment.’ Additionally, mothers were able to illuminate the meaning and reach these pedagogic practices had in their own personal lives and in the lives of their children. As I have argued, these practices are active in shaping the everyday actualities of social organization(s), relations and actions. Consequently, it was through this conceptualization that the coordination of subjectivity and transformation of maternal identity also surfaced as a major theme of this work.

Borrowing the ‘game’ metaphor from Bourdieu (2000) provided me with a framework to analyze the ways that the educational system functions for the ‘normal’ child but fails to function for a child labeled learning disabled. Within this framework, I conceptualized the mothers as the ‘players’ of the ‘game’. In my analysis of the game, I show not only how there are separate rules for those classified as able and those who are not, but also show how for mothers of children labeled learning disabled, there are also two playing fields to navigate. I use the metaphor of the
rulebook as a way to show how, despite claims to fairness and equity, there are separate rules or guidelines for students with disabilities, rules which often have little or no enforcement or power behind them. Further, for mothers who must try to work within these rules and who must also try to enforce them, the task becomes one which occurs both in the public and the private realm. This splitting both enables and disables mothers, resulting in their feelings of alienation from both places. Thus, we can see the importance of the mother’s role in her child’s educational ‘game.’

Working from the standpoint of these mothers critically enhanced my understanding of the educational system. As a result, I was able to interrogate ‘normal’ in ways that I had not anticipated. From their standpoint, I could see the contour and shape of an educational system that not only defined difference on a daily basis but also disciplined it systematically. I conceptualized the psycho-educational assessment as a rulebook because of the document’s inherent character as a set of rules, regulations and rights. However, assessments and disability designations do not guarantee educational rights, nor do they level the playing fields of the educational system. What they can provide are opportunities for success. As a result, I was able to unlock and divulge the incongruent and contradictory nature of these processes. Consequently, through this interrogation I was able to animate the extensive and formidable reach of texts that Smith (1990) discusses. As I have demonstrated, psychoeducational assessments act as a set of rules, regulations and rights in the educational system. Yet, the activation and utilization of these assessments depends upon the skill and capital of the parent of the child labeled ‘learning disabled’. The rulebook may contain guidelines and rules for the game, but it does not guarantee that their enforcement, nor that other players will always play by the rules.
Thinking in these terms also allowed me to expand the terms of Bourdieu’s (2000) theory of ‘capital’ and ‘capital accumulation’. For me, ‘ability,’ is a type of currency, and perhaps one of the most valuable currencies within the educational system. The fact is that the system functions best for a very specific population. The system privileges the ‘normal’ child. The mothers I spoke with were quite clear about the ways that the educational system favored ‘normal’ children over their own. They provided many examples of processes of exclusion and normalization that their children had undergone. Exposing this reality is central to educational equity and justice. However, this suggestion has analytical value as well. Understanding the social and institutional dimensions of disability is dependant on decoding and exposing ‘ability’ as an axis of power for classification and categorization within the educational system and beyond it. ‘Normal’ is as much a silent currency as whiteness, heterosexuality, gender, or class, albeit a reality that sociology has yet to take up.

Working from the standpoint of mothers also provided me with an analytical opportunity I had not anticipated. I was prepared to learn that processes of psychoeducational assessment and disability designation disciplined those subjected to assessment. I did not anticipate the actual reach of such processes to define and discipline mothers as well as children. These processes, had enormous impact and coordinated these mothers’ subjectivities in various configurations. Mothers were transformed and professionalized as a result of being a parent of a child or children labeled learning disabled. Further, many of them suffered the effects of the psycho-emotional consequence of disablism. The costs of this work on the mothers I spoke to were exorbitantly high. The costs ranged from economic, social to health-related.
Limitations of Study

No research project is perfect; this is due in large part to the incongruity between research design and planning and the real worlds that people actually inhabit. I learned this first-hand. There are a number of limitations to my research. First, due to ethical considerations I chose to speak to mothers of children labeled learning disabled. Here I traded the ethical issue of speaking with children, who are vulnerable, for the ethical issue of having one population speaking for another. This was not an easy decision to make, but an important one. My decision to focus on the mothers’ experiences, rather than have them speak only to their children’s experiences, however, was both productive and rewarding in its own right. Second, there was the issue of sample size. I would have liked to have talked with more mothers, in order to exhaust the full range of their experiences. However, this strategy was simply not possible. Third, my research was limited in analytical scope. Although I covered a fair bit of territory, there were analytical regions left to explore. There were a number of alternative and unanticipated themes that emerged from the data. These were ‘stories’ I was simply unable to tell in the current format of this thesis.

My grounding in feminist epistemology did not prepare me for all I had encountered in the field. The mothers who participated in my study expressed economic, social, and health-related hardships. Some of the mothers I spoke with had been so severely traumatized by their interactions with the health and teaching professionals that they required tremendous support. It was clear that they were hurting. There were so many things that the mothers in my study wanted and needed, to speak about that I was simply not prepared to deal with it all. The following is an excerpt from my field notes:
The self-assuredness unraveled after the interview ended, I knew that this mom had suffered, but I didn’t realize that she never allowed herself to feel the extent of the suffering. She was economically secure, was able to be a full-time parent, she could afford the assessments and the interventions necessary, she had family to support her and therefore, she seemed to feel like she did not have the right to complain, throughout our interview I found her confident and self-possessed. She seemed resilient and surprisingly forgiving. I was sure that we were done, but as soon as I stopped the tape I could see that I was wrong, she had been holding so much in. I watched the pain tumble out. I felt her pain, I could understand somehow I could understand. What it was like to feel that you were not entitled to complain is part of the education we get as women, at least my education looked like that. We talked for awhile afterwards, again, disclosure was the only thing that I had to give and of course my admiration for her bravery and courage. Was it really worth anything? So many emotions. I just didn’t know (January 3, 2007).

Nor was I analytically prepared or emotionally trained for the reality of these lives lived. *Eyes looking into my own, searching, pleading for connection. Affirmation*. Unsure of myself, I would often cling to my research schedule. I would try avoid deviations too far outside the realm of my own epistemological comfort. But this was not always possible:

As she spoke memories began to surface. My memories have teeth. I think “Why do they call it the past, oh, when nothing has passed?” (Harmer, 2002). There was little order to my thoughts to what I was feeling. She describes an account and then a version from my own past presents itself. My mind is like a motion picture.

The picture is perfect. There I am at 12. Just like her little boy, trusting no one. She tells me her son is “very vulnerable”. We are both unable to speak, I see her eyes well, I feel that lump in my throat and manage a few words, “That would make a lot of sense when you’re interacting with people that don’t make you feel good”. She breaks into laughter, I join her, but it is all so bittersweet, we laugh because “there are so many of them”. I know exactly what she means.

I am also overcome with embarrassment. I wish I had something to give her. Time, the exchange, our conversation, it seemed so insignificant having heard what she and her son had been through, I felt torn. Then I would remember that this was a research project. I would be reaching for my interview schedule, directing her back to the question all the while ashamed by my own agenda. (fieldnotes, June 24, 2007)

As I reviewed the transcripts I found myself asking ‘is this a mother’s story or a child’s’? These are partial articulations, whispers yet to be analyzed, stories I was not able to attend to.
**Directions for Future research**

There are two areas that arise out of this work that have not yet been explored. The first substantive area would take up issues of identity and how the actual assessment is *experienced* by the person with the ‘disability’. Future work in this direction would take up the operation of the psycho-emotional consequence of disableism in the lives of children and of parents. In particular, I would take up the subtle and not so subtle ways that children labeled ‘learning disabled’ and their families are disciplined through different forms of interaction. Bullying is an interesting type of interaction and one that has the potential to have enduring and lifelong impacts. From my research, I have learned that the effects of these interaction are so durable that they can be passed from generation to generation. It is this ‘negative balance’ capital that is often overlooked in analyses of social or cultural capital. As one of the key practices of disciplining difference in educational settings, bullying can be observed systemically or among peer-groups. Such an analysis would also be concerned with unlocking processes of ‘inter’ and ‘intra-generational’ disablisation. In other words, the ways that social, economic and cultural marginalization is transformed into what we comfortably refer to as ‘learning disability’.

The second substantive area would take a genealogical approach to psychoeducational assessment processes. Drawing on the secrecy, the authority and the mystery behind the testing process could provide a much deeper analysis into the construction of disability. Such processes have been socially and politically neutralized due to their grounding in scientific discourse. However, a genealogical approach would interrogate these processes and lead us, if not to the source, then at least to the ideologies and discourses that have inscribed and continue to inscribe the identities of children and adults labeled learning disabled.
BIBLIOGRAPHY


Online Sources

<http://www.drshred.ca/articles.php?subaction=showfull&id=1184551223&archive=&start_fro
m=&ucat=&> Date last accessed February 15, 2008
APPENDIX 1

The following questions are an example of the types of empirical questions I ask in order to generate data for this study. The questions that appear in brackets, however, are analytical questions.

1. When did the parent first suspect that the child had a disability? (How were these suspicions grounded in existing discourses of normalcy?)
2. How did the parent learn about their child’s condition? (Was this through medicalized discourses, lay discourses on disability or parental discourses?)
3. What precipitated the parent to seek professional advising?
4. Who first identified the learning disability?
5. What steps did the parents have to go through to confirm the diagnosis?
6. How were the parent’s inquiries about their child received by health, caring and teaching professionals?
7. What were the parent’s initial reactions to the documentation process? What were the parent’s initial reactions to the documents?
8. What did the parent know about learning disabilities prior to interactions with health, caring or teaching professionals? (For instance, would the parent’s knowledge be considered specialized, popular or common?)
9. Was the diagnosis a surprise to the parent? What was it about the diagnosis that surprised the parent? Was it the wording of the documents that surprised the parent? Was it the teacher’s reaction to the diagnosis that surprised the parent?
10. How was this news received by family members and friends of the parent?
11. What kind of support (if any) was offered to the parent? If support was offered was it welcomed or unwelcomed support? Was there any type of support that the parents wanted but did not receive?
APPENDIX 2

Certificate of Completion

This is to certify that

__________________________
Leamore Cohen

has completed the Interagency Advisory Panel on Research Ethics' Introductory Tutorial for the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS)

Issued On: November 29, 2005

# APPENDIX 3

## Certificate of Approval

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>Department</th>
<th>Number</th>
</tr>
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<tbody>
<tr>
<td>Currie, D.H.</td>
<td>O-Anthropology &amp; Sociology</td>
<td>B06-0488</td>
</tr>
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**Institution(s) Where Research Will Be Carried Out**

UBC Campus

**Co-Investigators**

Cohen, Lecanore, O-Anthropology & Sociology

**Sponsoring Agencies**

**Title:**

The Role of Parents in Negotiating Learning Disabilities

**Approval Date**

JUL - 6 2006

**Term (Years):**

1

**Documents Included in this Approval:**

June 28, 2006, Consent forms / Advertisement / Contact letter / Questionnaires

**Certification**

The application for ethical review of the above-named project has been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approved on behalf of the Behavioural Research Ethics Board by one of the following:

- Dr. Peter Suedfeld, Chair
- Dr. Susan Rowley, Associate Chair
- Dr. Jim Rupert, Associate Chair
- Dr. Armine Kazanjian, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures.