TEN FINGERS AND TEN TOES: MOTHERS OF CHILDREN WITH DOWN SYNDROME CONSTRUCTING THE SOCIOCULTURAL MEANING OF DISABILITY AND MOTHERHOOD

By

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Abstract

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Priya Lalvani

Advisor: Professor Anna Stetsenko

This qualitative study concerns the lived experiences and negotiated identities of mothers of children with Down syndrome in the context of the meaning of disability and normalcy in society. The study explored mothers' experiences of the birth and diagnosis of their children with Down syndrome, their perceptions of parenthood, their understanding of cultural attitudes towards disability, and their negotiations of the social world on behalf of their families. Additionally, the study examined mothers' beliefs about inclusive education and their support for particular educational programs for their children. Data were collected from 19 mothers of children with Down syndrome through semi-structured interviews, which were audio-recorded, transcribed, coded and analyzed. The findings highlight the existence of oppressive interpersonal and institutional discourses on families of children with disabilities, centered on notions of damage, burden, and stigma. The mothers in this study strongly resisted dominant discourses about families of children with disabilities, rejecting the notion that being the parent of a child with Down syndrome is a negative experience. Instead, they represented their lives and those of their families in terms that emphasized the more normative aspects. Furthermore, they rejected notions of otherness in their descriptions of their children, and defined normative motherhood as encompassing a wide variety of tasks, roles, and challenges. The findings are indicative of transformations in these mothers' understanding of what is like to parent a child with Down syndrome and suggest that they located disability not only in their child, but also in the environment. For a majority of the mothers, the social implications of having Down syndrome were among the most pressing issues, and concerns regarding social acceptance strongly influenced their beliefs about inclusive education. The results of this study strongly support a need for a conceptual shift in understanding the experiences of families of children with Down syndrome; one that shifts its gaze from the "problem" of Down syndrome to the problematic constructions of normative motherhood and of the otherness of children with Down syndrome.

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Scholarly works are not produced by individuals working in isolation, and knowledge is not generated in a vacuum. Rather, as stressed on numerous occasions by Dr. Anna Stetsenko, my academic advisor, they are, like all human endeavors, the result of individuals collaborating with their environments, which include those whose thoughts, ideas, and actions shaped the work, the social and political climate in which the work was undertaken, and the audiences to whom the work is addressed. While it would be impossible for me to enumerate every contributing factor, I would like to express my gratitude to those individuals who most directly influenced this dissertation by providing nurturance through its period of conception, gestation, and birth.

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CHAPTER 1

BACKGROUND AND THEORETICAL PERSPECTIVES

Introduction

> *Humanity depends on social recognition, as do all other forms of meaning.*
> *Only humans can decide the meaning of a thing, including a word like "human".*
>
> *(Berube, 1996, p. 85)*

I recall an interaction that I had some months ago with an expectant mother at a playground. Since she was due to deliver shortly, the conversation centered on the impending birth of her baby and her eager anticipation of becoming a mother for the second time. At one point, the topic steered toward the gender of the baby and I casually asked if she knew whether she was having a boy or a girl. She responded: "I don't care, as long as it has all ten fingers and ten toes." Most people would not consider this to be an unusual response for an expectant mother, just as it is not uncommon for a doctor to announce the birth of a new baby by describing it as having ten fingers and ten toes. In fact, the phrase appears with remarkable frequency in popular culture and social discourse; it can be found in children's rhymes, literature, radio commercials, and even on baby products. This seemingly innocuous phrase seems to echo a societal belief that the most desirable baby is a "normal" one and indeed, "ten fingers and ten toes" appears to have become a cultural euphemism for a child born without disabilities. But what happens when a newborn child does not conform to society's notions of the perfect baby? In the context of a society that views perfection as normative, what are mothers' interpretations of having a child with a disability? In this study, I examined the meaning of the event for mothers whose experience of a birth is different from the expected; for those whose children are not born with “ten fingers and ten toes.”

Families of Children with Developmental Disabilities

Historical and Current Perspectives

The birth of a child is generally considered to be a joyous event, though it is often accompanied by new challenges, conflicting emotions, and redefined roles for parents. The birth of a child with a diagnosed disability is, in some ways, no different in this regard and, yet in others, it is a uniquely different experience that transforms mothers’ expectations of parenthood as well as their definitions of normalcy**.** Families of children with disabilities have long held the scrutiny of mental health professionals, doctors, researchers, and policy makers. While much research and writing concerning families of children with disabilities was generated during the 19th and 20th centuries, representations of these families remained relatively unchanged during this entire time. During the 19th century, parents were assigned the causal and moral blame for a child’s disability; disability was attributed to the low breeding or the poor judgment of parents (Ferguson, 2002). As such, any deviation from the moral code was considered to be the cause of poverty and developmental disability was thought to be “passed on to children in an endless cycle of family degeneracy” (Ferguson, 2002, p. 125). Social policy was aimed at removing the children from the influence of the parents and allowing professionals to assume the parental role. These beliefs formed the basis for the beginnings of segregation of children with disabilities in the form of residential schools or asylums in the 19th century (Ferguson, 2002). The only significant change in conceptions of the family experience of disability occurred during the mid-20th century during which time there was a shift in blame from the parents to the children themselves as professionals focused their attention on the damage wrought to families as a result of a child with a disability (Ferguson, Gartner, & Lipsky, 2000). Using attitudinal categories and other research methodologies derived from the clinical perspective as well as a conceptual approach to disability that focused predominantly on the notion of pathology, studies sought to demonstrate that families of children with disabilities engage in negative behavior patterns and experience a quality of life that is less than satisfying. Researchers attempted to establish a connection between a child's disability and pathological functioning in parents, thereby arguing for the efficacy of various therapeutic interventions. Consequently, almost all response patterns among these parents, including their attempts to resist negative assumptions regarding their experiences, were pathologized. Displeasure over professionals' supposed lack of support was seen as displaced anger; acceptance was seen as an outgrowth of denial, and highly involved or active parents were viewed as demonstrating overcompensating behavior (Ferguson et al., 2000). The bulk of the research literature during the mid-20th century pointed to predominantly negative outcomes for parents of children with developmental disabilities, suggesting that the experience of chronic sorrow, helplessness and guilt, psychological distress, and a persistent state of "mourning" are typical among this group (e.g., Fowle, 1968; Olshansky, 1962; Solnit & Stark, 1961). As a result, professionals have long assumed that families of children with disabilities are engaged in never-ending struggles to alleviate the problems associated with having a child with a disability (Wickham-Searl, 1992).

These assumptions of the inevitability of grief and pathology among families of children with developmental disabilities are being increasingly challenged as researchers “are now turning more frequently to the parents themselves for their own interpretations of their situations” (Wickham-Searl, 1992, p. 251). More recently in research as well as in published parent narratives, the portrayals of families of children with developmental disabilities have become more nuanced and the bulk of the literature now suggests that after an initial period of uncertainty, most families of children with developmental disabilities tend to regain healthy family functioning or even thrive, and the quality of their lives resembles those of families in general (Ferguson et al., 2000; Lalvani, 2008; Van Riper, 2007). In comparing families of children with Down syndrome with families of nondisabled children, Van Riper, Ryff, and Pridham (1992) found no differences in individual, marital, or family functioning between these groups of parents and, in this study, families of children with Down syndrome were characterized by resilience and adaptive functioning. Moreover, there has been an increasing recognition in recent years that parents of children with disabilities report positive perceptions regarding their parenting experience in addition to negative ones. This should not be taken to mean that negative perceptions are not a part of these families’ experiences. Studies have indicated that parents of children with developmental disabilities may report higher levels of stress when compared with parents of more typically developing children (Hanson & Hanline, 1990; Hendriks, DeMoor, Oud, & Savelberg, 2000). However, a range of studies seem to indicate that, although parents of children with developmental disabilities report increased demands, higher levels of emotional stress, or negative feelings, they simultaneously report positive perceptions, increased familial closeness, personal growth, and enrichment in their lives as a result of their experiences with their children (Abbott & Meredith, 1986; Hastings & Taunt, 2002, Hornby, 1992; Lalvani, 2008; Stainton & Besser, 1998;). Goddard, Lehr, and Lapadat (2000) indicate that the narratives of parents of children with disabilities challenge and deconstruct the dominant discourse on the experience of having a child with a disability and represent a critical perspective that acknowledges both the difficulties as well as the rewards of this experience. These authors found that parents of children with disabilities "did not present themselves as suffering from chronic sorrow or inordinate amounts of stress" (p. 285) and that, while these parents acknowledged that the experience of some sadness and stress was a reality in their lives, their narratives focused on the ways in which they made sense of their child's disability and on their resistance to assumptions about their lives. Similarly, Lalvani (2008) indicates that mothers of children with Down syndrome resist the dominant discourses on parenting a child with Down syndrome and describe their own lives as encompassing the full range of parenting experiences from feelings of stress, uncertainty, or sadness to feelings of contentment and joy. These studies suggest that parents do not experience the birth of a child with a developmental disability in a homogeneous manner. There is now a growing consensus among researchers that there is considerable variability in individual responses to the presence of a child with disability as well as a wide range of outcomes for families of children with disabilities.

Despite this shift in orientation in the research findings, the notion of the birth of a child with a developmental disability as presenting unmitigated hardship for a family continues to frame the dominant discourse on this familial experience. The term *dominant discourse* has been used to refer to a set of culturally derived values about what is considered normal and desirable (Goddard et al., 2000) or situated ways of acting, interacting, believing, and valuing acquired through participation in socially meaningful groups and linked with social roles of status and privilege (Gee, 1999, 2001). According to Morton and Gibson (2003), the dominant discourse on disability encompasses the lay knowledge of disability that informs individual and institutional practices. It includes culturally accepted beliefs about people with disabilities as inferior or burdensome, disability as something to be feared or shunned and life with a disability as simply not worth living. The dominant discourse on parenting a child with a disability includes perceptions of these parents as either overwhelmed with ongoing difficulties and unmitigated distress or as stoic survivors continually overcoming seemingly insurmountable challenges (Goddard et al., 2000). Parents of newborn children with developmental disabilities are typically exposed to rhetoric that centers on themes of "devastation" and loss. This is perpetuated in the written literature that these parents receive as well as by mental health professionals who often focus on families' need to grieve for the child they had thought they would have. For instance, in "Babies with Down syndrome," a book that many new parents of infants with Down syndrome receive at hospitals or are referred to by clinical professionals, Trainer (1995) discusses that families of children with Down syndrome may grieve the child that they thought they would have as well as the loss of the family's "normalcy." While the notion that grief is an inherent part of the experience of the birth of a child with a disability is widely accepted by professionals and most often acknowledged by the parents themselves, the conditions that create, support, and sustain this sense of grief are not usually questioned. Similarly, the implications of the widespread acceptance of notions of suffering among families of children with disabilities are also left largely unexamined. Ferguson et al. (2000) assert that the notion that a child with a severe disability "represents an unquestioned tragedy and lasting hardship for the family of the child" (p. 72) has framed many discussions about prenatal genetic testing and selective abortion of fetuses with genetic syndromes. Similarly Parens and Asch (2003) argue that the practice of the selective abortion of fetuses with potential disabilities is based on misinformation regarding what life is like for individuals with disabilities and their families. According to Fine and Asch (1988), it is important to consider those factors in society that contribute to and sustain the belief that having a child with a disability is a predominantly burdensome and tragic event and those that would make for a different outcome.

Beliefs about disability are culturally based and they influence not only the ways in which individuals with disabilities are viewed, but also the implementation of public policy and the providing of services in specific cultures (Groce, 2005). For instance, among Asian families, some view disability as a sign of good fortune, while others view it as punishment or as an act of God that cannot be changed (Miles, 1997). Similarly, among Jamaican and Korean cultures, disability is often viewed as caused by supernatural forces or as a punishment for the wrongdoings of ancestors (Kim-Rupnow, 2005; Miller, 2005), and Koreans may also attribute a child's disability to the mothers' failure to adhere to prescribed dietary practices or the violating of social taboos during her pregnancy (Reardon, 1996). Kalyanpur and Harry (1999) assert that definitions of disability vary such that the same condition may be regarded as a disability in one culture and not in another. Furthermore, these authors suggest that attitudes towards disability and the extent of stigma associated with particular conditions are based on culturally determined parameters of normalcy. The value and meaning attached to a particular disability may also depend on sociocultural definitions of successful life outcomes and desired personal attributes. For instance, among the people of the Yucatan, economic productivity is not considered a measure of a person's contribution to society; individuals with disabilities are viewed as contributing just as much as those who contribute at the market through their engagement in community events and festivities and through their participation in activities such as paying mutual visits, spending time with and helping neighbors, or massaging one another. In the context of their beliefs about individual worth, it is notable that the Zapotec language does not have a word for disability (Holzer, 1999). Among the Manus of New Guinea, a group that relies on activities such as fishing and handling a canoe, the loss of a limb would be considered more of a disability than the inability to read (Edgerton, 1970). In contrast, in the United States and most other capitalist economies, individuals with disabilities are viewed as limited in their ability to contribute to the growth of the economy and are viewed as dependent on others (Hahn, 1986). In these societies, interpretations about the quality of life for individuals with disabilities, as well as criteria for successful outcomes, are often based on Anglo-European value systems that emphasize independence, autonomy, and self-reliance as indicators of personal growth and as desired life goals (Kalyanpur & Harry, 1999; Turnbull & Turnbull, 2001). The aim of this dissertation is to understand mothers' experiences of having a child with Down syndrome by linking it to societal assumptions regarding families of children with disabilities as well as to the sociocultural context of disability. With regards to this, it is important to understand that in this study, mothers' experiences of having a child with Down syndrome are framed within societal attitudes towards disability that are steeped in Anglo-European perspectives and belief systems.

Disability rights scholars assert that despite many advances in public policy and legislation, the attitudes of nondisabled people towards individuals with disabilities continue to be overwhelmingly negative (Asch & Fine, 1988; Gilbride, 1993). Shapiro (1993) asserts that individuals with disabilities represent not only the nation’s largest minority, but also one that has been hidden and “routinely deprived of the basic life choices that even the most disadvantaged among us take for granted” (p. 11). Many scholars have argued that the attitudes of health and rehabilitation professionals, employers, educators, parents, peers, and the individuals with disabilities themselves present subtle barriers to the full acceptance of persons with disabilities and to the attainment of their life goals (Antonak & Livneh, 2000). It is being increasingly asserted by individuals with disabilities that the most significant consequence of having a disability is not the reduction in mental or physical capabilities but rather the environmental and social system barriers encountered as well as the prejudice and discrimination inherent in society (Gilbride, 1993; Hahn, 1988). According to Hahn (1988), persons who fail to meet society’s prescribed standards of physical attractiveness and functional independence are “not only assumed to be biologically inferior, but they are also exposed to a stigma that depicts them as ‘not quite human’ ” (p. 41). In recent years, there has been increasing awareness about these issues and an emergence of a group consciousness among individuals with disabilities. However, the emerging disability movement has gone largely unnoticed by the nondisabled (Shapiro, 1993) and, in general, society tends to avoid the subject of disability as much as it avoids encounters with individuals with disabilities (Asch & Fine, 1988). Disability continues to be a stigmatized condition and people with disabilities generally elicit reactions of fear, pity, or repugnance. Negative beliefs about disability are so pervasive in society that, in social discourse, it is not uncommon to hear phrases like "better dead than disabled," and the birth of a child with a disability is considered by many to be "every parent's nightmare."

In examining the experience of having a child with Down syndrome, it is necessary to recognize its embeddedness within a dominant discourse that devalues individuals with disabilities and positions them as "other." In this study, I have explored the lived experiences of mothers of children with Down syndrome through the lens of the stigma associated with developmental disabilities as well as the stereotypical depictions of families of children with developmental disabilities. Lalvani (2008) indicated that the social implications of a child's diagnosis of Down syndrome, including issues of acceptance and rejection, are among the predominant concerns raised by mothers. Other studies have highlighted that issues of social acceptance by peers are among the important concerns raised by parents of children with developmental disabilities when discussing their beliefs or perceptions about inclusion as a schooling option for their children (e.g., Guralnick, 1994, 1995). In this study, I take the stance that the experience of the birth and of parenting a child with Down syndrome is inextricably linked with the social meanings ascribed to constructs like disability and motherhood.

The Birth of a Child With Down Syndrome in the Context of the Medicalization of Disability

The term *medicalization* refers to the identification of a behavior or condition as a medical problem and requiring that the medical profession provide some sort of treatment or therapeutic intervention for it (Conrad, 2004). To a large extent, conditions that become medicalized are both influenced by and, in turn, shape the prevailing beliefs and values in society. Historically, the medicalization of conditions that are termed mental illness, alcoholism, drug dependency, and behavioral disorders have been driven by increasingly sophisticated medical technology as well as need to control social behavior. The medicalization of any condition becomes an effective tool for social control; as such, defining that which is different as a medical problem allows for certain actions that would otherwise not be considered (Conrad, 2004; Foucault, 1965).

The medicalization of disability had its beginnings in the *rehabilitation movement*. The period between 1890 and 1920 are distinctive in disability history; it was during this time that 19th century beliefs in the supernatural causes of disability gave way to medical interpretations of disability and to the identification of disability as a social and economic problem (Byrom, 2004). The legacy of the rehabilitation model continues to exist and forms the core of what disability studies scholars currently refer to as the *medical model.* The medical model defines disability in medical terms and lends scientific credibility to the assumption that the source of the “problems” related to disability is located within the individual body, thereby absolving society of any complicity in the lived outcomes for people with disabilities (Byrom, 2004). In this view, increased levels of disability are associated with decreased quality of life (Saxton, 2000) and disability is viewed as a biological limitation that needs to be “fixed” or a condition that is better prevented. Asch (1989) asserts that at the core of the medical model view of disability is the assumption that “disability must be prevented because disabled people cannot function within existing society” (p. 98).

In perspectives of disability that focus on its biological nature and its impact on individual bodies, conceptualizations of disability are applied universally. Here, disability becomes a limitation that is seen as residing in the individual and one that the individual must strive to overcome. Individuals are seen as divorced from social contexts; the self is seen as embodied and separate from the environment. Medical interpretations of disability fail to acknowledge its culturally embedded nature. The social dimension of living with a disability becomes obscured and the argument that living with a disability has as much to do with its social consequences as with its biological ones, becomes silenced.

In discussing the attitudes of physicians towards individuals with disabilities, Rothman (1989) asserts that the medical establishment has “long regarded disability, like death, as a sign of professional failure” (p. 193). The medical conceptualization of disability is reflected in its language. There are many examples of medical terminology that reinforce negative or stigmatizing connotations of disability, for instance, terms like “defective fetus” and “fetal deformity” (Saxton, 2000). It is worth noting that the commonly accepted medical term “teratogen,” which refers to any toxic substance that can cause atypical fetal development, derives from the Greek words *teras* and *gen* which translates “to create a monster.” In fact, the word “monster” was itself once the standard medical term for an individual born with a demonstrable physical difference (Bogdan, 1988).

The medical discourse on disability is reflected not only in conceptual definitions and terminology related to disability, but also in the interactions of medical professionals with families of children with disabilities. It has been noted in the disability literature that much of the medical profession continues to be unaware of issues related to disability culture or ill-informed about the range of outcomes for children with developmental disabilities. Further, there is documentation that many physicians continue to rely on outdated information or demonstrate a negative bias toward disability when conveying a child's diagnosis to parents (e.g., Skotko, 2005). Specific studies documenting mothers' perceptions of the attitudes of medical professionals towards disability following a diagnosis are relatively few. However, the existing literature suggests that mothers and medical professionals/clinicians may react to a diagnosis of developmental disability in very different ways. Cooley, Graham, Moeschler, and Graham (1990) found that nearly 50% of genetic counselors believed that the problems of parenting a child with Down syndrome outweighed the benefits, whereas 94% of mothers and 83% of nurses believed that the benefits prevailed. Additionally, this study indicated that medical professionals are more likely to assume that mothers would want to terminate a pregnancy after a prenatal diagnosis of Down syndrome, whereas mothers are more likely to want to consider all options and gather more information. These findings are consistent with other studies that indicate that negative attitudes held by physicians are often reflected in their interactions with parents, particularly following a prenatal diagnosis of a genetic disorder. For instance, in a qualitative study of 10 mothers who had received a prenatal diagnosis of Down syndrome and opted to continue the pregnancy, Helm, Miranda, and Chedd (1998) conclude that the "uniformity of these mothers' requests for respect and consideration from their professionals cannot be overstressed" (p. 60). In this study, 6 mothers felt that their obstetricians and obstetric nurses displayed negative attitudes when discussing the diagnosis and the most frequently reported negative experience was that of the interaction with a clinician who assumed that a mother would choose to terminate the pregnancy if she could. Some mothers reported that their dissent or ambivalence around termination was often met with resistance, disbelief, or lack of support. In other studies, mothers have reported that their physicians had emphasized only the negative aspects of Down syndrome or had offered explanations that were factually incorrect and that obstetricians and obstetric nurses displayed negative attitudes when discussing the diagnosis of Down syndrome (e.g., Rapp, 2000; Skotko, 2005). According to Rapp (2000), when mothers of children with Down syndrome narrate stories about their birthing experience, they almost always include an account of the manner in which they were informed of their child's diagnosis and their medical practitioners' words and actions are often indelibly etched in their memories. In her study of the sociocultural impact of amniocentesis, she found that many mothers were deeply affected by the negative reactions of their medical practitioners and by the "medical dismay" at their children's births. Similarly, Lalvani (2008) indicated that stereotypical representations of Down syndrome as well as notions of persistent hardship for families of children with Down syndrome continue to exist in medical discourse and practice. In this qualitative study of 9 mothers of children with Down syndrome, most reported that their early perceptions and interpretations of the meaning of Down syndrome were influenced by the language and attitudes (both positive and negative) displayed by medical professionals. Some mothers in this study expressed deeply negative feelings about their interactions with their physicians following a positive prenatal diagnosis of Down syndrome. The findings in this study resonated with Featherstone's (1980) assertion that in stories narrated by mothers of children with disabilities, “the medical profession is the single largest target of parental anger” (p. 36).

Studies have documented that mothers are also likely to encounter a medical discourse that focuses on damage and defect through their interactions with genetic counselors (e.g., Rapp, 2000; Rothman, 1993). In theory, the field of Genetic Counseling adheres to an ethic of non-directiveness, value- neutrality, and the avoidance of coercion in reproductive decision- making (Biesecker & Hamby, 2000). However, according to Rapp (2000), genetic counselors cannot be thought of as providing “neutral” information within the context of a technology “explicitly developed to identify and eliminate fetuses with problem-causing chromosomes” (p. 59). Further, she argues that non-directiveness in genetics counseling is something of a myth; the very existence of the technology of prenatal genetic testing “implies anything but neutrality” (p. 59). Indeed, the widespread routinization of prenatal testing and the selective termination of fetuses with potential disabilities embodies the notion that having a child with a disability is an entirely undesirable experience and is laden with social implications for individuals with disabilities and their families (Asch, 2000; Parens & Asch, 2003). Furthermore, many scholars have argued that a cultural acknowledgement of prenatal genetic testing as a self-evident good alters expectations of parenthood and redefines the very meaning of “child” (Parens & Asch, 2003; Rothman, 1993).

Sociocultural Perspectives on Disability

Disability as a Socially Constructed Phenomenon

Recent years have witnessed the emergence of sociocultural perspectives in disability literature. This is the result of the work of researchers who identify with a growing disability rights movement as well as those whose scholarly works acknowledge the sociocultural dimension of human experiences. These emerging perspectives on the experience of disability have been referred to by different names such as the "minority-group model," the "cultural model," or the "social model" of disability. In stark contrast to the medical model, the social paradigm is based on a view of individuals with disabilities as a minority group that have been denied full access to mainstream life (Saxton, 2000). Consistent with this perspective, a growing number of people associated with the disability movement have advocated that the handicapping conditions that result from disability are better described as social constructs than fixed limitations that are situated in individual bodies. The basic thrust of this paradigm is the idea that individuals with disabilities have been subjected to the same forms of discrimination and segregation as members of other oppressed groups; in this perspective on the experience of disability, primacy is assigned to the attitudes of the nondisabled public rather than to the acknowledged functional limitations of the disabled person (Hahn, 1997). Examining the experience of disability through the lens of the minority paradigm provides a broad perspective on the ways in which social and environmental factors come to define the experience of disability. Moreover, this perspective lends deep insight into the meaning of the lived experience of disability, both for disabled individuals and their families. In conceptualizing disability as culturally embedded and socially defined, this paradigm is firmly grounded in social constructionism.

According to the social constructionist viewpoint, knowledge is a collaborative enterprise and individual experiences exist within a social, political, and historical context (e.g., Harre & Gillet, 1994; Holland, 1997; Vygotsky, 1978). The term social constructionism has been described as the position asserting that what is assumed by people to be objective reality is in fact constructed by them through the course of their activities, thoughts, words, and interactions (Danforth & Navarro, 1998). In this view, one questions or even suspends what is commonly accepted and alternatively, the world is understood in the context of social artifacts or as “products of historically situated interchanges among people” (Gergen, 1985, p. 267). Individual realities are seen as resulting not merely from factors inherent in the individual or in the situation but also through the dynamic and collaborative interaction between the individual and the environment. Social constructionism, as a way of accounting for and understanding phenomena, is consistent with the works of Vygotsky (1978), who emphasized that human cognition develops intrapersonally as well as interpersonally. Indeed, at the very crux of Vygotskian psychology is the idea that individual mental processes can only be understood by examining the social and cultural processes from which they derive (Wertsch & Tulviste, 1994).

Using a social constructionist paradigm, scholars have challenged commonly accepted categories such as gender (Kessler & McKenna, 1978), adolescence (Arnett, 2007), and childhood (Kessen, 1979), arguing that these are not absolute categories, but rather ones that are culturally defined. These researchers and many others have suggested that the categories we take for granted are, in fact, derived from and maintained by the social and institutional beliefs and practices at any given time. Consistent with this thinking, many scholars have asserted that disability is best understood as a constructed reality rather than a universal given, and one that is maintained by the language and practices prevalent in a society (e.g., Danforth & Navarro, 1998; Groce 1985). For instance, Danforth and Navarro (1998) asserted that:

> From a social constructionist position, the maintenance and furthering of the diagnosis and human condition called “mental retardation” relies on the words and actions of professionals and nonprofessionals. If western civilization suddenly lost the vocabulary of mental retardation, including terms such as *intelligence, normal, disability,* and so on, the constructed reality of mental retardation would no longer continue in its present form. (p. 32)

Similarly, Groce (1985) suggested that the concept of “handicap” is an arbitrary social category or simply a definition that can be redefined, leading to an elimination of many of the cultural preconceptions that are presently associated with the term.

Social constructionist views regarding the phenomenon of disability are not inconsistent with the work of many contemporary researchers who take into account the contributions of biology in human development. For instance, Dynamic System Theory (DST) posits the existence of a mutually interlinked relationship between organisms and their environments. According to this view, attributing individual differences to genetic or environmental factors alone is unnecessarily reductionistic. A central assumption in Dynamic System Theory is that human development is not merely the additive result of genetic and environmental factors, but rather it is seen as occurring through the complex interplay of individual biology and cultures (e.g., Lickliter & Honeycutt, 2003; Oyama, 2000; Thelen, 2005). Drawing from recent developments in Dynamic Systems Theory and emphasizing the more “revolutionary import” of Vygotsky’s work, Stetsenko (2009) rejects notions of the dichotomy of genes and environmental factors in developmental outcomes, asserting instead, that mutually influential relationships between individuals and the world are at the core of human development. Furthermore, she stresses that development is not the summation of genetic and environmental factors, but rather an emergent process arising from “an actual confrontation between the organism and the environment and an alive adaptation to the environment” (p. 135). In extending this view to understanding developmental disabilities such as Down syndrome, one could argue that the experiences and outcomes related to the presence of the condition cannot be attributed solely to biological characteristics embodied in the individual, nor can they be explained by reductionistic views of culture as an extraneous force that shapes development. Rather, developmental outcomes related to Down syndrome can be understood as the reciprocal and dynamical interaction between biological factors and the environment through the process of mutual engagement and participation in sociocultural practices.

Understanding the sociocultural nature of disability may also necessitate the examination of broader issues concerning the ways in which *normalcy* is defined. Davis (2006) asserts that too much of the writing about disability has focused on the disabled person as the object of study and suggests that “the “problem” is not the person with disabilities; the problem is the way that normalcy is constructed to create the “problem” of the disabled person” (p. 3). While today, a constellations of words describing “normal,” for example, “norm,” “average,” “mean,” and “abnormal” are part of everyday language and experience, these words and concepts are relatively recent having entered the English language only around 1840 (Davis, 2006). The construction of the idea of the “statistical norm” is relatively recent in human history. The growth of interest in

Statistics in England during the 1830s led to great interest in calculations of the mean or the norm. Once the central idea emerged that the population could be normed along a bell curve; the obvious next step would then be the identification of the non-normative, or the dividing of the population into standard and non-standard sub-populations (Davis, 2006). It is probably no coincidence that many of the early statisticians were also eugenicists.

Viewing the term *disability* in the context of the construction of normalcy renders the term with no inherent meaning. Rather, it is understood in relational terms or as a category that is defined by dominant groups at any given time. This idea is well articulated by Kliewer (1998) who asserts that normality and impairment are not absolute categories, but rather ones that reflect the current cultural authority of groups such as psychiatrists “who are charged with defining what constitutes the differences that matter” (p. 15). According to him, Down syndrome does not imply a scientifically deduced state as much as a social reality that exists within “constantly shifting relationships of power and control” (p. 15). He asserts:

> As such, it makes no sense to define any single person as intellectually defective. The presumed defectiveness exists not as an intrinsic commodity of the child whose thoughts fail to fit within the perceived static borders of normality. Rather, the idea of defect emerges from culturally devalued sets of relationships that the child has with his or her surroundings. (p. 82)

Consistent with the perspectives articulated in the scholarly works discussed in this section, this study examined mothers’ experience of the birth of a child with Down syndrome and of parenting a child with Down syndrome through the lens of the social construction of disability and normalcy. Rather than exploring reactions to universally fixed definitions of Down syndrome and culturally agreed upon assumptions of the birth of a child with Down syndrome as a “tragedy,” this study gives mothers of children with Down syndrome a voice in the ongoing discussion on fluid interpretations of disability and on the culturally embedded nature of their experience of motherhood.

Critical Disability Theory: Privileging Silenced Voices

Critical Disability Theory is informed by the epistemologies of critical race theory and by feminist research. Both contend that the perspectives of oppressed individuals and groups have been silenced by the larger society and that there are valuable messages to be gained from writings that focus on a critical examination of the lives of marginalized peoples (Asch, 2001). Matsuda (1995) argues that those who have experienced discrimination “speak with a special voice to whom we should listen” (p. 63) and that issues concerning social justice are best examined from the standpoint of the groups that have suffered oppression. Asch (2001) argues that this message can be applied to the fight for social change that has been engaged in by people with disabilities.

Historically, efforts at understanding the experiences of marginalized groups have originated from the perspectives of dominant groups; knowledge about marginalized lives has been generated by those in positions of power and privilege. The voices of those who can speak about their lives have been less heard. However, some scholars have asserted that it is through the lived experiences of those who occupy an “insider” position that true knowledge can be generated. This idea is consistent with Harding’s (1993) description of standpoint epistemology as strong, objective “grounds” for knowledge. Standpoint

Theory holds that all knowledge is socially situated. It is based on the premise that communities, not individuals, produce knowledge and that beginning thought from the lives of marginalized people is essential in illuminating critical questions that do not arise from dominant lives (Harding, 1993). Furthermore, Harding (1993) asserts that, in addition to listening to the voices of marginalized people, standpoint epistemology requires examining dominant institutional beliefs and practices that systematically place marginalized groups at a disadvantage as well as critical self-examination to understand how one unwittingly participates in generating disadvantage to them. She argues that researchers should engage marginalized individuals to elucidate silenced perspectives; marginalized lives often bring forth new perspectives on powerful groups and social norms overlooked by the powerful groups themselves. She suggests that by engaging and privileging multiple perspectives, particularly those that start with marginalized lives, research becomes more objective and informed compared with traditional positivist methods; marginalized lives provide the grounds for knowledge or the sites from which critical questions arise.

These arguments are consistent with the positions held in Critical Disability Theory, which argues that the perspectives of individuals with disabilities and their families have long been distorted or silenced by a dominant narrative. This theory stresses that any discussion on the experience of disability or on families' responses to having a child with a disability must include multiple perspectives, including the perspectives of those with a wide range of disabilities. For instance, according to Taylor (1996), any attempts to study the experiences of individuals with mental retardation must originate from the perspectives of those who are tagged with this label; their perspectives must provide the starting point of inquiry. Consistent with this idea, Biklen (2000) asserts that valuable insights regarding issues of inclusion for people with disabilities can be gained by drawing from critical disability narratives. He describes critical disability narratives as:

> . . . those works that recognize disability as a social construct and which see disability as occurring within shifting political, economic and social contexts, often highly marginalizing and discriminatory in nature; the critical narratives presume that experiences of people with disabilities cannot be understood simply as a function of individual make-up. (p. 337)

According to Taylor (1996), scholarship in the area of disability studies must also include the perspectives of family members or advocates, however, he emphasized that these perspectives should not substitute for the voices of individuals with disabilities themselves. In this study, I have given voice to mothers of children with Down syndrome. Here, there was no intent at implying that mothers' perspectives on disability are of primary importance or that they speak for those with disabilities. Rather, this study is based on the standpoint that the voices of mothers' of children with disabilities have long been silenced and, that by eliciting counter-narratives from these mothers, critical questions arise and alternative interpretations of motherhood and of disability emerge.

Self as Socially Embedded

Understanding Identity through a Sociocultural Lens

Variability in individual mothers' adaptation to the birth of a child with a developmental disability may be understood in the context of the ways in which this experience is interpreted by them or the meaning that they attach to this life event.

However, individuals do not experience events in isolation and the meaning of this experience, like all others, is culturally embedded. This idea is informed by sociocultural theory, which is grounded in the works of Vygotsky and other scholars who emphasized the interpersonal nature of psychic phenomenon. This theory takes the perspective that human psychological processes have sociocultural origins and that "each living organism exists only as part of a dynamic system that connects it with the environment and with other organisms" (Stetsenko & Arievitch, 2004, p. 482). At the crux of Vygotskian psychology is the idea that individual mental processes can only be understood by examining the social and cultural processes from which they derive (Wertsch & Tulviste, 1994). In this viewpoint, human consciousness has social origins and all individual cognition is a result of human interaction or the engagement of individuals in collective activity with others. The priority given by Vygotsky to social phenomenon is exemplified in his assertion that "the social dimension of consciousness is primary in time and fact; the individual dimension is derivative and secondary" (Vygotsky, 1979, p. 30).

The sociocultural framework provides a lens through which identity can be conceptualized as embedded in social contexts. The notion of the self as social in nature is present in the works of many theorists and scholars who have rejected traditional conceptions of the self as distinct, essential, or contained within individual minds or bodies. G. H. Mead, Vygotsky, Piaget, and others have supported a socially based and contextualized understanding of the self. Mead (1934) presented a theory of the self as arising through complex social process in a shared environment. His work emphasized that selfhood emerges through the joint participation of individuals in social activity.

Discursive psychology, which draws from the works of Wittgenstein, Vygotsky, and G. H. Mead, emphasizes the idea of meaning making in the development of identities. According to Bruner (1986, 1990), culturally adapted ways of life “depend upon shared modes of discourse for negotiating differences in meaning and interpretation” (p. 13). Thus, in Bruner’s (1986, 1990) view, self becomes defined through the constant act of negotiating and renegotiating meaning, both by individuals and cultures, and human experiences become endowed with meaning through narrative interpretation. While these views strongly support the notion of self as situated, other scholars have put forth different interpretation of situated selves, emphasizing greater levels of human agency within the constraints of social influences. For instance, Holland (1997) questions the assumptions made in discursive theory, that dominant discourses and categories in society are imposed upon people both in interpersonal and institutional ways and selves are socially constructed through mediated discourse and their artifacts. She rejects strong social constructivist views of the self because here, “selves become virtually ephemeral” (p. 170), or, selves are “overwhelmed by social influences and the positioning imposed upon them” (p. 70). She asserts that one should avoid the problematic view of self as living enactments of cultural themes. In response, she supports a view of *self in action,* which emphasizes a view of persons as having perspectives on their cultural worlds that are likely to different by virtue of their social position. The *self in action* authors or orchestrates the sites of self which includes intimate discourses, inner speaking, practices, and discourses of the past and those to which people are exposed. This view acknowledges human agency; individuals are seen as active participants in making sense of experiences and in constructing selves. This is similar to Harre and Gillet’s (1994) notion of mental life as dynamic activity; people operate within meanings available to them and jointly construct meaning through culturally embedded discourse. They emphasize the notion of self as agent. Here, it is precisely through the act of engagement in purposeful activity that individuals come to make sense of experiences in a unique way.

The views offered by scholars who emphasize the role of agency in the origins of the self are consistent with the grounding assumptions offered in Cultural-Historical Activity Theory (CHAT). This theory rejects the view of self as a mental construct that resides within individual cognitions; instead, it emphasizes the idea of the self as originating in the everyday processes of human interaction and activity. Here, self is seen as fused in contexts and inseparable from the daily processes of interaction and activity. From this perspective , it is argued that in identifying the nature of the self, the unit of analysis must shift from the individual to the transactions between individuals and the activities through which individuals transform the world and are themselves transformed (Stetsenko & Arievich, 1997). This view originated in the writings of Wittgenstein, Bakhtin, Vygotsky, Leontiev, Luria, and others, all of whom emphasized the sociocultural origins of human subjectivity. According to Leontiev (1983), self is embedded in human activity and originates from human activity. Stetsenko and Arievitch (1997, 2004) take this idea a step further in discussing the notion of self as activity, self is not seen as *emerging* from activity, but rather the activities that individuals engage in *are* the self. They emphasize the nature of the agentic self and explain that in post-Vygotskian versions of discourse analysis, selves are seen as constructed and reconstructed by individuals through mutual engagement in purposeful activity. According to Stetsenko (2009), human development is simultaneously derivative from and instrumental in social practices; goal-directed activities produce and are themselves reciprocally produced by social interactions and human subjectivity.

Centering on the notions of self as social process, this study seeks to understand the ways in which mothers' of children with Down syndrome are agentic in the construction of selves. From the standpoint of the theoretical perspectives discussed in this section, the identities of these mothers are understood as mutually negotiated and inextricable from the culturally embedded and purposeful activities through which they transform the world and are themselves transformed.

Positioning Theory: Dominant and Contested Discourses about "Other" Motherhood

The nature of selves as embedded in social discourse and mutual activity is further explored in this study from the standpoint of Positioning theory. Positioning theory has been conceptualized as an explanation of the ways in which psychological and social phenomenon are produced through the act of dynamic discourse (Harre & Langenhove, 1999). According to Harre and Moghaddam (2003), Positioning theory explains that "an important feature of social behavior is the collaborative construction of social reality and the mutual upholding of particular interpretations of the world" (p. 3). Through discursive practices based on power and social status, individuals position others and themselves, and collectively construct psychic realities and social worlds (Harre & Langenhove, 1999). Through the act of positioning, power dynamics are articulated, enacted, and resisted and claims are made about the nature of relationships. Thus, positioning simultaneously sustains and creates the shifting social dynamics that exist within society; it is both a means for enacting identities within social contexts as well as a tool for resisting perceived power differentials inherent in dominant discourses, both at the interpersonal and institutional level.

In this study, I explored the identities of mothers of children with Down syndrome by linking these with a dominant discourse of the meaning of motherhood. Among the most dominant cultural narratives are those that pertain to motherhood. Andrews (2004) asserts that the "story of mothering" is one of the most prevalent dominant discourses in society, yet there exists a "chasm between this discourse of mothering and the lived experiences of mothering and being mothered" (p. 8). Some scholars have challenged the dominant narratives of motherhood, reformulating the cultural scripts that exist related to this experience (e.g., Andrews, 2004; Lazarre, 1997; Rich, 1995). While there is little research on the ways in which mothers of children with disabilities are positioned in the master narrative, existing work in this area indicates that interpersonal and institutional discourses define normative motherhood and emphasize the otherness of parents of children with disabilities. An exploration of the ways in which mothers of children with disabilities accept or reject notions of otherness can inform an understanding of the process of identity construction among these mothers and also of the continually shifting constructions of motherhood itself. While the meaning of motherhood in general is fluid, and relies upon what motherhood is taken to be in cultural contexts, it can be argued that the meaning of mothering children with disabilities has become particularly transformed in recent decades, mainly as a result of medical advances and the technologies of prenatal genetic testing. McMohan (1995) argued that, whereas earlier motherhood had been associated with the care of children, today motherhood has become associated with *valued* children. Landsman (1999) asserts that there is a cultural expectation of maternal responsibility in “attaining perfection in fetal outcome” (p. 153) and that the birth of a child that is deemed by society as having diminished personhood is linked with the experience of diminished motherhood for the woman who nurtures it (p. 135). Further, she asserts that there exists a dominant discourse that places mothers of children with disabilities in a position that is not morally equivalent to other mothers. As such, these mothers are either blamed for their role in creating imperfect children or they are elevated to the role of “special” mothers who are “chosen by God to have special children” (Landsman, p. 136). Through an analysis of the strategies through which mothers of children with disabilities negotiate the meaning of personhood and perfection, Landsman (1999) concludes that while these mothers resist the devaluing of their children, create new interpretations of perfection, and reinstate their motherhood, many of these same mothers also represent themselves as the recipients of special “gifts.” Other studies have indicated that parents of children with disabilities become negatively positioned through a dominant discourse that places them in a category of ‘other,” however, these parents reframe and reconstruct the meaning of having a child with a disability and of the normative motherhood (Goddard et al., 2000; Lalvani, 2008). These studies are consistent with Bamberg’s (2004) assertion that, when individuals are positioned through master narratives or hegemonic discourses, they produce counter-narratives that assign meaning to psychic and social phenomena.

Firmly grounded in the idea that individual identity is performed within the constraints and affordances of a sociocultural context, this study explored the ways in which mothers of children with Down syndrome negotiate their selves through situated activity. The processes through which these mothers position themselves and are positioned in interpersonal and institutional discourse is the lens through which their constructed meaning of motherhood is examined. Framing the identities of mothers of children with Down syndrome in the context of the ways in which dominant discourses of otherness are accepted or contested, I attempted to unravel the dynamic process through which these mothers are simultaneously shaped by, and transform, the meaning of disability and motherhood. Furthermore, I examined the ways in which mothers of children with Down syndrome perform their identities in the context of education-related decisions for their children. As such, in attempting to understand the identities of these mothers, selves are conceptualized as inseparable from experience; indeed, the activities and the discourse that these mothers engage in *are* the self. Therefore, activities that these mothers engage in, with regards to the everyday integration or education of their children, are viewed as neither emerging from nor resulting in their identities, rather these activities are viewed as the selves of these mothers.

Framing Disability in the Context of Inclusive Education

Inclusive Education: An Historical Overview

Few issues in education have received as much attention and generated as much controversy as the movement to educate children with disabilities in the general education classroom (Winzer & Mazurak, 2000). Referred to as “inclusive education,” “inclusive schooling,” or simply “inclusion,” the term refers to the practice of educating children with disabilities alongside their typically developing peers in the general education classroom with the provision of the necessary accommodations. While inclusive education for children with disabilities may be a relatively recent phenomenon, the integration of excluded children into the mainstream of the education system is not a new concept. The inclusion movement did not begin with students who had disabilities, rather throughout educational history there has been a movement toward greater integration of students into mainstream education (Stainback, 2000). In 1779, Thomas Jefferson advocated that the children of the poor should have access to public education system. Approximately a hundred years later publicly supported education became available to all students regardless of their ability to pay for schooling (Stainback, 2000). Even so, many students continued to be denied access to the mainstream, for instance, Native American students, African-American students, and children with disabilities were typically educated separately. Children with significant disabilities were generally institutionalized, often receiving no education at all (Winzer, 2000). Even with the passing of compulsory education laws in the early 1900s, most children with disabilities were excluded from the public education system. Although some children with moderate disabilities received whatever education their parents could arrange for them in church basements or in their homes, the vast majority of children with severe disabilities continued to be housed in institutional settings (Winzer, 2000).

In the 1954 landmark Supreme Court *Brown v. Board of Education* decision, it was ruled that “separate is not equal.” As this decision opened the doors for the integration of African Americans and other minorities in education, it simultaneously planted the seeds for the beginnings of the integration of children with disabilities into the mainstream of society. In 1975, educational equality for children with disabilities was addressed when Congress passed PL 94-142 (The Education for All Handicapped Children Act) which guaranteed a *free, appropriate public education* in the *least* *restrictive environment* to all students regardless of the level of their disability. This marked the formal beginnings of the inclusive education reform and of the movement towards educational equality and justice for children with disabilities.

The term “inclusion” is sometimes confused with a practice that was termed “mainstreaming,” however, it is essential to note that the two terms do not mean the same thing. Mainstreaming involves the practice of providing students with disabilities with varying levels of opportunities for access to the mainstream classroom; inclusion involves full membership in a restructured mainstream. Although in theory, inclusive schooling has been elevated to dominant education discourse, the idea of full inclusion is one that is not endorsed by all those concerned with the education of children with disabilities (Winzer, 2000). The notion and practice of inclusion is conceptualized in many different ways and it continues to be redefined and reinterpreted. The discussion on inclusion has been at many levels; some see it as general school reform, others present the issue as a moral imperative, and yet others have argued that, at its heart, inclusive schooling is a civil rights issue; intricately connected to matters of social justice (Winzer, 2000). For many, the move from segregation to integration of children with disabilities is as much about educational practice as it is about a democratic value system. Thousand, Villa, and Falvey (1995) put forth the view of the inclusive education movement as a “predictable moment in educational history that simultaneously reflects and pushes forward human rights and personalized educational philosophy and practice for everyone” (p. 3).

Despite the lack of consensus on the interpretation of this practice, inclusion has become a mainstay in the field of special education and educational discourse is increasingly focused on how to successfully include children with disabilities in general education classrooms. However, in practice, large numbers of students with disabilities continue to be educated in segregated settings. National statistics for recent years indicate that approximately 33% of all preschool children with disabilities are placed in inclusive classrooms and approximately 52% of all children with disabilities between 6 and 21 are educated predominantly (i.e., spend at least 80% of the school day) in the general education classroom (U.S. Department of Education, 2006). These statistics vary by school district and by state, with some districts placing the overwhelming majority of children with disabilities in separate special education settings. In New Jersey, for example, available data indicate that only 22% of preschoolers with disabilities are placed in inclusion classrooms (NJ Council on Developmental Disabilities, 2004) and, for the 2007-2008 school year, approximately 45% of school age children with disabilities were educated predominantly in general education settings and approximately 10% of school-age children with disabilities are placed in separate school facilities (NJ Department of Education, 2009). Moreover, it has been documented that children with mild learning disabilities tend to be placed in inclusive settings more often than children with more severe disabilities (Mcleskey, Henry, & Hodges, 1999) despite research findings that schooling in inclusive classrooms has numerous benefits for children with a range of disabilities (e.g., Anderson & Brady, 1993; Staub & Hunt, 1993). In general, studies comparing the benefits of inclusive education with those associated with segregated classrooms have concluded that the educational and social outcomes for children with cognitive disabilities who are educated in general education classrooms are better than for comparable students educated in non-inclusive segregated classrooms (e.g., Baker, Wang, & Walberg, 1994; Hundert, Mahoney, Munday, & Vernon, 1998). Additionally, studies have shown that inclusion is not detrimental to students without disabilities (e.g., Hollowood, Salisbury, Rainforth, & Palombaro, 1995). The research findings concerning the benefits of inclusion for children with Down syndrome is consistent with the findings of the above studies. A 1996 published report by the National Down Syndrome Society which analyzed extensive teacher and parent questionnaires concluded that with proper supports inclusion is a favorable schooling placement for children with Down syndrome. Despite these research findings, inclusive classrooms are not the most common school placement for children with Down syndrome and not all parents of children with Down syndrome support or advocate for this particular schooling practice.

Vygotskian Perspectives on Inclusion

Although the passage of Public Law 94-142 marked the formal beginnings of the inclusion movement for children with disabilities, ideas about inclusion were put forth by scholars before the practice emerged as school reform. The notion of inclusive education as beneficial for children with disabilities can be found in the writings of Vygotsky, though the term itself emerged more recently in relation to educational practice. Vygotsky’s work, grounded in a firm belief in that development occurs through a dynamic process of children’s interactions with their environments, stresses the importance of opportunities for the child to engage in the full range of learning experiences. Vygotsky (1993) emphasized that a child’s social environment is the venue for the development of higher mental functions and suggested that segregation of children with disabilities is, at least in part, responsible for attenuated cognitive growth. In his words:

> Why do higher mental processes fail to develop in an abnormal child? Not because their defect directly impedes them or makes their appearance impossible. . . . The underdevelopment of the higher functions is a secondary structure on top of the defect. Underdevelopment springs from what we might call the isolation of the abnormal child from the collective. (1993, p. 199)

Further, Vygotsky suggested that segregation of children with disabilities not only hinders cognitive development, but that it also results in a loss of already existing developmental functioning. In referring to the segregated education of children with disabilities, Vygotsky asserted that: “Here, not only is there no development, but those forces in the child which would subsequently have helped him enter life become systematically atrophied” (1993, p. 205-206).

In this view, the process of cognitive development is neither unidirectional nor fixed; it is the result of a child’s acting upon the environment and internalizing the social experiences encountered. Vygotsky also expressed a belief that the very act of labeling a child as “defective” results in a different treatment of the child which can have a profound impact upon the child’s development. In his words: “Once labeled a fool or handicapped, the child is placed in entirely new social circumstances and his/her entire development proceeds in an entirely new direction” (1993, p. 153).

Thus, in Vygotsky’s view, a “culture of segregation” is partly responsible for the underdevelopment of cognitive thinking in children with developmental disabilities through the systematic isolation of these children from socially valued opportunities

(Kliewer, 1998). This idea is supported in current educational research. It is becoming increasingly accepted that inclusive education provides opportunities for children with developmental and intellectual disabilities to engage in meaningful and varied social interactions which promote the development of a range of skills. However, discussions about the benefits of inclusive education raises important questions regarding the extent to which children with developmental disabilities are socially accepted by their nondisabled peers and the extent to which they have social opportunities that facilitate their integration into their school environments.

The Social Context of Inclusive Education

The passage of Public Law 94-142 opened the doors for the integration of children with developmental disabilities into mainstream education. As a result of this legislative mandate, increasing numbers of children with developmental disabilities have begun to participate in general education classrooms. However, one of the most central issues in inclusion today concerns the acceptance of children with disabilities by their nondisabled peers and the extent to which these groups of children form friendships with one another. Indeed, one of the expectations of inclusive practice is precisely that meaningful social relationships will form between children with and without disabilities as a result of familiarity with one another in early childhood settings (Guralnick, 1999). Additionally, social interaction with peers is considered critical for the cognitive, emotional, and moral development of children as well as for the development of a sense of self or identity. In sociocultural theory, development of cognition is understood primarily as a social phenomenon and, in this view, cognition is not only acquired socially, but also collaboratively. The importance of the impact of peer interaction upon children's development is addressed in both Piagetian and Vygotskian thought; both acknowledge that cognition develops interpersonally as well as intrapersonally. However, in Vygotskian sociocultural theory primacy is assigned to the social dimension of cognition. This is exemplified in Vygotsky's general law of genetic development, expressed here:

> Any function in the child's cultural development appears on stage twice, or on two planes. First it appears on the social plane, and then on the psychological plane. First it appears between people as an interpsychological category, and then within the child as an intrapsychological category. (Vygotsky, 1981, p. 163)

According to Rogoff (1998), cognition is a collaborative process and individual learning occurs only as a consequence of mutual participation in sociocultural activities with both adults and peers. Play activities with peers of similar and "expert" status present opportunities for shared problem-solving and create a "zone of proximal development" which, in turn, provide fertile ground for cognitive growth in children (Bearison & Dorval, 2001). In relating the issue of inclusive education to this particular view of human development, it becomes necessary to examine the environment of mainstreamed or inclusive classrooms and the nature of the social interactions that occur between children with and without disabilities in these settings.

It has been argued that, while the physical integration of many children with developmental disabilities into mainstream education has become a reality, the social integration of these same children with their typically developing peers remains an elusive goal. Guralnick (1999) notes that, while there are no established criteria for determining the degree of social integration experienced by children with disabilities in an inclusive classroom, social integration may be said to be achieved when typically developing children form and maintain the same quality of interpersonal relationships with children with disabilities as they do with other typically developing children. To this effect, it seems that most children with developmental disabilities do not meet the social integration criteria. One of the most replicated findings in early childhood inclusion literature is that children with developmental or intellectual disabilities are at risk for becoming socially isolated from their peers in inclusive classrooms and that these children have a restricted number of reciprocal friendships; less developed peer networks and a lower rate of participation with peers in the classroom (Guralnick, 1999; Guralnick & Groom, 1988). Some studies have indicated that typically developing children are likely to interact with other nondisabled children to a greater extent than with their peers who have disabilities in the inclusive classroom (e.g., Hestenes & Carroll, 2000). Through an examination of the play interactions of young children with and without disabilities in an inclusive classroom, these authors found that children with and without disabilities interacted with each other less than was expected, even though children with disabilities exhibited similar patterns of activity choices as children without disabilities. In this study, typically developing children’s awareness of disability was related to their reported willingness to play with a child with a disability, as measured by a questionnaire; however, this was not related to actual behavior on the playground. Additionally, it was found that teacher presence and facilitation had a positive effect on play interactions between children with and without disabilities. These findings are consistent with other studies indicating that teacher support and behavior is crucial in the extent to which social integration occurs in general education classrooms (e.g., Odom, Skellenger, & Ostrosky, 1993; Odom et al., 1996). This suggests that classroom interventions and environmental changes may influence the success of inclusive education. Odom (2000) asserts that inclusive education has been shown to result in overall positive outcomes for children with disabilities, however, if children with disabilities are to reap the benefits of participation in inclusive classrooms, they must be further socially integrated into the classroom environment and this goal has yet to be achieved.

In studies that examine the social integration of children with Down syndrome into their classroom communities, it is similarly indicated that the degree to which these children are socially integrated with their typically developing peers is less than expected. Kliewer (1998) discusses the three cultural representations of children with Down syndrome in the inclusive school system, which he refers to as “the alien,” “the squatter,” and “the citizen.” The representation of “alien” focuses on assumptions of community burden and presumes that children with Down syndrome are intellectually and developmentally defective. This defectiveness is deemed as foreign and burdensome and places unfair demands to teachers and nondisabled students. The consequence of this representation is that children with Down syndrome are segregated from their typically developing peers with brief forays into the larger school community. The “squatter” representation retains the view of children with Down syndrome as community burdens with reduced educational potential; however, they are given access to the periphery of the regular education community. Here, while inclusion is viewed as a democratic right, a new border is created within the classroom from which the student with Down syndrome can peripherally access the classroom environment. The representation as “citizen” is one where children with Down syndrome are viewed as valued members of the general education classroom community and a child’s developmental functioning is not considered as setting the conditions for community acceptance.

The above findings suggest that the lack of full social integration continues to be an issue that presents problems to the full integration of children with developmental disabilities, including those with Down syndrome, in inclusive education. This raises relevant questions regarding whether parents of children with Down syndrome take into account the social consequences of inclusion when making educational choices for their children. In this study, I examined the attitudes and perspectives of mothers of children with Down syndrome regarding the benefits of inclusive education and their understanding of the nature of the social relationships that exist in inclusive and segregated settings. The identities of these mothers were explored as inextricable from the activities that they engage in related to accessing mainstream education for their children or to their enactment of otherness through advocacy for specialized educational settings for their children.

Parent Perspectives on Inclusive Education

There has been considerable research focused on parents’ perspectives on the benefits and drawbacks of inclusion for their children as well as their understanding of this educational practice. Erwin and Soodak (1995) explored parents’ understanding of inclusion and found that among those who advocated strongly for placement in general education classrooms, inclusion represented belongingness, group membership, and access to the mainstream. Additionally, these authors highlighted that, in discussing their reasons for their commitment to inclusion, these parents raised pertinent issues of social justice, equal opportunity, and fundamental civil liberties. Similarly, Soodak and Erwin (2000) indicated that parents who are committed to inclusive education for their children view it as an avenue for community membership and belongingness. It is generally noted in the research literature that parents whose children participate in inclusive settings report a range of positive perceptions about inclusive education. According to Ryndak et al. (1995), parents of children with moderate and severe disabilities reported overwhelmingly positive outcomes for their children who had participated in general education classrooms. These authors found that parents perceived numerous benefits of this kind of schooling for their children, including increased acquisition of academic and social skills, increased vocabulary, improved coping skills, and an increase in social interaction with nondisabled peers. Similarly, other studies have highlighted parents' beliefs about inclusive education as leading to increased academic gains among children with disabilities as a result of a being in stimulating learning environments, as associated with increased social gains, and as an avenue for the acceptance of individuals with disabilities in the larger community (Grove & Fisher, 1999; Palmer, Fuller, Arora, & Nelson, 2001; Rafferty & Boettcher, 2000). However, it is also found that the nature and severity of the child's disability as well as the child's age may be a factor in parents' support for inclusive education. Parents whose children have severe disabilities do not support inclusive education to the same extent as parents whose children have mild disabilities (Palmer et al., 1998, 2001; Rafferty & Boettcher, 2000). Kasari, Freeman, Bauminger & Alkin (1999) indicated that parents of children with Down syndrome were more likely than parents of children with autism to endorse inclusion as an educational placement, and parents of younger children and of children who were already placed in inclusion programs had more favorable attitudes toward inclusion than parents of older children or those whose children were attending separate special education programs.

While inclusive education is generally perceived positively by the parents of children who attend these programs (Rafferty & Boettcher, 2000), a number of studies also highlight some of the concerns that parents raise regarding this educational practice. In discussing negative perceptions about inclusive education for their children with disabilities, parents generally raise concerns about teachers’ lack of competency, preparedness or willingness in working with children with disabilities, and hold beliefs about general education classrooms as being unwelcoming of children with disabilities (Palmer et al., 2001; Ryndak, Storch & Hoppey, 2008; Turnbull & Ruef, 1997). Additionally, studies show that issues concerning the social isolation of children with disabilities in inclusive classrooms are predominant concerns among parents, and that parents’ lack of support for inclusive education is linked with their beliefs about inclusive classrooms as presenting greater threat for peer rejection of children with disabilities than self-contained classrooms (Freeman & Alkin, 2000; Garrick-Duhaney & Salend, 2000; Turnbull & Rueff, 1997). Guralnick (1995) noted that parents of children who are in inclusive settings *and* in specialized classrooms perceive rejection to be more likely to occur in inclusive settings. These concerns are pertinent to issues in the field of inclusive education and may well underlie parents’ resistance to or their lack of enthusiasm for inclusive programs (Guralnick, 1994). Additionally, studies have explored the interactions that occur between and among the *parents* of children with and without disabilities in inclusive settings. Bailey and Winton’s (1987) comprehensive analysis of the friendship patterns among parents whose children were in inclusive classrooms indicate that parents of children without disabilities tend to be more likely to interact with other parents of children without disabilities than with the parents of children with disabilities. Erwin et al. (2001) question the extent to which parents perceive that they *themselves* will experience social exclusion if their children participate in settings where other families are unlike their own.

Parent’s perceptions regarding the practice of inclusive education as an appropriate and beneficial schooling option are important in placement decisions for children with developmental disabilities. While the perceptions and beliefs of teachers and school districts are critical in placement decisions, it can be argued that when parents have positive beliefs and expectations of inclusive education, they are more likely to advocate for this particular option for their child. Parents who have negative beliefs regarding inclusion or those that are not aware of this placement setting as a beneficial option are likely to concur with a placement decision that identifies a separate classroom as the most appropriate one for their child. The existing literature on parents’ perceptions on inclusion is largely based on samples of parents whose children already attend general education classrooms. Studies addressing the beliefs regarding inclusion of parents whose children attend segregated classrooms are few. Similarly, the beliefs and attitudes towards inclusion of parents of young children with developmental disabilities who have not yet begun preschool is a topic that has been underexplored. This study aims to fill a void in the area of understanding the expectations and beliefs about inclusion of parents whose children with Down syndrome who are transitioning to preschool as well as of those whose children are already attending specialized or inclusive schools. Ultimately, in this study, mothers' resistance to a dominant narrative of otherness as well as their yielding to notions of otherness through activities related to the education of their children provides the lens for understanding their constructed identities and their interpretations of the meaning of having a child with Down syndrome.

Objectives and Significance of the Study

In this study, I examined the experiences of mothers of children with Down syndrome in the context of the social constructions of disability and normalcy in society. Historically, the story of families of children with disabilities has been told through clinical and medical perspectives. Arguing that any attempts to understand this experience must necessarily include the perspectives of the family members themselves, in this study, I have explored the lived experiences of mothers of children with Down syndrome, allowing critical questions to emerge from the stories they tell about the birth of their children and their daily activities related to mothering. Using this approach, this study aims to challenge the dominant social and medical discourse regarding outcomes for families of children with developmental disabilities and to give mothers of children with Down syndrome a voice in representing their lives and interpreting the meaning of their lived experiences.

Emphasizing sociocultural perspectives on the nature of psychological phenomenon, the study situates the meaning of mothering a child with Down syndrome in the context of oppressive dominant discourses on being the parent of a child with a developmental disability, both at the interpersonal and institutional levels. At the same time, based on theoretical perspectives that individuals are not passive in the process of meaning-making, the engagement of mothers of children with Down syndrome in contextualized and culturally embedded activity is the lens through which these mothers' process of constructing identities is understood. Through this study, I aim to elucidate the ways in which mothers' of children with Down syndrome negotiate their identities, through collaborative activity and social discourse, and ultimately come to make meaning of this transforming life event. By focusing on the process through which mothers position themselves and are positioned through their interactions, discourse, and activities, the study aims to highlight both the situated as well as the agentic nature of the act of identity construction. Through an exploration of these mothers' understanding about issues of belongingness as well as the enactment or resistance to notions of otherness in their everyday parenting activities, the study aims to understand the performed identities of these mothers.

In challenging widely held assumptions regarding outcomes for families of children with Down syndrome and in exploring the experience of having a child with Down syndrome as one that is culturally embedded rather than as a universally acknowledged "tragedy," this study aims to contribute to the ongoing dialogue on the meaning of disability in society and highlight the socially embedded meaning of normative motherhood.

Research Questions

This study addresses many broad questions regarding outcomes for families of children with developmental disabilities and the ways in which having a child with Down syndrome is experienced by mothers. In the earliest stages of conceptualizing this study, I was interested in the ways in which mothers of children with Down syndrome come to make sense of their experiences in the context of a dominant discourse on disability. However, new questions emerged as the study proceeded; in listening to the narratives of the mothers, questions related to the ways in which mothers resist the discourse and participate in meaning-making emerged. In listening to the mothers, I also began to understand the importance of focusing on issues of belongingness and resistance to otherness as key aspects in the enactment of their identities. Furthermore, questions related to the ways in which their engagement in daily activities and their beliefs regarding their children's education are intertwined with their identities became important. As a result, research questions became defined and redefined through the process of conducting the study. Ultimately, I was able to identify three broad categories of specific research questions, which are identified below.

Research Questions Related to the Meaning of Down Syndrome

Consistent with the social paradigm of disability which emphasizes a view of disability as a culturally embedded phenomenon as well as recent literature on critical disability narratives (Biklen, 2000), the research questions in this category relate to the meaning-making processes engaged in by mothers of children with Down syndrome and to the ways in which their experiences are embedded within the contexts of a social, political, and medical discourse on the birth of a child with Down syndrome. The specific research questions here are:

1. How do mothers experience the birth of a child with Down syndrome?

2. What are mothers' perceptions of the dominant discourse on disability, both at the interpersonal and institutional levels?

3. Are mothers' initial perceptions following a diagnosis of Down syndrome influenced by their interactions with medical professionals and the language used by physicians in delivering a diagnosis?

4. Where do mothers of children with Down syndrome locate their child's disability?

5. How do these mothers participate in constructing the meaning of their experiences and of Down syndrome?

Research Questions Related to the Construction of Identity

Consistent with current literature on the familial experience of the presence of a child with a developmental disability in the family (e.g., Ferguson et al., 2000; Goddard et al., 2000), the questions in this category aim to explore the lived experiences of mothers of children with Down syndrome and the extent to which they resist the dominant discourse on parenting a child with Down syndrome. The questions in this category focus on how these mothers negotiate their identities and define themselves as mothers. These broad objectives are guided by the following specific research questions:

6. How do mothers of children with Down syndrome position themselves as mothers in discourse and activity?

7. How do mothers of children with Down syndrome represent their lives and how do they interpret their familial experiences?

8. What do mothers of children with Down syndrome want others to know about their lives and their families?

9. To what extent do mothers of children with Down syndrome resist the dominant discourse in daily activities related to parenting?

Research Questions Related to Mothers' Understanding of Inclusion

Building on existing research concerning mothers' attitudes towards school inclusion (e.g., Erwin & Soodak,1995; Turnbull & Winton, 1983) as well as findings that highlight issues of social acceptance as important concerns for mothers of children with Down syndrome (Lalvani, 2008), the questions in this category explore the ways in which the identities of mothers of children with Down syndrome are performed through their preference or advocacy for particular educational settings for their children. These questions relate to the enactment and the resistance to otherness in these mothers' beliefs about, as well as their support for, inclusive education for their children. The specific research questions here are:

10. What are the perceptions and beliefs of mothers regarding inclusive education for their children with Down syndrome?

11. To what extent do the perceived social implications of Down syndrome play a role in mothers' preferences regarding particular schooling programs for their children?

12. How do mothers enact their identities in the context of activities related to education of their children with Down syndrome?

CHAPTER 2

RESEARCH METHODS

Study Plan

In this study, I took the standpoint that, in order to understand mothers' experiences of having a child with Down syndrome, the starting point of knowledge must be the mothers themselves. Based on this grounding assumption, I used a narrative analysis approach, which is an appropriate method for achieving the objectives identified for this study. Using qualitative methods, in-depth narratives were collected from mothers about the birth and diagnosis of their child with Down syndrome, their perceptions of being a mother, and the ways in which they make sense of their experiences in the context of the society in which we exist. This method is consistent with the study's emphasis on the social contexts within which meaning is derived. Mothers generated stories in response to open-ended questions; however, their stories guided my questions to a great extent. This is consistent with Standpoint epistemology (Harding, 1993) which stresses that the shared and situated perspectives of those who have been marginalized provide the "grounds" for knowledge or the "sites" from which critical questions emerge.

Participants

The participants for this study were 19 mothers of children with Down syndrome residing in the New Jersey area. The ages of their children diagnosed with Down syndrome ranged from approximately 6 months to 6 years. At the time of the interviews, the ages of the mothers in the sample ranged from 24 years to 48 years. In terms of ethnicity and background, the sample was comprised of women who identified themselves as Caucasians (15), African-American (1), Filipino (1), Spanish (1), and Biracial(1). While this sample is not representative of a wide range of diverse groups in terms of ethnicity, it should be noted that these mothers were not homogeneous in terms of their family backgrounds, lifestyles, and family structure. The mothers hailed from middle-class and working-class backgrounds. In terms of religiosity, the sample consisted of women who identified themselves as Christian, Catholic, Islamic, Jewish, Orthodox Jewish, and non-religious. The majority of the mothers in the sample were married, 2 were single mothers, and 1 was in a domestic partnership with her long-term girlfriend.

Of the 19 participants in the study, 8 had received a prenatal diagnosis of Down syndrome after having prenatal genetic testing; all the rest became aware of their child's diagnosis after their birth. Among the mothers who did not have a prenatal diagnosis, 3 reported that they had not undergone prenatal genetic testing because it had not been offered or recommended by their doctors, and 8 reported that they had voluntarily opted to forgo prenatal tests despite their physicians' recommendations. Their explanations about why they had declined prenatal testing included concerns regarding the risk of miscarriage or their commitment to carrying their pregnancies to term despite what prenatal tests would have indicated. While some mothers in the sample expressed religious reasons for declining prenatal tests or for their commitment to their pregnancies after a diagnosis of Down syndrome, the majority of the mothers in the sample expressed that religiosity was not a factor, either in their refusal to have prenatal testing or in their decisions to continue their pregnancies after a positive prenatal diagnosis of Down syndrome. Indeed, some of the women in the sample made it a point to emphasize to me that they were “pro-choice.”

Some of the mothers in the sample had children with Down syndrome who were in the early intervention system; others had children with Down syndrome who attended preschool or elementary school, in kindergarten or first grade. Among the 13 mothers whose children with Down syndrome were of school age, 4 had children who were enrolled in inclusive classrooms and 9 had children in separate, specialized classroom/school settings. Due to the fact that this study is concerned with understanding the early experiences of mothers of children with Down syndrome and the ways in which they make sense of their children’s diagnosis, only mothers of young children with Down syndrome were included in the sample. Another reason for recruiting only mothers of younger children is the study’s focus on mothers’ early beliefs and expectations of the practice of school inclusion and whether or not their preference of any particular educational placement reflects their concerns about social acceptance of their children.

Of the 19 mothers, 17 had children in addition to their child diagnosed with Down syndrome. Among the group of 35 siblings, 2 were diagnosed with a developmental disability other than Down syndrome. Of the 19 mothers in the sample, 2 had professional experiences with children with disabilities prior to having their own children; 1 as a special educator and 1 as a speech therapist. All others reported that they had had limited contact with individuals with disabilities prior to the birth of their own children with disabilities. Notably, despite the variability in the backgrounds of these mothers, each mother in the sample shared a strong willingness to participate in this study as well as a desire to tell their stories from their own perspectives.

Procedure for Recruitment

Participants for the study were predominantly recruited from Stepping Stones, ARC, which is a learning program for infants, preschoolers, and children with developmental disabilities up to the age of 9 in Livingston, New Jersey. The program provides individualized instruction and therapeutic services for children through early intervention and specialized schooling. While the program is intended for children with a variety of developmental disabilities, it specializes in the educational and therapeutic needs of children with Down syndrome and is predominantly attended by children with Down syndrome. The early intervention program costs are paid by the families of the children on a sliding scale basis. Tuition for the specialized school is generally paid by school districts. My own association with this program is non-professional; I have no professional affiliation with it.

Mothers whose children attend programs at Stepping Stones were recruited for this study. Flyers pertaining to the study were posted at the center and they were also distributed to parents by the program’s social worker. Additionally, I obtained permission to speak with families at the weekly parent group that is held at the facility. During a scheduled parent group, I introduced my project as one that is aimed at understanding what it is like to be the mother of a child with Down syndrome from the viewpoint of the mothers and at gaining a better understanding of families of children with Down syndrome. I explained to potential participants that the study is an opportunity to tell their stories from their own standpoint and to contribute to the ways in which disability is defined in our society. I explained the amount of time that would be needed in order to participate in the study and gave a brief overview of the procedures that would be involved. I provided brief written information that described the project as well as my contact information informing them that they may contact me directly if they should choose to participate. Mothers who were interested in participating contacted me via email or phone in order to schedule a convenient time for an interview.

Additionally, participants were also recruited via word of mouth. I handed flyers containing information about the study and my contact information to the mothers who participated in the study and requested that they provide these to other mothers of children with Down syndrome that they may know. This served as an additional recruitment method. Mothers contacted me by phone or email and were recruited for the study. Additionally, some mothers in the study spontaneously shared information about this project with other families of children with Down syndrome that they knew and I was contacted by mothers seeking to participate in the study.

Procedure for Data Collection

Prior to making contact with participants or commencing data collection, an Institutional Review Board application was submitted and approved by the CUNY Graduate Center. (Please see Appendix C, which contains Institutional Review Board related materials, including the Informed Consent Form.)

Data were collected through semi-structured interviews conducted with mothers of children with Down syndrome. I arranged to meet with mothers at a time and location that was convenient to them. The location for the interviews varied, ranging from a room at Stepping Stones, the mothers' homes, my own home, or local coffee-shops depending upon mothers' indications of what would be most convenient and would present maximum opportunities for an unhurried conversation. On occasion, the mothers were accompanied by their infants or young children during the interviews.

Before commencing the interviews, the consent forms were discussed and signed (see Appendix C, Consent Form). Additionally, I asked the mothers to provide demographic information, on age of mother, age of child with Down syndrome, ages of other children; ethnicity, family structure, education level, and occupation of mother. Once this was completed, I commenced the interviews. I asked a series of open-ended questions and, in responding to these, each mother generated an extensive and detailed narrative related to the birth and diagnosis of her child with Down syndrome and their experiences as a mother. The interviews were guided by open-ended questions that were intended to focus the narratives on particular aspects of mothers' experiences, such as, details of their pregnancies, when and how they became aware of their child's diagnosis of Down syndrome, their interactions with medical professionals, the reactions of others following their child's diagnosis, and so on. Following questions of this nature, mothers were asked to reflect upon their perceptions of their present lives as mothers, as well as their expectations for their children's futures. Additionally, mothers were asked to discuss their beliefs and perceptions about inclusive education and if their child was already attending school, to discuss what kind of classroom or school program they had been placed in. These questions pertained not only to mothers' recollections of particular events and interactions, but also their interpretations of the same. (Refer to Appendix A. for a detailed interview protocol that was used.) It should be noted that, while the questions on this protocol provided a framework for the generating of the narratives, the narratives were not strictly directed by these questions, nor were the questions necessarily asked in this particular order. Using the clinical method, the content of the narratives were guided by the questions; however, once the interviews had begun, the issues raised by the mothers themselves served as starting points for inquiry. To a great extent, mothers determined what they wanted to focus upon and generated “stories” spontaneously about those aspects of their experience that were meaningful or significant to them. The interview protocol served to fill gaps in stories or to generate thought in areas that were not spontaneously raised by the mothers. This method is consistent with Harding’s (1993) Standpoint epistemology; the critical questions emerged from the stories of the lived experiences of these mothers and the situated meaning of their experiences.

As part of the methodology, the mothers were also asked to engage in a Q-sort task. For this part of the interview, I asked them to sort a stack of index cards containing statements that characterize the rhetoric that parents may encounter in social discourse in response to the birth of a child with Down syndrome. I instructed mothers to sort the stack of cards into two piles: (a) those containing statements that resonate with their own experiences or are representative of statements that they had heard after the birth or diagnosis of their child and (b) those containing statements or reflecting sentiments that do not resonate with their own experiences in the days following the birth or diagnosis of their child. The cards contained statements that were characteristic of the dominant discourse on families of children with disabilities as well as those that represent an alternative view of this experience. I compiled this list of statements largely based on anecdotal conversations with families of children with developmental disabilities over a period of time. (Please refer to Appendix B for the list of statements that were contained in the Q-sort cards.) Additionally, I asked each mother to create three more cards, containing recollections of reactions, either positive or negative, that they received from others in response to the news of their child's diagnosis or a description of any interpersonal or professional interaction that was particularly significant to them with regards to the birth of their child with Down syndrome. The purpose of using the Q-sort was to generate "stories" about the nature of the discourses on families' of children with Down syndrome. Further, the stories generated in response to the Q-sort cards were intended to highlight the ways in which these mothers are positioned and position themselves through social discourse.

Each interview lasted between 2 and 4 hours. Mothers were provided with a compensation for their participation in this study. They were asked to choose a children's book from among a few that featured a child with Down syndrome as its main character and contained themes of inclusion for children with disabilities, as well as a memoir written by a parent of a child with a disability. All interviews were audio-recorded. Written field notes were also made immediately following the interview about any relevant aspects of the interview sessions that are not captured on audiotape.

Time-Lines for Data Collection

This study utilized data from interviews that had been conducted with 9 mothers of children with Down syndrome for a previous study. In addition, 10 more participants were recruited. In order to include the data from the original 9 participants in a meaningful manner, I met with those mothers once again after a period of approximately 2 years had lapsed. This provided an opportunity to meet with them again and conduct a second interview during which I asked questions concerning aspects of their experiences which had not been the focus of the original study, particularly those that pertained to their beliefs about inclusive education and their efforts to gain access to mainstream educational settings for their children. The second interviews with these 9 participants provided in-depth information about how they currently perceived themselves as mothers and filled gaps in the narratives concerning the ways in which they enact their identities through activities related to the education of their children. Consequently, the data for this study were obtained from interviews that were of two types: (a) those conducted at a single time, providing a single snapshot of lives and (b) those that were conducted at two stages providing two snapshots of the lives of these mothers each separated by a period of approximately 2 years. The data obtained in these 2 ways were combined; data from all 19 participants were analyzed in the same way, and are presented together in this study.

Procedure for Data Analysis

All audiotaped interviews were transcribed. The transcribed interviews ranged in length from approximately 20 to 39 pages. During the initial stage of data analysis, I listened to audiotapes and reviewed the transcribed interviews exhaustively for commonalities in the core experiences of the mothers and for shared perspectives on their interpretation of their experiences. This is consistent with Bogdan and Biklen’s (2002) approach to qualitative data analysis as well as with the Emergent Themes Approach. Glaser and Strauss (1967) describe the Emergent Themes Approach (ETA) as a method for analyzing data in which conceptual themes emerge from the evidence rather than the other way around. ETA is closely related to a qualitative research approach known as Grounded Theory (Strauss & Corbin, 1990), in which researchers do not seek to support or verify already established theories and instead allow hypotheses or conceptual codes for data analyses to arise from the data. Generating hypotheses by listening to what research participants say and by using their subjective experiences as primary sources of knowledge allow for meaningful theories to emerge (Auerbach & Silverstein, 2003). As a method of data analysis that supports this particular view on theory building, the Emergent Themes Approach begins by documenting all recurrent patterns in the available information in a non-discriminate manner. This allows the researcher to consider all possible directions in data analysis rather than becoming focused on predetermined areas of relevance. Further, this ensures that the theories which will eventually emerge will indeed be of relevance to the area of inquiry. When particular patterns are observed with some frequency, codes can be identified which may then be organized into broad conceptual categories of findings. In this dissertation, codes for analyzing data were identified only after the process of listening to and transcribing interviews was completed. In the first stage, I made notes of all patterns in the narratives in a non-discriminate manner and identified codes based upon frequency and consistency of shared experiences or perspectives reported in the stories of the mothers. Following this, more abstract stratifications or coding categories were identified, each consisting of a cluster of codes containing salient and discrete accounts or perceptions that appear to pertain to a broader conceptual phenomenon. Once the core categories of shared experiences were identified, the data were coded based on identified codes. To further ensure authenticity of codes, I made use of “in-vivo” labels (Strauss & Corbin, 1990) for the codes, i.e., the labels for the codes were derived from verbatim words used by the mothers in the study. Whenever gaps were found in the data, I made phone contact with the mothers and asked them to fill the gaps or to clarify the information. This is consistent with Strauss and Corbin’s (1990) methods in which the researcher returns to the field to seek clarifications from those who are most qualified to provide these. All of the data analysis and coding was done by me.

Final Coding Scheme

Drawing from the emergent themes approach (explained above), codes were identified and defined. The identified codes organized mothers’ perceptions and interpretations of the events, actions, and verbal exchanges that surrounded the birth of their child with Down syndrome as well as those that are descriptive of their present lives. The final codes that emerged are identified and described below.

1. Initial Interpretation of Diagnosis: Mothers’ descriptions of their initial reactions to their child’s diagnosis of Down syndrome as well as their early perceptions of what life would be like for themselves and their family were coded here. This code also pertained to descriptions of mothers’ initial image of a child with Down syndrome and of outcomes for their child or their family.

2. Mother’s Perceptions of Medical Discourse: Mothers’ recollections of interactions with medical or clinical professionals following a diagnosis of Down syndrome, either during the prenatal or post-natal stage, were coded here. Data coded here pertained to mothers’ perceptions of the language, affect, and actions of professionals in relation to a diagnosis of Down syndrome as well as in relation to prenatal genetic testing.

3. Becoming Positioned Through Discourse and Activity: Mothers’ accounts of verbal and non-verbal social interchanges in response to their child’s having Down syndrome were coded here. Additionally, mothers’ stories about the kinds of comments

they heard from others with regards to the nature of being a parent of a child with Down syndrome or the nature of families of children with Down syndrome were included in this code.

4. Positioning the Self Through Discourse and Activity: This code included mothers' recalled accounts of their own verbal and non-verbal contributions during social interchanges pertaining to their child's diagnosis and any activities through which they attempted to communicate their interpretation of having a child with Down syndrome or of their familial experience. This code also pertained to efforts made by mothers to actively seek explanations or interpretations of Down syndrome and of outcomes for people with Down syndrome and their families beyond those that were provided by medical or clinical professionals.

5. Mothers' Contextualized Understanding of Down Syndrome: Aspects of the narratives in which mothers refer to their understanding of the nature of disability or Down syndrome as being socially embedded are coded here. This code also included mothers' references to cultural attitudes towards disabilities and differences, their beliefs about which children are "valued" in society, and their perceptions of the extent to which children with Down syndrome are socially accepted by society in general.

6. Resistance to Otherness: Any aspects of the narratives that pertain to mothers' resistance to the notion that children with Down syndrome are different in a significant way from children in general or that their parenting experience is significantly different from parenting per se were coded in this category. Also coded here were statements that reflect mothers' rejection of labels like "special parent" and of notions that mothers of children with disabilities have any sort of exceptional qualities.

7. Alternative Interpretations of Mothering a Child with Down Syndrome: Descriptions of daily life as a mother of a child with Down syndrome or a mother in general and perceptions of the quality of life of their family are coded here. Statements that illustrate mothers' resistance to the dominant discourse on the familial experience of having a child with a disability and to assumptions of grief, tragedy, and unmitigated hardship among these families are coded here.

8. Enacting Alternative Meanings of Down Syndrome: This included accounts of mothers' engagement in organized activities or informal interchanges related to raising awareness or educating others about their child and/or about Down syndrome. It also included mothers' efforts to gain greater levels of acceptance or access to mainstream settings for their children, either on an interpersonal or institutional level. Additionally, it included the mundane parenting choices of these mothers as well as less mundane and more significant decisions, such as those related to prenatal genetic testing in subsequent pregnancies.

9. Constructing Motherhood and of the Nature of “Child”: Aspects of narratives in which mothers reflect upon their understanding of the nature or expectations of motherhood and of what it entails are coded here. Also included in this code were mothers' perceptions of what motherhood is expected to be in society and their own responses to these societal beliefs. Additionally, statements that pertain to these mothers' definitions or understanding of normative childhood or normative motherhood were coded here.

10. Classrooms as Venues for Belonging: Aspects of the narratives which pertain to mothers' descriptions of particular classroom settings (either inclusive or self-

contained) as places where their child naturally belongs or where the child would “fit in” were coded here. Also included in this category were references to their child’s “rights” to be in particular educational settings.

11. Classrooms as Venues for the Enactment of Otherness: Descriptions of self-contained classroom settings as places where the exceptional needs of their child can be best addressed or expressed beliefs that specially trained individuals are necessary in order to meet the educational needs of their child were coded here. Additionally, mothers’ expressed beliefs that their children’s behavior, cognitive level, or other abilities are different from typically developing children, such that inclusive classrooms settings would be inadequate to meet the special education goals of their education were coded here.

12. Inclusive Classrooms as Venues for Exclusion: Mothers’ reflections about the extent to which they believe their child will be socially accepted or excluded in inclusive classroom settings were coded here. This category included any comments or expressed concerns about whether their child (or children with disabilities in general) would be teased, rejected, or shunned in inclusive settings as well as concerns regarding whether their child with Down syndrome would have friendships, social networks, or be a fully accepted member of such a classroom.

Once these codes and their operational meanings were identified, I then clustered them into categories of codes based on the broader and more abstract phenomenon to which they relate and which ultimately inform the objectives of this study. The three conceptual categories or clusters of codes are described as follows:

The Contextualized Meaning of Disability

This cluster includes codes that pertain to mothers' interpretations of the experience of having a child with Down syndrome within a sociocultural context. It includes perceptions about their initial reactions to their child's diagnosis, accounts of their verbal and non-verbal interchanges with medical and non-medical people following the birth and diagnosis of their child, accounts of their engagement in activities to shape others' understanding of Down syndrome, activities related to seeking alternative interpretations of disability or the lived experiences of families of children with disabilities, and their descriptions of their understanding of the nature of having a child with Down syndrome.

This category relates to those contextualized and culturally embedded experiences that define the mothers' early perceptions of the meaning of their child's diagnosis and of their expectations for their family as well as their engagement in social activities that contribute to the ways in which they come to define the meaning of their experiences. The codes in this category inform research questions related to the sociocultural embeddedness of the phenomenon of disability and of the familial experience of raising a child with a disability. It is important to note that the data coded in this category relate to the process through which mothers become positioned as well as position themselves through interpersonal and institutional discourse, and as such, shed light on both the culturally embedded as well as agentic nature of these mothers' process of meaning-making with regards to having a child with Down syndrome.

Constructing the Self

The cluster of codes in this category pertains to mothers' perceptions of their lives and those of their families and the ways that they define their experience of motherhood. Codes that pertain to mothers' resistance to the dominant discourse on families of children with disabilities and their alternative interpretations of this familial experience are included here. Additionally, this category contains codes that relate to mothers' resistance to being positioned as "other" and to their efforts to shape the discourse about families of children with Down syndrome. More broadly, this category pertains to the ways in which the selves of mothers' of children with Down syndrome are constructed through collaborative activity and social discourse. The data coded in these codes elucidate the profoundly social as well as agentic nature of identity construction and ultimately contribute to an understanding of the situated nature of the meaning of motherhood itself and of notion of the normative child.

Performing Selves in the Context of Inclusive Education

The codes in this category pertain to mothers' beliefs, perceptions, and expectations about their child's education, particularly those that relate to the placement of their child with Down syndrome in either inclusive or self-contained classroom settings. These codes organize aspects of mothers' narratives that speak of their understanding of classrooms or school settings that would be most appropriate for their child with Down syndrome. Codes pertaining to mothers' beliefs about where their child with Down syndrome does or does not belong as well as their expressed concerns regarding issues of social acceptance or exclusion of their children by peers in classroom environments are included in this broad category.

The tables shown below provide further clarity into the organization of the coding scheme. Each table is illustrative of a broad category of findings and identifies all of the codes contained in it with operational definitions and paraphrased examples from the narratives.

Table 1

Codes Related to the Constructed Meaning of Disability

	Code	Description	Paraphrased Example from Narratives
A1	Initial interpretation of diagnosis	Accounts of initial reactions to their child's diagnosis, accounts of early perceptions of what life would be like for themselves and their family, descriptions of initial image of child with Down syndrome	*It was like the earth opened up and swallowed me into a pit.*
A2	The medical discourse on families of children with disabilities	Recollections of the way that their child's diagnosis was conveyed by medical professionals, perceptions of the language and actions of doctors, information and recommendations provided by medical or clinical professionals.	*I have some bad news* - *Your baby has Down syndrome. I'm so sorry.*
A3	Becoming positioned through discourse and activity	Accounts of verbal or non-verbal social interchanges with regards to their child's diagnosis of Down syndrome.	*You must be a saint to choose to raise a child like that* - *I could never do it.*
A4	Positioning the self through discourse and activity	Stories about mothers' responses to people's reactions, attempts at shaping people's perceptions or at conveying alternative interpretations of the diagnosis, seeking contact with other individuals with disabilities or their families.	*I said to people* - *don't be sorry. I'm not.* *I told the nurse* - *I just needed to meet another child with Down syndrome. If I could just see another child with Down syndrome, I would understand what it means.*
A5	Contextualize understanding of disability	Mothers' reflections on what disability means in society, beliefs about the social implications of Down syndrome.	*I don't get sad about my daughter. I get sad about the way the world views her and values her.*

Table 2

Codes Related to the Constructing the Self

Code		Description	Paraphrased Example
B1	Resistance to a discourse of otherness	Expressions of disagreement with the notion that children with Down syndrome are different in a significant way, rejection of the notion that their parenting experience are significantly different than those of other parents or that they have exceptional qualities as mothers.	*We're not special parents - We're just normal like everyone else.*
B2	Alternative Interpretations of families of children with Down syndrome	Descriptions of daily life as a mother; descriptions of family life; perceptions of quality of life of family; resistance to the discourse of "devastation," grief, and unmitigated hardship among families of children with Down syndrome.	*(a) I have a busy life, but my life is satisfying. I would not change it.* *(b) People think it's all work and that we have no fun. I disagree. We have lots of fun.*
B3	Enacting identity	Accounts of participation in activities related to disability awareness or disability advocacy, efforts to gain access to mainstream settings for their child, accounts of particular courses of action taken for their families	*(a) I fought for inclusion from the time she was a little girl.* *(b) For my subsequent pregnancy, I did no prenatal tests.*
B4	Interpretations of motherhood and the meaning of child"	Reflections on the nature of motherhood and what it entails, reflections of the nature of normative childhood.	*It's not supposed to be perfect - being a mom is hard whether or not your child has Down syndrome.*

Table 3

Codes Related to the Meaning of Inclusive Education

Code		Description	Paraphrased Example
C1	Classroom as places of belonging	Descriptions of either inclusive or self-contained classrooms as the place where their child “belongs,” would be most accepted or would “fit in,” beliefs about access to inclusive classroom as a matter of “rights.”	*I want him to always have a place where people understand him and don’t expect him to be perfect in a way that they might in a typical class.*
C2	Classroom as places for the enactment of otherness	Beliefs about self-contained classrooms as places where the “exceptional” needs of the child can be addressed, descriptions of inclusive classrooms or general education teachers as lacking in the area of addressing “special” needs.	*In a specialized environment, I know that the teachers and the teacher’s assistants are all trained especially for special needs and so I know that they would have the patience and the understanding, the training and the ability.*
C3	Inclusive classrooms as places of exclusion	Reflections about the extent to which children with Down syndrome are socially accepted in inclusive settings, concerns about rejection or teasing, concerns about whether their child will have friends or socially integrated in a general education classroom.	*In an inclusion classroom, I’d like to think that people won’t ridicule her, but I’m not sure whether she would be socially accepted.*

CHAPTER 3

STUDY FINDINGS

Constructing the (M)other: Dominant and Contested Narratives of Normative Motherhood

Stories about their pregnancies and their birthing experiences are ones that many mothers enjoy relating. Accounts of their children, their families, and their lives as mothers are also among those that mothers tend to readily share and, as one might expect, these are often accounts of the accomplishments of their children, the joys related to being a parent as well as the frustrations, stress, or disappointments involved in the realities of parenting. The narratives of the mothers in this study are no different in this regard. Each one tells the story of becoming a mother, of untangling the positive emotions from the negative, and of ultimately discovering the uniqueness of a child. Like the stories of any family, these narratives are filled with accounts of the accomplishments of children, of everyday familial events, of strengths and weaknesses, of happy surprises, of frustrations, difficulties, and challenges. These stories paint pictures of the simultaneously extraordinary and ordinary nature of motherhood. As such, they are about experiences of motherhood that in some ways, were different than what was expected, and in other ways, just as expected. Like many accounts of motherhood, these are stories about the children that these mothers were expecting to have and about the children that they have. Like *any* story of motherhood, these are accounts of the mothers that these women expected to be and the mothers that they have become.

But, while these narratives are like any other, they are also different. The stories of these mothers reveal not only their transition to motherhood, but also their negotiation of access to the category of motherhood. These mothers discuss their encounters with oppressive discourses that create a separate category for children with Down syndrome, and about institutional practices that sustain and perpetuate notions of the "otherness" of children with Down syndrome. Their stories are about being the focus of medical scrutiny and medical dismay, of being the object of pity as well as of social disapproval. They are also about real and perceived exclusion and about their efforts to access the mainstream for their children and their families. Most of all, these are stories about resistance. The narratives of these mothers are their responses to the discourses of grief, tragedy, and stigma that surround the birth of a child with Down syndrome and to assumptions of damaged babies and burdened lives. Finally, these are stories about the competing discourses of normative and "other" motherhood and of mothers' negotiation of the meaning of *child.*

Organization of the Study's Findings

In this chapter, I present the main findings of this study using the codes that were identified during data analysis as a framework for the organization of the findings. As described in Chapter 2, the codes for the analysis of the data emerged through the process of listening to the narratives as well as reviewing transcribed interviews and were used to organize commonalities in the perceptions and interpretations of the mothers in this study. In this way, data analysis was a circular process rather than a linear one. Once the codes were identified, they were then clustered into three broader conceptual categories of codes. In this chapter, I organize the findings of this study into the following three sections, each pertaining to one of the three broad conceptual themes of findings that emerged:

1. Constructing the meaning of disability

2. Constructing the self
3. Enacting identity in the context of education.

Each of these sections begins with an introduction entitled “snapshots,” which contains illuminative and pertinent excerpts from the narrative of a particular mother in this study. The section is further broken down under sub-sections, each of which pertains to data contained under a specific code as outlined in the methods chapter. The headings of the sub-sections are the same as the titles of the codes to which they pertain. Furthermore, “in-vivo” labels (Strauss & Corbin, 1990) are used in addition to the actual title of the codes as the headings for each sub-section to add authenticity to the identified codes. In this manner, using the coding framework as a tool and a guide, the study findings are presented under the following headings and sub-headings:

I. Constructing Disability
  A. Initial Perceptions of a Diagnosis of Down Syndrome
  B. Medical Discourses on Disability
  C. Becoming Positioned Through Social Discourse and Activity
  D. Positioning Oneself in Discourse and Activity
  E. Mothers Contextualized Understanding of Disability, Normalcy, and Down Syndrome
II. Constructing the Self
  A. Resistance to Discourses of Otherness
  B. Alternative Interpretations of Families of Children with Down Syndrome
  C. Enacting Identity

D. Interpreting the Meaning of Motherhood

III. Enacting Identity in the Context of Education.

A. Classrooms as Places of Belonging

B. Classrooms as Places for the Enactment of Otherness

C. Inclusive Classrooms as Places of Exclusion

I. Constructing Disability

Snapshots: Mary's Story

I was having ultrasound and I thought - these are the first pictures of my child! ...When the doctor said Down syndrome, my first reaction was – OK, the baby has Down syndrome and I'm not going to think it doesn't. Even though I don't have test results. Because I'd rather think this way and get news that it's the opposite than think the other way and then, you know, then find out.

So, I was there and this lady was like, overly sympathetic, like, I'm so sorry for you. . . . And she starts talking about the trisomies and Down syndrome. My mom started to cry. . . . My husband was just quiet. . . . I said: "Well, if it's Down syndrome, that's fine. I can do Down syndrome." I said it like that - "I can do Down syndrome." And she's like: "Well, you know, you have to understand what it involves. He can have hydro – what's it? Hydrocephalus? You know, from the beginning, it's going to be a bumpy road." And she starts going into everything that can faze us. You know - all the health issues. But she never retracted, or said, you know, there's a different side to it – they do, they can have very productive lives. There's a lot going on with Down syndrome - research –

schooling. She never showed us the other side. And by not doing that, I felt that she did not recognize from the beginning that I was, in my mind, I was OK with what happened. She never turned around and said anything about that. Which made me very upset. She never gave me a sufficient packet of information to walk away with. I think she was more, trying to tell me everything that could go wrong, because I think in her mind, the best decision would have been an abortion. And also, her facts were very, not up-to-date. . . . She never said: “I acknowledge what your feelings are so let me work from there.” She just laid out what would be a lot of negative things.

My mom was very upset. And my husband was quiet. . . . I felt very alone. I felt that I want to have this baby, no matter what, and why didn’t somebody acknowledge that? I was still pregnant with a baby that I want. It’s still a baby and it’s going to be wonderful and we’ll treat it in a wonderful way. All of a sudden I felt like - I couldn’t let people rob me of that, rob the baby of that. Because all of a sudden, everything is knocked out from under you, and then you and people around you start to rebuild your foundation.

People started to feel sorry for me, and I started to hate that. . . . Everybody started saying “I’m sorry” and “I’m sorry.” . . . Having people apologize to you, it made me feel very sad and very bad. We went to a Christmas party at my aunt’s house and that’s where I confronted more people who started saying to me: “How can you do this? This is going to be a tragedy.” . . . My uncle (said): “This is a tragedy to do this to the baby. Why would you do this to the baby by having it?” I said: “This is not a tragedy for the baby. What you’re telling me is that this is a tragedy for you. I think this is a bigger issue for you, and its people like that give problems to people with Down syndrome.”

The next four months I spent finding out about Down syndrome. I found out about Stepping Stones. I got in contact with some parents - I actually called a lady who had a boy in Stepping Stones. . . . (I was) feeling like I wasn’t accepted as a pregnant woman . . . I felt that by meeting these people I had a chance to claim my pregnancy back. Mine was a different one and it’s an okay one. . . . You can be pregnant and it can be different. But it can still be - pregnant! And that’s okay. And it can still be this great baby.

I did labor at home. Finally, when it was 5 minutes apart, I went in and I, you know, just had her. Twenty minutes, no epidural - it was a great feeling. . . . Her heart rate was dropping and they said, you really gotta push her out. And I did. My husband and my mother said she wasn’t crying immediately but then, she started crying. They wrapped her up and gave her to me and . . . I said, Oh, my god, she’s so beautiful. She has so much hair and, she looked like my husband and she looked like me and I was so excited to see her.

We were waiting for the surgery. . . . She ended up going to surgery at five weeks. Everyone just marveled at her. All the doctors loved being with her. She was very interactive. . . . Even though I am a Muslim and it was a Catholic hospital, I felt we could get along, and we could talk to each other.

(After the surgery), they sent me to a genetic counselor. (The counselor said): “You know that she’s probably going to have a weight issue.” Like, just like this. . . . “And she’s, you know, she’s probably not going to live very long.” And I’m like, well, first, is it a weight issue - Because you know, we really weren’t giving them as active of a life. And she goes: “No, they’re just predisposed.” So, I started giving her information. I said: “Just in case anyone wants to call me, here’s my number. And here’s this book about a special child - it’s a really great book, mostly on Down syndrome. Here’s the name. And there’s this school if you know anybody who needs . . .” I started giving her all this information. And she’s like: “Wow, thank you so much! “. . . It kind of upset me that she gave me the same stereotypes that everybody else had. She was young . . . Isn’t she supposed to be coming out of school with a lot more information?

My cousin said: “You know, I admire you. Because even looking at my kids right now, I don’t think I would have had them if they had Down syndrome.” . . . People ask me a lot: “Did you have an amnio?” I think people want to get a sense like - were you just surprised when you had this baby or did you actually choose this way of living. . . Sometimes people don’t know she has Down’s and they’d be looking and sometimes I’ll indulge them and say “She has Down syndrome.” And they’ll say: “Oh, okay- So, I was wondering, so, did you have an amnio?” And I can see like, all of a sudden their eyes do this funny thing, like the little brow furrow. And I say “Yeah I did.” And they go into this thing where you know they’re curious, like, how could she have done that. You know, their face just contorts.

Every normal child has issues. You’re a parent. You handle it. You handle all things. I get upset, because I'm like - well, what's your definition of parenting? Oh, it looks really good with my Burberry bag? The baby? . . . I think I'm just being a parent. And maybe they're walking away thinking: "Wow, I'm glad I don't have to deal with what she has to deal with." . . . I really don't like when they say that one.

I feel like (Down syndrome) makes people scared. I really think so. I feel like they get scared. I feel that people - they need normalcy. They need their children to be normal. People want everything to be normal and calm. And having a child with Down syndrome, it would ruin their image. Like remember how I was telling you about the Burberry pocketbook? It's like, a Down's kid doesn't go with one of those!

My life as a parent is very fulfilling. I feel very ambitious. It's very hectic, there's a lot going on all the time. And sometimes it is a little hard for me to digest, because I feel I am young and I am constantly trying to forge ahead and get things done. . . . As a person I feel that I've done so much in the two years since Leila's birth and I've changed so much as a person. I've been more confident because of having this experience than if I'd never had it. I'm afraid of thinking if I never had my daughter, what kind of person would I be . . . I need her. You know, I think it's okay to need your kids, and I need Leila. I don't want you to think that I'm abusing her, like, I'm feeding off her disability and it makes me a better person. No, no, no, no no! It's like I need Katia, my younger one. They just make me feel amazing.

I think that people view my life as being very hard and that I'm putting on a brave face.

> . . . Which I hate ’cause I’m not. They feel that I’m a trooper, yeah – a trooper. I’ve gotten that before.” “You’re a trooper” (laughing). I rather dislike that. Sometimes, I feel like I would want to convince some friends – No, this is not the reality. I’m not putting on a brave face. This is my happiness. It’s different from yours, but it’s the same thing. Happiness. You know, the definition is different, but it’s still happiness.
>
> I’m sad that there are people walking around with these biases. That’s what makes me sad. I’m so angry that people won’t educate themselves. . . . The sadness is not associated with the fact that my daughter has Down’s, it’s associated with the fact that we live in a place where people won’t educate themselves about the diagnosis. You know, we’re living in a world where people are living with Down’s. Don’t you want to know who your neighbor is before you feel bad for them? . . . I don’t think Down’s people walk around saying: “My god, I have Down’s and it’s horrible.” You know, I think it’s normal people in society go around imposing it on them - that they should feel un-normal -abnormal.

Mary represents the voices of the mothers in this study with regards to the ways in which they came to construct the meaning of disability in collaboration with their environments. I chose to highlight her story in this snapshots section because it is illustrative of the ways in which mothers engaged in negotiating the culturally embedded meaning of their children’s diagnoses of Down syndrome. It should be noted that in one significant aspect, Mary’s story was different than those of the other mothers in this study - she is the *only* one who did not respond to the diagnosis of Down syndrome in a highly negative manner and, reportedly, at no time did she experience feelings of grief or anger. Although Mary described her initial feeling that everything is “knocked out from under you,” it is apparent from her narrative that, for her, the process of redefining Down syndrome in alternative terms began almost immediately after she received a prenatal diagnosis. Her accounts about the ways in which people reacted to the news, her interpretations of their reactions, and her attempts to “give cues” to people about how to react highlight the processes through which mothers become positioned and position themselves in interpersonal and institutional discourses. Mary’s articulation of her belief that she was being “robbed” of her pregnancy and her resolve to “claim” her pregnancy back underscore both the power of dominant discourses on disability as well her active participation in redefining the meaning of her own experiences. Her questioning of institutional and interpersonal discourses on disability and her repeated assertions that the “problems” related to Down syndrome lie in society’s definitions of “normality” highlight the ways in which mothers of children with Down syndrome challenge culturally accepted beliefs about disability and normative motherhood and the extent to which they are agentic in meaning-making with regards to having a child with Down syndrome.

In this section, I discuss those aspects of the findings that pertain to the ways in which mothers in this study made sense of their children’s diagnosis of Down syndrome and to their engagement in constructing the meaning of disability. Specifically, mothers’ early perceptions of their children’s diagnosis as well as their engagement in culturally embedded activities through which they negotiated the meaning of their experiences are elucidated here. The findings in this section inform those research questions related to mothers' perceptions of the familial experience of raising a child with Down syndrome. Furthermore, the processes through which the mothers in this study became positioned and positioned themselves in interpersonal and institutional discourses are explained here. These findings shed light on the culturally embedded as well as the agentic nature of meaning-making with regards to having a child with Down syndrome.

A. "The Earth Opened Up and Swallowed Me into a Pit:" Initial Reaction to a Diagnosis of Down syndrome

Each narrative contains an account of the manner in which the mother was informed about a diagnosis of Down syndrome. Some mothers in the study received a prenatal diagnosis of Down syndrome following prenatal genetic testing; others were informed that there was indication of Down syndrome shortly after the birth of their children, which was confirmed later through genetic tests. Regardless of whether there was a prenatal or postnatal diagnosis, all mothers recalled the event vividly and described their most immediate reactions to it in great detail. The majority of the mothers in this study with the exception of one (Mary, whose story is highlighted in the snapshots section above) said that they had reacted to the diagnosis of Down syndrome in a highly negative manner. Some made references to initial feelings of "devastation," others described emotions of sadness, anger, fear, guilt, or rage. The nature of mothers' immediate reactions to the diagnosis of Down syndrome is reflected in Leah's words:

> *I was consumed with it. I couldn't stop thinking about it. . . . I was very upset. I was angry as hell. I felt like I was getting screwed. I did not want my son to have Down syndrome. I was distraught for about 4 day – Miserable. . . . I think distraught is the best word. Distraught. I was so afraid - How am I going to love*

> *this child? (I was) filled with anger. So angry about it. I grieved the whole nine months. A constant state of grief. (Leah)*

Mothers reported having experienced emotions that ranged from feelings of failure or disappointment at having produced an "imperfect" child to feelings of anger or rage at being "ripped off." In describing the emotions that they had experienced, some mothers used metaphors that were illustrative of the deeply negative manner in which the diagnosis was initially perceived. For example;

> *It's like the earth opened up and swallowed me into a pit. And I was - I was shell-shocked. I was horrified, I was saddened. (Josephine)*

> *Everything was just empty. . . . I just kind of felt like alone. . . . I was going to be in this bottomless pit. . . . Falling. (Jane)*

> *Like the air being taken out. Poof. Like a balloon. (Maggie)*

These descriptions are consistent with the findings of other studies that indicate that initial reactions to a diagnosis of Down syndrome tend to be characterized by intense sadness and are often similar to those associated with bereavement and loss. While these kinds of feelings may indeed be experienced by parents after a diagnosis of Down syndrome, it is also important to frame the findings in the context of cultural expectations of grief following the birth or diagnosis of a child with a disability. In almost all of the literature that is aimed at providing information to families of children with disabilities (e.g., Kingston, 2007; Trainer, 1995) as well as in social work rhetoric, it is commonly accepted that grief is a "natural" response to this event and family members are encouraged to acknowledge and work through their full range of negative emotions. The reactions of the mothers in this study should be understood as embedded in the context of cultural beliefs about the “naturalness” of grief in these circumstances and of unquestioned assumptions or expectations of depression and despair among families of children with disabilities.

In discussing their initial reactions to their children’s diagnoses, I asked mothers to reflect on the nature of their feelings and on how they interpreted their reactions. In explaining the intensity of their sadness, mothers recalled their earliest beliefs about how their lives would change and their initial expectations of what it would be like for them to live with a child with Down syndrome in the family. Many reported that their most immediate understanding of the implications of the diagnosis had been that it would change their lives and their families in a negative way. Some recalled that they had believed their lives would become difficult or filled with trials, tribulations, grief, sadness, and hardship and that they had not envisioned “any possibility of joy.” Some interpreted the diagnosis to mean that their family would no longer be able to have enjoyable times.

> *I felt like I would be miserable every day. Like I would cry every day and I just - I felt like (it would be) burdened, miserable, unhappy. Like I would be crying every day. And I would never - I felt like I would never be happy again. (Ivonne)*
>
> *I remember one of my feelings was like - now I won’t even be able to meet anyone ever again because who is going to want to be with someone with a child with Down syndrome. . . . I would feel very isolated from the world. Like I would be*

> *very isolated again and like nobody would want to be with me because nobody is going to want to be with a child who, I don't know - what's going to happen with her. I didn't know if she would be walking, talking, if she would be, you know in Pampers the rest of her life. (Paula)*

> *I can tell you the feelings I had. I immediately felt like - will life ever be light hearted again? That's how I felt. That was my first concern. Will we go on vacations with our friends? Will we go out to dinner with our kids? Will life ever just be light hearted? (Rose)*

These excerpts indicate that mothers' initial feelings of sadness were related to fantasized negative outcomes; the "tragedy" was not in the present, but in an imagined future. Mothers expressed that they felt grief, however, in articulating the causes for their grief, they did not enumerate concrete difficulties or losses in the present; instead they gave accounts of the dismal lives that they believed lay in store for their families. Their feelings of "devastation" were not directly related to the child that they were pregnant with or the child to whom they had given birth. Rather, their anxieties were rooted in an ideology that framed the present as devastating future. This is further seen in mothers' accounts that their initial reactions to a diagnosis of Down syndrome included concerns over the exclusion of their child or their family. Some mothers reported that after hearing the diagnosis, their concerns were about whether or not their children would be accepted by others and that their fears included the possibility of social exclusion for their child or family:

> *I cried. I mean, I was upset. But I can honestly say that I was upset for Michael. We had already picked out a name for him since we knew it was a boy. Because I didn't want him to go through life being teased, kids can be cruel. Grown-ups can be cruel. I was concerned about just how people would treat him, more so than anything else. Right after the diagnosis. I was thinking about Michael and I just was worried about how people would accept him and everything and umm - didn't even think about the other possible medical consequences which I knew from a nurse could be there. That wasn't even a concern at that point. I didn't want Michael to be teased and everything. . . . We were worried about this little guy we'd already named. (Anne)*

This last excerpt sheds light on the nature of the negative emotions that these mothers experienced. Here again, it is indicated that feelings of sadness were related not to the present, but to what was envisioned for the future. Anne's feelings are representative of those of many mothers in the study and indicate that, even in the earliest stages of making sense of Down syndrome, mothers took into account the social implications of the diagnosis and began to locate disability not only in their child but also in the environment.

In discussing their initial appraisals of their situations, some mothers recalled having stereotypical perceptions of people with developmental disabilities. In reflecting on the reasons for having these negative images of people with Down syndrome as well as of life with a child with Down syndrome, many mothers believed that their reactions may have been distorted by the fact that they had little knowledge about the real outcomes of having Down syndrome for children and their families. Most reported that they had not had any significant contact with individuals with developmental disabilities prior to having their children and, in the absence of exposure or knowledge, “fear of the unknown” had dominated their perceptions. This acknowledged “fear of the unknown” can be situated in the historical context of the treatment of individuals with disabilities in Western society. Given that until the 1970s, individuals with disabilities did not receive public education or, in some cases, any education at all in the U.S. and that, even in the decades since the passing of special education laws, students with disabilities continued to be educated in segregated facilities, most nondisabled adults today may have had limited opportunities to know individuals with disabilities as children. Additionally, considering that individuals with disabilities have historically been institutionalized, denied access to many aspects of public life, and have been a largely invisible group, it is not surprising that many mothers in this study reported that they had not met people with developmental disabilities or that they had stereotypical perceptions about children with Down syndrome when they were informed about the diagnosis. At the same time, it is also important to acknowledge that in their beliefs that they did not really know anyone with a disability prior to the birth of their own children; mothers were expressing ideological views of disability as non-normative. Their lack of acknowledgement that they may indeed know individuals with disabilities, including elderly members of their families or people with invisible disabilities, represents a reflection of cultural definitions of disability as outside the range of normative human experiences.

B. “This is a Tragic Day:” Medical Discourses on Disability

Individual parents’ adaptation to the birth of a child with Down syndrome may be understood in the context of the ways in which this experience is interpreted by them or the meaning that they attach to this life event. However, individuals do not exist in isolation and the meaning of this experience, like all others, is culturally embedded. Like any human experience, that of the birth and diagnosis of a child with Down syndrome is shaped not merely by factors inherent in the individual or in the situation, but also by the dynamic interaction between the individual and the environment. The narratives indicate that the experiences of the mothers in this study were deeply embedded in medical discourses on disability. In their interactions with medical professionals beginning at the moment that a diagnosis was conveyed, mothers in this study perceived negative messages regarding the meaning of Down syndrome. The language, affect, and actions of doctors at the critical time of diagnosis were remembered by most mothers in great detail. The findings indicate that in delivering a diagnosis of Down syndrome, doctors tended to use the language of bereavement, loss, and regret. For example, these mothers reported:

> *I got a phone call from the OB doctor and he basically said: "I'm really, really sorry, but the results are not good. (Andrea)*

> *(The doctor said) "I wish I had better news." (Leah)*

> *Because they didn't have the official diagnosis they pretty much said: "Let's hope for the best and prepare for the worst." (Stacey)*

Each mother in this group recalled that, almost immediately after a diagnosis of Down syndrome was confirmed or even indicated, they encountered medical rhetoric that centered on themes of "burden" and "tragedy." The participants in this study included women who had received a prenatal diagnosis of Down syndrome as well as those who became aware of their child's diagnosis post-natally, and the experiences of these two groups of mothers were different in some aspects and similar in others. In this section, I discuss the findings concerning the experiences of these two groups of mothers separately.

Among the group of mothers who had received a prenatal diagnosis of Down syndrome following prenatal genetic testing, every mother recounted at least one interaction with a medical professional during which they perceived subtle or overt pressure to consider terminating their pregnancies. Some recalled interactions with doctors or genetics counselors in which they were categorically informed about the “burden” and the difficulties related to having a child with Down syndrome; others reported that medical professionals alluded to the idea that terminating their pregnancies would be the better choice for the parents and for their other children. The following are examples of accounts where doctors were either coercive or overtly attempted to steer mothers towards termination of their pregnancies:

> *I got a phone call from the OB doctor and he basically said: “I’m really, really sorry, but the results are not good.” Those were his words - yeah. “The results are not good. Your child has Trisomy 21, it’s very clear. This is for real.” And then he did proceed to tell me about my options for termination… I said I don’t know if I can make this (decision) . . . I really have to think about this. . . . But he said: “I’m just telling you that it’s really not fair to the sibling. I hear your hesitation . . . But it puts a burden on them. You know, you’re emotionally attached right now because you are pregnant and feeling the baby kicking and*

> *whatever, but you have to think about the children and that's all I want to say. Is that when the child gets older, and you're not around - think about that."* *(Andrea)*

> *It was pretty clear to (our doctor) that we were thinking every possibility or every option that we had with this pregnancy. We never totally shut out the idea of terminating. But I-we made it clear that we were leaning very heavily towards continuing with the pregnancy, but gathering information. . . . The other interesting thing is - the information that she gave us was not accurate at the beginning. First - having not delivered a child like this, she was not up to speed on what individuals with Down syndrome experienced in life right now . . . she also said that you need to go home and consider. Two things that really rang in my ears that bothered me - and again overall I had a positive experience, but the two things that bothered me - she said you really need to go home and think about how this could negatively affect the daughter that you have now. And you need to consider how this is going to affect your life. Because the fact is that you are home with the child more than your husband and you'll probably never work again. I didn't think that was true but that really bothered me. . . . And that's what I was offended by. And that came up a few times in the pregnancy. (Rose)*

Other accounts shed light on medical professionals' unspoken disapproval of mothers' decisions to forgo prenatal testing or to carry their pregnancies to term. Some mothers recalled that, although their doctors had not specifically said anything negative and were overtly non-directive, they had perceived non-verbal indications that their doctors did not support their decisions to continue their pregnancies. This is reflected in the following example:

> *She was very clinically proper with me, but I felt that most of the doctors there felt that given the fact that you can control for Down syndrome, you should definitely terminate. Definitely. . . . They never said anything. They never said: "We think you should terminate." Never. Ever. There was a lack of warmth, let's put it that way. They were always professional. Always. Always clinically correct. But there lacked a warmth . . . I always felt this way about the doctors at (the hospital). . . That they really thought I should have aborted. Like I really thought, like, the doctors there really value their intelligence. And, to voluntarily choose, when you didn't have to, to have a mentally retarded child, I could tell, for them - they couldn't understand that. (Sarah)*

Additionally, several mothers in the group who had received a prenatal diagnosis believed that their physicians or genetics counselors had not provided them with adequate information about outcomes for people living with Down syndrome or about available supports. This was reportedly the case even when doctors were aware that the family was assessing all relevant information in considering whether or not they would continue with the pregnancy. Some mothers believed that inaccurate information or random facts about children with Down syndrome were provided by physicians; and in three instances, doctors used terms like "vegetable" and "mongoloid' in discussing a prenatal diagnosis of Down syndrome. Stories in which mothers were informed about the difficulties or the negative impact of raising a child with a disability far outweighed those in which they were given information about the possibility of normative outcomes for families of children with disabilities or about medical and educational advances that have drastically changed outcomes for children with Down syndrome during the past few decades. The following are examples of the kinds of interactions mothers reportedly had with their physicians:

> *Dr. Daniels said to me that, basically I was having a vegetable. He said: Down syndrome children - 75% of them will never be able to feed themselves." This is Dr. -the neo- what's it called - the specialist, the high risk specialist. . . . I meant to write a letter. Three years later I've still not written that letter. . . . He told me I was having a vegetable basically. He said 75% of them will never be able to feed themselves, and I feel that's bullshit. Because, they're all feeding themselves. I would have to say 75% can feed themselves. It's 25% maybe. He said their IQ's are. . . . I don't remember exactly the number he used but he gave us a very low IQ, said their IQ's are never above and he gave us a really low number of the IQ. And he was actually talking us into terminating. Trying to talk us into terminating, like - he even said he would do the termination. I was - I was a mess. Then we go to the genetics counselor, which, we'd seen a genetic counselor years before when I had lost my son. They're a total waste (unclear). They tell you, your baby has Down syndrome. They give you a 101 version of what Down syndrome is and then you walk out of there. (Charlotte)*

> *I was distracted more by the way the doctor presented it to me. Because he used very archaic terms to describe Gillian's condition . . . He didn't even use Down syndrome. He said that she's going to be a Mongoloid. Yes, there would be a*

> *Mongoloid baby. I walked out of there really upset. . . . That just really caught me more than anything else that was going to come down the pipe. I thought this is -this guy is going to actually deliver my baby? (Victoria)*

Among the group of mothers who become aware of their children's diagnoses after their birth, some believed that their doctors had expressed excessive sympathy or dismay, and some had perceived medical or hospital professionals as being uncomfortable around them. One mother recounted that her doctor's negative affect and behavior, particularly his use of the term "tragedy" in response to the birth of her child, had angered her and had impacted negatively upon her earliest experiences as a mother. She related the following:

> *The doctor comes in and he says: "Did you see the baby." And my Mom said: "Yeah I did. He's beautiful." And the doctor said: "Yes but he has Down syndrome." . . . And my Mother was like, so furious -so now they start to get into it. And so my Mom says: "Well he's beautiful. So what difference does it make if he has Down syndrome?" . . . And then the doctor proceeds to say: "This is a tragic day. And my heart is breaking and it's just a tragedy." . . . And I was also stunned because I couldn't believe that this was a medical professional - an educated person would actually be saying that to somebody who just had a baby. He never said congratulations. That was just – it was terrible. . . . It's just - it makes me feel like all people are interested in are having a perfect baby, which is ridiculous. (Ivonne)*

Additionally, among the group of mothers who had opted to forgo prenatal genetic testing, some believed that they had received a lack of support from their physicians with regards to their decision. These mothers also reported that they had perceived medical professionals as disapproving of their decisions to forgo prenatal genetic testing, both during their pregnancies and after the birth of their children. For instance:

> *(The genetic counselor) couldn't understand why I didn't want an amnio. And I was, I think, seventeen weeks at that point. . . . Because of my test results, she kept repeating: "You don't want to know? You don't want to know? I can't believe you don't want to know. . . . "She was not good, and she wasn't - she wasn't appropriate. (Donna)*

Some doctors spontaneously provided statistical information regarding the percentage of women who terminate their pregnancies after a prenatal diagnosis of Down syndrome or, in some manner, conveyed the message that the overwhelming majority of people would *not* make the choice that these mothers had made:

> *(My doctor) told me that I was the only patient that she'd ever had who (had opted to continue the pregnancy). She said most people decide to terminate the pregnancy. (Rose)*

These excerpts reveal that medical practice operates from an ideological position that is steeped in assumptions that women would necessarily avail of the technologies of prenatal genetic testing and that, if they received a prenatal diagnosis of Down syndrome, would opt to have an abortion. It is important to examine these findings in the context of available statistical data on rates of abortion following a prenatal diagnosis of Down syndrome. It is indicated that approximately 91-92% of women who receive a prenatal diagnosis of Down syndrome elect to have an abortion (Britt et al., 2000). These findings are similar to those of Marteau and Drake's (1995) literature review which compared pregnancy termination rates after prenatal diagnoses of the following five conditions: Down syndrome, Spina Bifida, Anencephaly, Turner syndrome, and Klinefelter syndrome. In this review, combined data from studies done in 11 countries found that termination rates were highest after a diagnosis of Down syndrome. The data concerning the United States indicated that approximately 92% of women who received a prenatal diagnosis of Down syndrome opted to have an abortion. Framing the results of this section in the context of available data discussed above, it is worth noting that many of the mothers in this study seemed to have an awareness of statistics related to pregnancy termination rates after a prenatal diagnosis of Down syndrome. Some stated that they had "heard about the statistics," others, like Rose, were specifically informed by their physicians that their choice to continue their pregnancies represented an unusual or unlikely one for most people or were furnished with statistics by their physicians. Stories of this nature reveal yet another way in which mothers were steered towards considering terminating their pregnancies after receiving a prenatal diagnosis. By spontaneously providing information about pregnancy termination rates after a prenatal diagnosis of Down syndrome, physicians and genetic counselors validated abortion as the most expected and obvious course of action and positioned these mothers as making choices that were not entirely responsible as well as ones that were inconsistent with the recommendations of the medical community. This is seen most clearly in the following story shared by Sarah who recalled her interaction with a pediatrician at the hospital. Sarah recounted that the pediatrician, who had recently become a mother, spontaneously informed Sarah that she (the pediatrician) had opted for an amniocentesis during her own pregnancy and would certainly have terminated her pregnancy if she had received a prenatal diagnosis of Down syndrome. This interaction reportedly took place after the birth of this Sarah's child with Down syndrome:

> *I remember I had one doctor who told me, who just had a baby and she said: "Oh, I did an amnio and I definitely would have aborted if it was Down syndrome." One of the pediatricians said that to me. . . . (She) said she would have aborted if she had a baby with Down syndrome. (Sarah)*

Overall, the findings in this section reveal that interpretations of Down syndrome that were presented by physicians were steeped in the medical paradigm of disability, which views disability as biologically determined, universally defined, and contained in individual bodies or minds. These mothers' experiences of the birth of a child with Down syndrome were embedded in the medical belief that children with Down syndrome present unmitigated hardship and grief for families. This aspect of the findings support the works of scholars who have asserted that medical discourses on disability are based on the belief that disability necessarily results in a diminished quality of life for individuals and their families as well as the endorsement of prenatal genetic testing as an unequivocal "good" because it prevents "tragedy" and "suffering" (e.g., Asch, 1989; Saxton, 2000). This is further highlighted in accounts where mothers' efforts at conveying to their physicians that they were "all-right" with their children having Down syndrome or at conveying their positive feelings as mother-to-be or new mothers were minimized or invalidated by physicians. Some mothers believed that their physicians demonstrated "pity" or felt sorry for them even when they were expressing positive perceptions as mothers. This is captured in Ivonne's words below:

> *I'm telling him (that the baby is doing great) and he's looking at me like – Oh you poor woman you're in denial. . . . You know that same look. And at that moment I thought, he's never going to get it. He's just never going to get it. (Ivonne)*

Not all interactions with medical professionals were described in negative terms. It is important to note that, although many mothers emphasized their disappointment or anger at medical professionals' responses to their atypical pregnancies or birth experiences, there were also some accounts of positive interpretations with doctors who attempted to give balanced information or made efforts to provide alternative interpretations of Down syndrome and of what families can expect in raising a child with Down syndrome. Mothers who had positive experiences with doctors identified these as being critical in shaping their early responses to a diagnosis of Down syndrome and in transforming their initial negative perceptions to expectations of more normative outcomes for their families. For instance, one mother, Maggie, related a story about her meeting with a geneticist shortly after her daughter was diagnosed as having Down syndrome. She recalled that, at first the geneticist tried to explain the meaning of Down syndrome to her husband and herself by showing diagrams of the typical human chromosomal karyotype and of individuals with Down syndrome in "an old classic text-book." These medical illustrations did little to contribute to Maggie's understanding of the real implications for her own life and for her family. Then, as Maggie described, the geneticist attempted a different approach. Reaching into his desk drawer, he reportedly found and showed the couple a card that had been sent to him by a child with Down syndrome with whose family he had worked in the past. Maggie remembered the card as having a heart-shaped cut-out and in it, a photograph of the child at her birthday party.

Maggie recalled that almost immediately her perceptions of the diagnosis had changed. The photograph of the child at a birthday party provided an image of normative outcomes for the family. Maggie related this incident as one that had meant to her that “it’s gonna be OK” and that she would “have these pictures too.” Maggie’s story about the photograph shared by the Genetics Counselor is pertinent and powerful because it sheds light on the ways in which individuals engage in the dynamical process of assigning meaning to words and events. Maggie’s expression of dissatisfaction with the medicalized interpretations of Down syndrome furnished in the counselor’s “old, classic text-book” and the counselors’ act of offering an alternative visual image of a child with Down syndrome are illustrative of the ways in which the meaning of Down syndrome was collaboratively negotiated between Maggie, her husband, and the counselor.

There are other descriptions in the narratives of positive interchanges between mothers and physicians, which by the mothers’ own accounts, profoundly impacted upon their interpretations of their child’s diagnoses. However, positive experiences with medical professionals and accounts of doctors providing balanced information regarding what families of children with Down syndrome can expect were either relatively few or largely missing for most of the mothers in this study. Generally, the attitudes and actions of medical professionals were recalled by many mothers as characterized by biased viewpoints, inaccurate information, assumptions of “burden,” and, for those mothers who received a prenatal diagnosis, as conveying a belief that it would be better to terminate their pregnancies.

C. "Didn't You Get an Amnio?": Becoming Positioned in Social Discourse and Activity

The narratives indicate that, while the early experiences of the mothers in this study varied, there was considerable commonality in terms of their encountering interpersonal discourses that centered on notions of tragedy, hardship, and burden among families of children with Down syndrome. The stories that these mothers told highlighted the existence of dominant discourses on disability that are based on beliefs that having a child with a developmental disability leads to negative outcomes for a family and that being such a parent is a largely undesirable experience. Specifically, mothers in the study discussed the reactions that they received from people when they informed them about the diagnosis of Down syndrome, either prenatally or after their child had been born. Most mothers expressed that people responded with expressions of sympathy. Some recounted that members of their family or their friends had reacted in a strongly negative manner, either by crying or by otherwise indicating that they were deeply saddened by the news.

> *My sister looked horrified. My sister looked devastated. . . . She started to sob hysterically. (Josephine)*

> *I could tell from (my dad's) voice that he was shocked. Everybody was shocked, you know, totally shocked. (Karina)*

> *My in-laws were completely devastated - in tears. My mother in law was crying. (Leah)*

In analyzing the data pertaining to the reactions that mothers received from family members, friends, and acquaintances, three categories or types of responses could be identified: (a) Those characterized by expressions of sympathy or assumptions of difficulties and burden for the family, (b) Those affirming the “special” nature of the child and of the mother, and (c) Those involving questions about whether or not a mother would continue her pregnancy (if the diagnosis was prenatal) or whether or not she had undergone prenatal testing (if the interaction took place after the birth of the child).

Expressions of sympathy from others were common in the stories of these mothers. Each of the mothers in this group expressed at least one person had reacted to the news of their child’s having Down syndrome by saying: “I’m so sorry,” and some reported that people had reacted to the news as if it were news of a bereavement instead of the birth of their child. In discussing the reactions of their friends or members of their communities, mothers believed that most people had been supportive and helpful, however, they also perceived social interactions to be frequently characterized by some level of discomfort and pity:

> *Most people seemed sorry for us. Most people would be like: “Oh, I’m so sorry.” (Adele)*

> *I felt pity from a couple of people. I could tell from the body language and the way their face - as if you walk by after an automobile accident, you don’t wanna look. There’s an uncomfortable look on your face. I got that from a few friends. . . . I felt they were freaked out by it . . . I think that was one of the worst responses: “I’m so sorry.” (Leah)*

An important finding in this study was that, while these mothers were the recipients of social sympathy, they were also attributed with having extraordinary qualities and characteristics. This is reflected in accounts of interactions in which mothers were told that they are “brave,” “courageous,” “blessed,” or ‘special.” Some mothers recounted that they were told by people that they are “a saint” or “chosen by God” to have a “special baby.” Others reported that people expressed their admiration for the supposed courage that the mother must possess, stressing that they themselves were unable to “handle” having a child with Down syndrome. In interpersonal discourses, mothers were sometimes elevated to the status of a “saint,” and many recalled that people expressed their beliefs that since they did not themselves possess any extraordinary qualities, they would be ill equipped to raise a “special” child. This is reflected in the accounts below:

> *She said: “Special people get special children.” . . . And another mother told me I was chosen by God. (Donna)*

> *(My neighbor) said to me: “You know, I really admire you for having that baby. It took us a long time to get pregnant and we had fertility treatments and my husband and I talked about what would happen if one of babies we ended up carrying had Down syndrome. And we decided that there was no way that we would have had a baby like that.” . . . And she said: “You must be very religious - that must be why you made that decision.” I said: “No, actually we’re not religious at all. We made the decision because we wanted to have a baby.” (Rose)*

> *They were all very supportive, saying: "It's a great thing you're doing, but I wouldn't do it. . . . Oh, I couldn't do that. Good for you, but I couldn't do it." (Leah)*

Most mothers in the study perceived these kinds of comments to be well intentioned, however, they also perceived them as clearly conveying the idea that others would not choose this situation for themselves and as reiterating a stereotypical belief that being a parent of a child with Down syndrome is a largely undesirable experience. From their accounts, it is also clear that they did not accept these sentiments in a passive manner. In response to being positioned, these mothers made efforts at positioning themselves, which took the form of a variety of activities primarily aimed at educating themselves and others and at redefining the meaning of their experiences. Many recalled that they had spent time reading books about Down syndrome, particularly narratives or memoirs written by individuals with disabilities or their families had looked for information through online sources or had actively sought contact with children with disabilities or their families in attempts to gain alternative interpretations of what is involved in raising a child with a disability. Thus, the mothers in this study, rejecting notions of difference and stigma, took an active role in educating themselves and sought allies in this end. This aspect of their constructed selves will be further discussed in the section that follows.

In addition to dominant discourses that center on the notion of the undesirability of parenting a child with Down syndrome, it was also evident from these mothers' stories that there continues to exist a belief that it is better to prevent "suffering" for children and hardship for families by availing of the technologies of prenatal genetic testing and through the selective abortion of fetuses with Down syndrome. The narratives indicate that it was not uncommon for mothers to be asked whether or not they would continue their pregnancies (when Down syndrome was diagnosed prenatally) or to be questioned about whether or not they had had an amniocentesis and about why they had chosen to forgo prenatal testing (if the interaction was taking place after the birth of the child). Most mothers in the study related at least one account of being questioned casually by others regarding amniocentesis. The narratives are rife with stories in which colleagues, friends, acquaintances, or neighbors reacted to the news of a child's diagnosis of Down syndrome by inquiring whether or not the mothers had undergone prenatal testing by expressing surprise at the decisions that mothers had made and, in some cases, by stating that they themselves would have made a different choice.

> *I had questions like that because some people say: "Did you know that you were going to have a child with Down syndrome?" And I say: "No, I did not." "Oh, you didn't have a . . ." And I say: "No but what's the difference?" Some people ask you that. I just think that it's a very silly question or inappropriate question. What do you want me to do if I find out? Did you want me to have an abortion? That's what you wanted? . . . I'm pro-choice but it's a silly question. (Paula)*

> *(Great-aunt) said: "Didn't you get the amnio?" And I'm like: "No." She's like: "Why? If you had known, you could have started over again and gotten - you know - had another baby." (Jane)*

It is worth noting that among mothers who had received a prenatal diagnosis following prenatal genetic testing, there were accounts of pressure from family members to consider terminating their pregnancies, even among those who identified their families as more traditional and religious. In some stories family members alluded to the notion that an abortion would be the best course of action and subtly gave "permission" to mothers to make this choice and, in other stories, family members overtly attempted to coerce mothers into terminating their pregnancies. For instance:

> *My in-laws were completely devastated - in tears. My mother in law was crying, she said: "You know you have options. . . . People would understand if you choose not to have it." I wanted to kill her. (Leah)*

> *My father, however, wanted me to abort the baby. I told him about it. He cried . . . and, one night he went out and had a couple of drinks with his buddies . . . and he called me up and he told me the best thing I could do is get rid of this baby . . . it was . . . that was like only a few days after I had found out, so I was still in the sensitive stage, cause I did tell my mom and dad, first my mom and then my dad. And he started screaming into the phone at that point: "Abort this kid. Abort this baby. Get rid of it." (Charlotte)*

The findings in this section reveal the ways in which mothers of children with Down syndrome are positioned in interpersonal discourse. Harre and Moghaddam (2003) assert that through discourse and activity, social realities become collaboratively constructed and particular interpretations of events are negotiated. They explain positioning theory as the process through which power dynamics are articulated, enacted, and resisted in discourse and activity and claims are made about the meaning of events. Consistent with these assertions, the findings in this section revealed dominant discourses that emphasized the undesirability of parenting a child with a disability and upheld socially constructed interpretations about children with disabilities as burdensome. The stories of these mothers underscore the ways in which children with Down syndrome were identified as having lesser value than children without disabilities in discourses that centered on notions of sympathy, loss, tragedy, and devastation as well as through expressed beliefs that it is better to avoid the birth of children with disabilities through the use of prenatal genetic testing.

D. "I'm Just Being a Parent:" Positioning the Self in Discourse and Activity

The previous section focused on the ways in which the mothers in this study were positioned in interpersonal and institutional discourses and activity. However, their stories also showed that they were not passive in the process of meaning-making and that by positioning themselves in discourse and activity, they participated in interpreting their family's experiences and redefining the meaning of Down syndrome. Many mothers recalled that they had actively sought interpretations of the experience of having a child with Down syndrome alternative to the explanations provided by medical or clinical professionals. Engagement in activities that contributed to these mothers' understanding of Down syndrome and the familial experience of having a child with a disability took a variety of forms. The internet was a source of information for many mothers who reported that they or their spouse/partner had spent a great deal of time online, seeking information that would clarify the implications of their children's diagnosis. Some mothers reported that they turned to spiritual forums or religious teachers to provide interpretations of Down syndrome alternative to the ones that doctors had provided.

Many reported that they had read books, particularly narratives or memoirs written by parents of children with disabilities during their pregnancies or shortly after the birth of their children. Notably, several of the mothers in this group reported that they had actively sought contact with children with disabilities or their families in attempts to gain an understanding of the lived experience of disability for individuals and their families. These mothers reported that contact with other families of children with disabilities had provided them with balanced information and more meaningful interpretations of the experience of raising a child with a disability.

> *I just felt we weren't getting the full picture. . . . And we even asked (the genetics counselor): "Have you ever worked with a child or a person with Down syndrome?" And she said - no she hadn't. And here we are taking information about Down syndrome from somebody who has never interacted with a person with Down syndrome. And we just kind of left that feeling almost more confused than we had been when we went in. And more scared . . . I talked to a woman Angela who runs the clinic and at that time, had a seven and a half year old boy with Down syndrome. With some pretty significant medical issues that she had to get through and definitely a lot of stuff going on. . . . But you know it was so evident that she felt all this joy about her son and he's doing well. . . . And after that conversation, for the first time I felt this was something manageable. (Adele*)
>
> *(We) talked to other families. Besides my more trivial question about vacations, those were the questions we asked the most. How does this affect your other children? Negative? Do you feel like they're getting negative indications? And*

> *my questions for the women - how does this affect you as Mother? Do you work? Do you feel like you could work? . . . It became clear to me very early on that I could have a career and work if that's what I chose to do. And we did get positive feedback from the siblings. (Rose)*

In addition to actively seeking alternative interpretations of a diagnosis of Down syndrome, mothers in this study also spoke about their efforts at conveying their interpretations to others. These ranged from attempts at shaping people's reactions to their child by providing non-verbal cues to specific actions that were aimed at facilitating a positive reaction to their child. For instance, one mother reported that she did not inform anyone about her daughter's diagnosis of Down syndrome until people had already "bonded with" her child; another mother recalled that she had instructed family members about the language they should use and the affect they should demonstrate when talking about her daughter with Down syndrome. Some discussed their current involvement in organized groups concerned with disability awareness, advocacy, or policy-making at the local or state level; and others expressed a desire to engage in activities aimed at changing the ways in which individuals with disabilities and their families are perceived in society. Levels of awareness among mothers regarding the extent to which they engaged in efforts to shape perceptions of their children and of their familial experiences varied. Some mothers, like Yolanda (quoted below), said that whenever they encountered discourses of sorrow ("I'm so sorry"), they responded by "correcting" people:

> *I'm like: "No—no—no, there's no sorrow." You know what I'm saying? It's like - this is our child and we love him. He will have challenges in life but there is no*

> *sorrow. We don't need you guys to feel sorry for him or for us. And so I quickly corrected that. (Yolanda)*

Some mothers explained that they had anticipated reactions of sympathy and had tried to pre-empt it through their careful choice of words and their affect when discussing their children. These mothers were aware that they were attempting to give cues, "control" people's reactions, or convey alternative interpretations of a diagnosis of Down syndrome. This is illustrated in the words of these mothers:

> *I didn't want someone else telling it in a way that we wouldn't have told it. . . . I worried that people would say: "Poor them" and also I think that armed with that knowledge, they would watch us more to see how we reacted. . . . So, I just - I think I didn't let things out of my control, if I could. . . . I remember actually at one point, my mom was on the phone or something, and she made me upset the way she was talking about it, like "ooohh" . . . And I remember saying to her: "That's not how you can do it. Because the way you're going to be showing it is the way they're going to be reacting." (Maggie)*

> *I wanted people to know that we made a decision to have this baby. That she was welcome in our life. And that we were not ashamed and disappointed. We wanted people to know that we knew and we were happy. . . . I feel - a certain amount of societal pressure sometime, in that, I feel like we have to be role models for other people. To show them that you can have a child with a disability and lead a happy life. (Rose)*

Lending support to the work of scholars who have asserted that positioning is not merely a means for enacting identities within social contexts, but also a tool for resisting perceived power differentials in hegemonic discourses (e.g., Harre & Langenhove, 1999), the mothers in this study responded to being positioned by positioning themselves in alternative terms. In voicing their disagreement with notions of suffering, hardship, and burden as characterizing the experience of having a child with Down syndrome and in their direct efforts at shaping the perceptions of others through their deliberate choice of language and actions, the reactions of these mothers are consistent with Holland's (1997) assertion that selves are not merely imposed upon people in interpersonal and institutional ways and nor are people "overwhelmed by social influences and the positioning imposed upon them" (p. 70). Rather, as she explains, individuals "orchestrate the sites of self" and are agentic in the construction of meanings. The findings in this section strongly support the idea of human agency by revealing the extent to which mothers viewed themselves as active participants in defining their families and their lives and the extent to which they assumed a role in shaping others' interpretations of the same.

E. "Ten Fingers and Ten Toes" : Mothers Contextualized Understanding of Disability, Normalcy, and Down Syndrome

The narratives generated by the mothers in this study indicate that they came to understand the meaning and implications of a child having Down syndrome in very different terms than those implicit in dominant discourses on disability. When these mothers talked about Down syndrome or issues related to disability, they almost always did it in the context of the social implications for children and families. In speaking about what it means to have Down syndrome in our society, mothers' expressed beliefs could be grouped into two general themes: (a) Beliefs about children with Down syndrome as devalued in society and (b) Beliefs about children with Down syndrome as socially isolated or excluded. These two themes in mothers' understanding of the meaning and implications of having Down syndrome are discussed in detail here.

(a). Children with Down syndrome as devalued: Many mothers in the study expressed beliefs that individuals with Down syndrome are not "valued" in society and that children with disabilities in general are regarded as other than the desired child. These beliefs were discussed by mothers in the context of cultural definitions of "normalcy" and "perfection." Some mothers expressed beliefs that children with Down syndrome are not valued because they are not *normal*; others believed that they are not valued because they are not *perfect*. From these mothers' perspectives, in a society that simultaneously emphasizes normalcy and perfection, a child with Down syndrome does not meet the standards for acceptability or desirability. Some articulated beliefs that children with Down syndrome are devalued because they appear different and that their different appearance arouses anxiety among people. This is reflected in the following statements:

> *In terms of the Down syndrome, it's not much of an issue (for me). It becomes an issue when I walk outside the house, in terms that I do see people looking at him differently. Men tend to have a more frightened look. Women tend to look a little longer and – give a little smile. . . . I think what scares people about my life is that they're different physically. Because we live in a society where the physical attributes are an obsession. (Leah)*

> *Sometimes I watch people as they look at Annie. . . . They're trying to figure out – (if) there's something different about her. And then they smile at her. . . . Sometimes people don't want to look at her -they look away. People don't like different. People are uncomfortable with different. And with kids with Down syndrome, it's there. (Donna)*

In discussing their understanding of the value of children with Down syndrome, some mothers used the language of damage and stigma:

> *(People view him as) Damaged. Not normal. Different. Damaged goods. . . . I know people will look at him differently. (Leah)*

> *I think (people) probably view her as a burden that they would like to avoid. . . . I just know that that's how the world thinks of her. I think that when they see her - I think some people are very uncomfortable with her. Because I can't think, I can't remember seeing people with Down syndrome too often. And so I'm sure that for some people she could be the only person with Down syndrome that they encounter. So I think the world in general view her as a burden. (Stacy)*

Some others framed the issue of the value of children with Down syndrome in the context of a societal emphasis on perfection. They articulated their understanding of society's definition of a desirable child as one that is not only "normal" but also " perfect." Indeed, many of these mothers expressed a belief that they live in a culture where perfection is considered to be an expected or normative outcome of childbirth and parenting:

I just think it's out of the norm of what people think is the perfect child. And we're just in a place where people think there has to be the perfect child. And I think that she doesn't fit the mold of what the perfect child is supposed to look like. (Victoria)

Everyone wants perfection. . . . Everybody's darling with their incredibly unusual, inappropriate names. . . . And kids like Cathy are an affront. I really think they're an affront to the established order. (Josephine)

My babysitter was pregnant this summer. And I asked a question that many people ask when you're pregnant - what do you prefer, a boy or a girl? Many people ask that question, "Do you know what you're having? What do you want to have? (People say): "Oh . . . I don't know but as long as the child is healthy . . . or as long as the child has ten toes and ten fingers. That's all that I want." And I do remember to tell these girl - I say: "Well you know something? It doesn't really matter you know, because it's going to be your child. It doesn't matter how the child comes. It's going to be your child." . . . What are we looking at here when we have children? Everybody wants like - a Hitler-type - you know, particular type of personality. Everybody looking the same. You know that's what Hitler wanted. Hitler wanted a perfect race. He didn't want anybody with illness. He didn't want the Jewish. He didn't want, you know, with darker skin. So he was really trying to have everybody from the Aryan race . . . you know the white, the blonde, the perfect, the strongest. But everybody has a meaning in

> *this world. Everybody has a job to do. . . . It bothers me because like I'm saying what are you going to do if you don't have a perfect child? What are you going to do? Are you going to just put the child in the garbage? I don't want it - my child has four toes? (Paula)*

In addition to beliefs that children with Down syndrome are devalued because they are not "normal" or "perfect," some mothers articulated that the meaning of Down syndrome in society may be related to economic factors. With regards to this, they expressed beliefs that society considers children with Down syndrome to be of lesser value because they may not be able to contribute financially as adults, or because they may place a financial "burden" on society. This is reflected below:

> *The word "value" - that word has many different meanings - how they value. Not only are they making assumptions about her about what she can and can't understand, but they're making assumptions about what she can, will or will not be able to do, and will and won't be able to contribute. It's monetary. I hate to say it, but it comes down to financial economics. . . . I just feel like this comes down to like, economics. A child with special needs is - economics. And I hate that. You're getting low return for the input. I think that's the way she could possibly be viewed by a segment of the population. (Donna)*

Additionally, it is worth mentioning that, in discussing the "value" of individuals with Down syndrome, some mothers expressed beliefs about the increasingly routinized nature of the practice of prenatal genetic testing as an indication that children with disabilities are not welcome in society. In discussing prenatal genetic testing, some mothers articulated concerns that the practice itself has implications for the ways in which motherhood is perceived as well as for the societal acceptance of children like their own.

> *You hear that statistic - that 90% of people who find out their child has Down syndrome are terminating that pregnancy. . . . I just look negatively, personally, at this willingness to pick and choose what child you're given. Or what child you have. One thing it means is that there aren't a lot of kids with Down syndrome out there. So, in some ways, for that reason and for the fact that families are terminating these pregnancies, is just showing me that there is some lack of acceptance. (Maggie)*

> *Statistically, we see that 90% of people who find out their baby has Down syndrome terminate . . . I think that implies there's something wrong with the child. (Leah)*

(b). Children with Down syndrome as socially isolated: A common thread in the narratives of these mothers pertains to their expectations of the social climate within which their children with Down syndrome will live. In discussing the meaning of disability, these mothers frequently voiced beliefs that having Down syndrome often implies that one will be socially excluded by peers or, at the very least, not fully accepted. Issues pertaining to social acceptance versus rejection were raised by every mother in this group. Although there was much variability in each mothers' individual interpretations of the experience of having a child with Down syndrome, there was commonality in their interpretations of a diagnosis of Down syndrome as being

associated with social exclusion and in their understanding that having Down syndrome equates with being marked as the outsider. Some mothers expressed worries about whether their children will be teased or made fun of in the future; others raised concerns that their children will become invisible, ignored, or excluded from childhood activities like birthday parties, playground games, or sleepovers, and many verbalized their fears concerning whether or not their child will have friendships:

> *I do hope that she gets invitations to birthday parties . . . I hope she gets included in that. (Maggie)*

> *Is she going to have friends? Will she go to parties? And then when she's older, how do I make sure someone doesn't take advantage of her. . . . Is she going to be rejected? I worry about that. (Josephine)*

> *I think that's what scared me and stuns and I mean every parent wants their child to fit in and to be accepted. And it's like, the thought of that breaks my heart - Leo not being invited to parties and feeling left out. And I feel sorry and that makes me want to cry just thinking about it. (Karina)*

In discussing their understanding of the meaning of Down syndrome, these mothers raised the social implications of having a disability more often than they referred to the biological impairments or functional limitations that are associated with having Down syndrome; their gaze focused more frequently on societal obstacles than on the acknowledged cognitive or physical impairments of their children with Down syndrome. Beliefs about the possibility of social exclusion of their children and about the general devaluing of people with disabilities were the most frequently raised issue in the narratives and mothers articulated these more than any other category of concern. Overall, the stories of these mothers indicate that the meaning of disability cannot be extricated from a social context. In their stories, the “problems” related to Down syndrome were identified as a lack of acceptance or understanding about disability in society coupled with a societal devaluing of individuals with disabilities. The narratives indicate that, for mothers of children with Down syndrome, disability was located not only in their child, but also in the environment:

> *I’m sad that there are people walking around with these biases, you know, or attaching these stigmas to these children. That’s what makes me sad. . . . The sadness is not associated with the fact that my daughter has Down’s. It’s associated with the fact that we can live in a place where people won’t educate themselves on these diagnoses. . . . I don’t think Down’s people walk around saying: “My god, I have Down’s and it’s horrible.” You know, I think, the normal people in society go around imposing it on them, you know, that they should feel un-normal - abnormal. (Mary)*

> *I’m still sad. I’m sad when I hear kids playing. Because I’ve already made assumptions that my daughter won’t be included. . . . I don’t get sad about my daughter. I get sad about the world and how I think the world views her and values her. (Donna)*

> *You go from a doctor who calls your baby a mongoloid before the baby is even born . . . gives you a negative slant on it. People screening for Down syndrome before the child is even born. And pretty much the idea is to abort if you do have a child with Down syndrome. That doesn't tell me it's seen as a positive light. Because if it was, why are you trying to destroy this child. So, they definitely have bad PR. . . . I think that if you look at everything - you look at the laws, you look at the school systems, you look at the way people are segregated. I don't think there's anything that says we, like, stand up and say: "wow, we're really happy that people with special needs are around." I mean as a society, I don't think we do. It's usually like a pity thing or a second-class citizen thing, maybe, or a charity thing. I don't think it's like, stand up and look at the value. I just don't see it. (Victoria)*

These excerpts are indicative that the ways in which a child's diagnosis of Down syndrome is perceived by mothers is contextually bound and has as much to do with the sociocultural constructions of disability and normalcy as with the biological realities that accompany it. The findings in this section lend support to the works of scholars who posit sociocultural conceptualizations of disability and view disability as a socially constructed phenomenon (Bogdan & Taylor, 1994; Danforth & Navarro, 1998; Kliewer, 1998; Taylor, 2000). For the mothers in this study, the meaning of having a child with Down syndrome was linked with cultural definitions of disability, normalcy, and perfection and embedded in the context of a diminished value of individuals with disabilities in society.

II. Constructing the Self

Snapshots: Veronica's Story

The pregnancy was excellent . . . no nausea, no discomfort, a very good pregnancy. Very good. . . . The delivery was extraordinarily easy. Born within half hour of reaching the hospital. And instantly I felt within myself that something was wrong. . . . And when I was transitioned to a room, and he was kept back with the babies, I kept saying "Where's my son? What's going on? Where is he?" . . . Everything just appeared differently to me. I'm very, very perceptive. People were coming in the room and kind of acting differently.

The next morning the doctor comes in and says: "I can't see really well with the light in here. Let me take him out and I'll be back. Let me take him out to examine him." And so he comes back within a few minutes and he pulls the curtain and he goes; "The baby has Down syndrome." And I'm like: "No, no. My baby is - the little black boy born last night. I don't think so." He was like: "No, he does."

I called my husband and I told him: "Can you come? Come right away." And I explained what the doctor suspected. And then I hung up. And then I called back. And I said: "Let's bring and do everything the same way we did for our daughter. Bring the video camera. Bring the pictures. Bring everything, because I don't want him to feel any less loved. You know what I mean? And I don't want anyone at the hospital to feel like, Oh god, you know, she had a baby that was imperfect . . . I'm like, bring everything, bring the outfit I laid out, bring the camera, bring this. And he brought it all. That was kind of it.

I was fearful for him. What would his life be like? . . . I had fear for ourselves. I was upset with myself and in some ways I felt like, wow, is this my fault? . . . I felt confused . . . I probably felt every range of emotion, you know, about the diagnosis. So, (after the) initial diagnosis, probably fear. I wouldn't say anger . . . Probably fear.

Right from the beginning . . . I just felt like, this will not veer my entire life plan. He having one extra chromosome was not going to rock my world. So, I just felt like, my life will be probably a little bit tougher. In terms of people getting to understand him and accept him. But my purpose and how I am going to live my life and the person that I am and the family that I want, is going to be 99.9% the same.

(People's reactions were) Surprised and then like "I'm so sorry." And I'm like: "No, no. There's no sorrow." You know what I'm saying? It's like - This is our child and we love him. He will have challenges in life, but there is no sorrow. We don't need you guys to feel sorry for him or us. And so I quickly corrected that.

People say that to me all the time ("You must be a saint; I couldn't handle it). . . . I don't feel complemented by it. I just feel that this is my child. And I always say to them, whatever is on your plate, you would find a way to eat it. . . . I really don't feel saint-like.

You know what I mean? I just feel like this is my child. You know, my other child requires a lot of me as well.

The doctor, the pediatrician (said: “God gives special babies to special parents). I felt like it was a bit too cliché-ish. . . . I think I’m a good parent. Special with special powers and special callings? Probably not. . . . I have a lot of personal shortcomings but being a bad parent is not one of them . . . I really invest in the parenting of both my children. I don’t think I’m a special parent. I think I’m a really good parent. My every thought is my two kids.

In comparison to people who are in our same religion, income, and education and everything, I would say, our lives are at least as good as people we know. We live well. I’m not talking about material things. My daughter asks me “Mommy, are we rich?” We are rich because we have each other. We have love. We have God. We have a cover over our heads. We are so rich. . . . I think our lives are just so good. Our lives are perfect, really. It’s a wonderful life. . . . And it’s funny because I know that initially when people hear about Jessie, I think they are tentative and think that our lives are going to be different.

Being a mom - it’s really tough and it’s good. . . . It’s tough in terms of, I like to have things in a certain order and do things in a certain way. And it’s really tough when you have kids because they kind of take you out of your groove and your game. . . . It’s tough. But it’s so much fun. . . . I love being a mom. Yeah. I love it and I wouldn’t trade it. Of all the things I've ever done and accomplished, being a mother is like, just tops the list. Nothing else comes close. Yeah, just tops the list.

I think that people think our life is tougher than it is. I almost feel guilty because they say things like "oh, you must be a saint. Oh, you guys are so amazing." And I'm like, it's really not that tough. It really isn't. Probably the biggest thing is that our lives as two parents and two kids are more closely aligned to the lives of – two parents with two typical kids. That's probably the biggest thing. That our lives are pretty – 99.9% there. We do have to make provisions, but they're so minimal in so many ways. . . . Our lives are pretty regular. Pretty regular.

My only thing about inclusion is that I know as a rule that kids can be kind of mean. And my daughter is typical and she comes home and tells me very mean stories about things that people have said to her or done to her. And I'm always worried because he doesn't talk much. And I get, like, protective of him when he is in an environment with typical kids sometimes. I don't want them to hurt him or push him or say mean things to him. . . . I know in a specialized environment, I know that the teachers and the teachers' assistants are all trained especially for special needs and so I know that they would have the patience and the understanding and the training and the ability. In an inclusive environment . . . I'm not exactly sure how the teacher would treat him . . . I feel that he would be most accepted in a specialized environment.

> We do a lot of things to pursue friendships for Jessie. . . . For example, we have made ourselves friendly with parents of other special needs children, and so, hence, because we are friends, the kids are friends. . . . I find that friendships are tougher for Jessie. . . . I think there would be more natural friendships in his special needs setting. By the time my daughter was six, she already had kids playing over here; play dates that weren't arranged by me. I didn't have to. Now we have family play-dates. . . . I find that the run-of-the-mill children are very kind to him but mostly ignore him . . . they're not mean to him, they don't say unkind things, but if I could summarize it, it would be – ignore. (In an inclusive classroom) I think that maybe, eventually, if it is encouraged by the adults in the classroom, that he be included. I think it would have to be encouraged. . . . You know, most kids are not like: "Oh, come play with us." Most of them are like: "You're a little different – stay away." (In a self-contained classroom), I feel total acceptance.

Veronica's story is representative of the ways in which mothers in this study actively engaged in defining families of children with Down syndrome and came to understand themselves as mothers. I chose to highlight Veronica in the snapshots section because her narrative underscores alternative interpretations of families of children with disabilities throughout, and her story is one which clearly illuminates the agentic nature of human identity. Like other mothers in this study, Veronica discussed her resistance to the ways in which families of children with disabilities are viewed by those who have not lived the experience and articulated beliefs that parenting a child with a disability is not distinct from parenting in general. Throughout her narrative, Veronica articulated her feelings of satisfaction as a mother and, on more than one instance, expressed that, for her, motherhood is a central aspect of her life. In her words – “being a mom just tops the list.” In her descriptions of her own deeply gratifying experiences as a mother and in her assertion that her family is “99.9 percent like everyone else,” Veronica lends voice to the beliefs of many mothers in this study who rejected notions of non-normativeness among families of children with Down syndrome and, in doing so, reinstated themselves as mothers.

In this section, I discuss those aspects of the data that inform this study’s research questions concerning the ways in which mothers of children with Down syndrome define themselves and collaboratively construct their identities. The sub-headings in this section relate to aspects of the narratives that contribute to an understanding of how these mothers interpreted their present lives in the context of dominant discourses on disability and on the familial experience of raising a child with a disability. I discuss the identities of the mothers in this study by focusing on their beliefs about the ways in which their lives have been represented by others and on their counter narratives about their lives. More broadly, the findings discussed in this section pertain to the ways in which the selves of mothers of children with Down syndrome are performed through collaborative activity and social discourse. The data presented here elucidate the profoundly social and agentic nature of the self and ultimately contribute to an understanding of the culturally embedded meaning of motherhood.

A. “99.9 Percent There:” Resistance to Discourses of Otherness

When mothers talked about their perceptions of their present lives, they frequently voiced their resistance to notions of the otherness of children with Down syndrome and of families of children with Down syndrome. The narratives indicate that most of these mothers strongly resisted interpretations of disability that positioned them in a separate category of motherhood and positioned their children with Down syndrome in a separate category of child. Some mothers spontaneously discussed their reactions to statements about the "specialness" of parents of children with disabilities; others discussed these when prompted by the Q-sort task. As discussed in Chapter 2, mothers engaged in a Q-sort activity as part of the interview during which I asked them to sort a stack of index cards containing a variety of statements, including those that are characteristic of the dominant discourses on families of children with disabilities as well as those that represent an alternative view of this experience. Mothers were instructed to sort the stack of cards into two piles: (a) those containing statements that resonate with their own experiences or are representative of statements that they had heard after the birth or diagnosis of their child and (b) those containing statements or reflecting sentiments that do not resonate with their own experiences in the days following the birth or diagnosis of their child. (Refer to Appendix B for the list of statements that were contained in the Q-sort cards.) Here, the purpose was to explore mothers' understanding and interpretation of the nature of interpersonal or institutional discourses about families of children with disabilities. The cards served as cues to generate stories about the ways in which these mothers were positioned and positioned themselves in discourse and activity.

This method yielded a wealth of data pertaining to the ways in which mothers resisted assumptions about their lives and about what it meant to be a parent of a child with a disability. Mothers sorted the cards into the piles as requested, and also provided details with regards to their own experiences with the particular statements contained in them. In general, the statements “You must be a saint - I could never handle it” and “You are a special parent” generated considerable thought from mothers, and it is also worth noting that that the statement “God gives special babies to special parents” emerged as the one sentiment that *all* mothers in this study reportedly had encountered in one form or another.

In elaborating on their experiences related to these statements, the majority of the mothers in this group asserted that they perceived any allusions to the qualities of “specialness,” bravery, or courage among mothers of children with Down syndrome as having negative implications. While many believed that these kinds of remarks are generally made by people in their attempts to make mothers “feel better,” they also understood them as implying that their experiences of motherhood are not only outside the range of normative parenting expectations and demands, but also ones that are predominantly negative. Many resisted the idea that they were “special” mothers because they perceived these as implying that there is “something less” about their child. With regards to people’s assertions that they are “special parents” chosen by God to have “special babies,” these mothers’ said:

> *I’m not doing anything spectacular. I got pregnant and had a baby. Just like everybody else did. (Leah)*

> *I don’t necessarily agree with the statement but I accepted - like the people who were saying it were trying, sort of like, to make you feel better kind of thing. . . . I thought to myself we’re just normal people like anybody else. And that this is just - no kid is perfect. . . . Having had two older children, and knowing that for them,*

> *life is not perfect - I mean this is the same thing, people. But I know that they were trying to make you feel better, that you must be a real special person to have this. . . . I don't think we're special just because we've got Gillian. I don't buy that. I really don't see it as helpful to be honest with you. And it probably rubs me more the wrong way. Because then it makes me feel like I have to be a super parent, beyond the challenges of just being a parent. That there is something less about her. (Victoria)*

Others had similar perceptions and articulated their beliefs that the demands of raising a child with Down syndrome are not outside the range of what might be expected of any parenting experience. Some mothers were emphatic in asserting that they were doing no more than that which would be expected of any parent. This is seen in the statements below:

> *(We are) no more special than anyone else. (Rose)*

> *It's not special. It's taking care of your kid. Doing what you have to do. (Maggie)*

> *Probably the biggest thing is that our lives as two parents and two kids are more closely aligned to the life of two parents with two typical kids. That's probably the biggest thing - that our lives are pretty, - 99.9% there. We do have to make provisions but there are so minimal in so many ways - I guess the word is negligible. Not even to mention. You know what I mean? Our lives are pretty regular. Pretty regular. (Yolanda)*

In general, notions of specialness were resisted or rejected by the mothers in this study because they were perceived as implying the otherness of children with Down syndrome as well as denying them access to the category of motherhood. This finding informs questions about the process of identity construction among these mothers and also lend themselves to an understanding of the constructed nature of definitions of motherhood itself. Landsman (1999) asserted that there exists a dominant discourse that places mothers of children with disabilities in a position that is not morally equivalent to other mothers. As such, these mothers are either blamed for their role in creating imperfect children or they are elevated to the role of "special" mothers who are "chosen by God to have special children" (p. 136). Consistent with her findings, the mothers in this study rejected the label of "special" because they perceived it as implied a devaluing of their children. In asserting that they were merely "doing what you need to do" and that they were "just taking care of" their children, they created new interpretations of what is involved in the mothering of a child.

B. "How the Hell Did We Get So Lucky?": Alternative Interpretations of Families of Children with Down Syndrome

Mothers in this study discussed their perceptions of their present lives and their interpretations of the familial experience of having a child with Down syndrome. The majority emphatically rejected the notion that their experiences of motherhood were negative ones. In describing the nature and quality of their daily lives, most of these mothers highlighted both the difficulties as well as the positive aspects of their parenting experiences. Their narratives contained accounts of sadness and stress as well as many accounts of joys. In reflecting on the experience of having a child with Down syndrome, one mother described it as “a different kind of happiness.” The mothers in this study were acutely aware of dominant narratives on their lives and of societal assumptions of negative outcomes for families of children with Down syndrome. Yet, they told very different stories of families like their own. These mothers rejected notions of suffering, hardship, and sadness as characterizing their families’ experience and chose to define the quality of their own lives and those of their families in much the same terms as one might expect from mothers of children without disabilities. It is important to note that, generally, they did not discount the difficulties or challenges that often accompany a diagnosis of Down syndrome and that they discussed some of the frustrations and stressors in their lives as a result of their child’s diagnosis. However, many mothers emphasized that these are only some aspects of their experiences and simultaneously highlighted the more positive, normative, or mundane aspects of their everyday lives and parenting experiences. It is also noteworthy that, although some of the life stressors that these mothers identified were related to having a child with Down syndrome, most seemed related to other factors, such as, financial issues, being a single parent, being a parent of young children, and balancing the demands of work with the demands of parenting. Indeed, many mothers articulated that the most stressful aspects of their present lives were unrelated to their child’s diagnosis.

> *Well I think my life is perfectly fine. . . . I went back to school and I finished my degree. And now I am about to go back to school, you know, to go for a Master’s degree. She has not been an impediment in any kind of way, to do the things that I needed to do. So there are things that I want to do with my life that is just right now a matter of money but not a matter of having a child with a disability. And so I don’t really think that my daughter has been an obstacle in any kind of way.*

> *I mean if I have to say something about having a child with Down syndrome, she probably has been a strength, you know, for me to really do the things that I want to do. So again - I just don't see - I don't see her like an impediment in any kind of way. This is my child. This is my life. (Paula)*

> *I have no free time for myself. [Laughing] I can't sit down and read a book. Or you know, go to the bathroom by myself. [Laughing] Yeah - it's not any different from anything that my friends have, you know it's not really any different. . . . Like I mentioned before he's going through the terrible twos. For as much as it may drive me crazy, I do enjoy it. I just enjoy watching him express, watching him grow. I love introducing him to new experiences. And seeing his reaction and he still thinks I'm great. And so I like that. (Ivonne)*

Like Ivonne, many mothers expressed positive perceptions as parents in conjunction with the stressors and beliefs that their experiences with their children have enriched them in ways that they had not previously imagined possible. For example:

> *I think my life is more rich - more rich than I would have imagined at that particular day. I always felt that we had excellent opportunities but it's more enriched. . . . I meet people and I talk to people that I probably would never, ever have interacted with for whatever reason. And it's great. I enjoy it. I always felt as if our life was going to be good. I never felt like it was going to be this good. And I think that this good is because of all of the enriching experiences of being around people with special needs . . . The Special Olympics and -. we love that stuff. We volunteer . . . Jacob has opened up a world to me that I probably would*

> *never have considered. That I know I never would have considered. He just opened up a whole world to us. . . . I relate to people with disabilities on a person-to-person or an evenness as opposed to like - you're special and I have to talk to you like you're stupid. You know what I mean? (Yolanda)*

> *My life as a parent is very fulfilling. . . . Wonderful. There's nothing I would change about it. (Mary)*

Some mothers emphasized that they would like to convey to people that their parenting experiences are not particularly different than those of parents in general, and that to be the mother of a child with Down syndrome is not a negative experience.

> *People don't realize that, yes, it's a lot of work but it's a lot of pleasure too. You know you don't have to be a saint. I'm not. Yes my life has changed but it isn't a terrible life. . . . We have a wonderful, wonderful life. And we have great kids - it's a happy life. . . . She does take a lot of focus and just, it goes through phases. . . . But we have a nice life, we travel. . . . (I want people to know) that I have a happy life. I don't want people to look at us and feel bad for us. Or think we picked the short stick or had bad luck . . . I want people to know that we're very happy. And that Eva has not taken away any happiness. (Rose)*

> *Why do you think I go around work and I'm showing everybody pictures of my kid? And I'm always talking about he . . . I want them to see I'm normal . . . I'm well-adjusted - well - [laughing] that's up for interpretation. I don't think I've ever been well-adjusted. . . . I love my kid and we have our life. Things are going*

> *forward. I'm back to work. I'm not wearing rags. I'm not weeping in the corner. I want people to see this. I want people to know this. I want to be out there with it to show people there is absolutely nothing to be ashamed about. (Josephine)*

The narratives also point to transformations in these mothers' understanding of what life is like for families of children with Down syndrome. In their accounts of their present lives, the negative language and metaphors that they had used to describe their initial reactions to the news of their children's diagnosis were largely absent. Instead, they described their lives in terms like: "active," "busy," "stressful," "fulfilling," "wonderful," and "content." To a great extent, these mothers were aware that their interpretations of Down syndrome had changed and that their perceptions of what it means to be the family of a child with Down syndrome had become transformed. For example:

> *Today is - you know, it's pretty good. I hear myself laughing and I remember thinking in the hospital - am I ever going to be happy again? . . . Right now it's pretty good. (Maria)*

The extent of the transformations in the some of these mothers' interpretations of the meaning of having a child with Down syndrome is revealed in Josephine's account of daily life, highlighted as follows. To illustrate, I juxtapose this with her account of her initial reaction to hearing her daughter's diagnosis of Down syndrome. In her narrative, Josephine described her initial perceptions after hearing her daughter's diagnosis in this way:

It was like the earth opened up and swallowed me into a pit. I was shell-shocked. I was horrified. I was saddened. (Josephine)

In describing what life is like for herself and her family at the present time, 5 years after the birth of her daughter, Josephine said:

> *If anybody told me five years ago, it was going to be this good. I would look at them and tell them they're crazy. You're Pollyanna. You're sugar coating it. It's going to suck. You know a couple of the older Moms did try and tell me that at Stepping Stones, and I didn't believe them. . . . And as we go along and I see her doing more and more things, you know being more quote, unquote - more and more like a regular kid. It's like holy-moly, they were right. [Laughing] It does get better . . . Having an extra chromosome isn't the best - whenever your kid has challenges ahead of them, you know I think it does make you sad sometimes and it does bother you. But as far as living in a perpetual state of gloom, if I am it's not because of my daughter. [Laughing] I mean she's just great. . . . Sometimes like, we'll be hanging out with her maybe on a Friday night, we'll be eating a pizza and have music on. And we'll be laughing and she tells us about her day, as much as she can. And my husband will turn around and say: "How the hell did we get so lucky?" I'm like, you're right. I agree 100%. How the hell did we get so lucky? (Josephine)*

Here, Josephine provides us with a snapshot of her family. Her emphasis on both the ordinariness and the everyday joys of being a parent as well as her description of what a typical Friday evening looks like in her life reveal the transformations in her understanding of what is it is like to raise a child with Down syndrome. In this last excerpt, Josephine lends voice to the changed perceptions of many mothers in this study who came to understand their experiences of parenting a child with Down syndrome as not being particularly distinctive from parenting any child and their families as not particularly distinctive from families of children without disabilities.

C. "I Have to Fight:" Enacting Identity

Consistent with Harre and Gillet's (1994) notion of mental life as dynamic activity as well as with the grounding assumptions offered in Cultural-Historical Activity Theory, the data suggest that mothers in this study, operating within meanings available to them, participated in constructing meaning through engagement in purposeful activity. Many discussed their perceptions of their roles as mothers of children with Down syndrome or as mothers in general in terms of the activities in which they engaged or the decisions they have made with regards to their family and children. Often in discussing what it means to be a parent of a child with Down syndrome, they described their engagement in efforts to educate others about their children, their attempts to gain access to resources or educational programs for their children, and their involvement in organized disability advocacy groups. For these women being the mother of a child with Down syndrome was enacted daily in the ways in which they represented their lives, the choices that they made for their children, and in "fighting" on behalf of their children. Some discussed their involvement in organizations or programs aimed at educating people about disability or at having a voice in public policy. For instance, one mother described her efforts at establishing an outreach program for new mothers of children with Down syndrome; others described involvement in Down syndrome organizations at the local or regional level or expressed a strong desire to become involved in initiatives to the same end.

> *I run the (name of group), which is a local parent support group for families with Down syndrome. Basically I run the group. And one thing that's really important to me is the outreach to new parents. Because I know in my own experience that that was the first sense of relief that I got. . . . Doesn't mean that their experience is going to be exactly like yours. But it's another viewpoint that you can take and one that is a lot more consistent with what you're going through than with doctors and counselors telling you what it's like to raise a child with a disability. (Adele)*

> *One of the ways I deal is by action - intellectualizing things. . . . I joined an advisory panel about people with disabilities. . . . It's over different things. It's not over the fact that she has Down syndrome, it's more related to the hurdles she's going to have to surmount. (Josephine)*

These accounts reveal that for many mothers, active engagement in parent support groups and in activities related to disability advocacy became an important avenue for resistance. Their stories are resonant of what Darling (1988) refers to as "parental entrepreneurship," a pattern of activism among parents of children with disabilities which begins as a response to what is perceived as a failure in society to meet the needs of children with disabilities and their families and often becomes a life activity or career. In this way, parenting takes on dimensions that involve a vision and commitment for systemic changes in service delivery or public policy. Similarly, Wickham-Searl (1992) noted that mothers of children with disabilities, critical of professional practices and attitudes, experience a level of personal growth that often extends to leadership positions and civic engagement in disability related work. Consistent with the works of these scholars, the findings of this study support the idea that, in varied ways, mothers enacted resistance to ideologies of burdened families and perfect children by educating themselves and their communities, engaging in civic activism, organizing parent-to-parent support networks, or taking a leadership role in disability rights issues. Drawing from their own experiences and perspectives, they took on roles in public work related to disability; their transitions to becoming educators, organizers, and activists were derived from their personal processes of meaning-making and, in turn, influenced the meaning that they assigned to disability and to their constructed identities as mothers.

For some mothers, engagement in advocacy took the form of initiating a dialogue with school district officials regarding the education of their children. In discussing their ongoing efforts at securing inclusive classroom settings for their children, they described themselves as advocates who must "fight" to access mainstream settings for their children. This "fight" was viewed by them as a central aspect of their parenting roles. Activities related to "fighting" for their children's "rights" emerged as a consistent theme in their narratives and these activities were viewed by many mothers as unique to the experience of raising a child with a disability. This is seen in the following accounts:

> *I fought (for inclusion) from the time that she was little. . . . There was a little fight when that happened because we did not have an Inclusive Pre-School. We didn't have an Inclusive Pre-School or Nursery School in our district. It was a Handicapped Pre-School. And that's how it was labeled and that's what it was. And so we went to the district and we sat down and we did our little presentation on who Gillian was and here's Gillian's portfolio. . . . I did the whole research part. And I showed them all the background and the research that shows that*

> *children with Down syndrome do better with typical peers. And my goal for Gillian is to be able to function day-to-day in the real world. . . . And that was the fight. And at first, they thought I was nuts and I mean I know they thought that I was nuts because this was something that they'd never done. (Victoria)*

> *Raising my daughter is never a hardship. It's a very small price, than I would have imagined. . . . But it's more that you have to fight with the school district. You're constantly, kind of questioning what other people are thinking about your child. (Adele)*

These comments reflect that, for some mothers, resistance to discourses on disability takes the form of advocating for their children on an individual level with regards to their schooling. Erwin and Soodak (1995) indicated that parents of children with disabilities who actively pursued inclusive school placements held beliefs about the education of their children with disabilities which were inconsistent with prevailing cultural perspectives on the same. Furthermore, the authors asserted that for these parents, school inclusion represented membership to society and was linked to matters of social justice. Similarly, for the mothers in this study who pursued inclusion, the issue of educational placement was linked with their understanding of disability and difference. Their advocacy for inclusive school settings became an avenue for challenging notions of separate categories of children and emerged as central aspects of their enacted identities.

Under the previous sub-heading, I discussed that the mothers in this study were acutely aware of the transformations that they had undergone in terms of their interpretations of their child's diagnosis as well as their perceptions of what it means to have a child with Down syndrome. In addition to discussing transformations in their perceptions, many mothers also discussed what these changed perceptions had implied in terms of their subsequent pregnancies. Of the 19 mothers in the sample, 8 had subsequently given birth to other children at the time of the interviews. I explored these mothers’ perceptions of their subsequent pregnancy experiences and asked them whether or not they had opted for prenatal genetic testing during their pregnancies. These kinds of questions were asked because I was interested in exploring mothers’ experiences of pregnancy and prenatal genetic testing after their own experiences as mothers raising a child with Down syndrome. In particular, I was interested in whether these mothers’ transformations in perceptions of disability and Down syndrome were enacted in their activities related to pregnancy and the mothering of their other children. Among this group of 8 mothers, 2 reported that they had chosen to have prenatal genetic testing during their subsequent pregnancies and 6 mothers reported that, despite strong recommendations from their physicians to have prenatal genetic testing during their subsequent pregnancies, they had declined the testing procedures. It is also worth noting some of the mothers who had opted for prenatal genetic testing when they were pregnant with their child with Down syndrome, i.e., those who were *not* opposed to the idea of prenatal testing for religious or other reasons, chose to forgo the same tests after they had a child with Down syndrome. In discussing the reasons for declining prenatal genetic testing during subsequent pregnancies, some mothers said that they had not felt the need to know whether or not their child would have a particular disability because it no longer “made any difference.” Although there were some differences in the reasoning of the mothers concerning this decision, there was also a thread of commonality: all articulated beliefs that having prenatal genetic testing in subsequent pregnancies would have implied that they were making a judgment about their own child with Down syndrome. All mothers in this group expressed a new discomfort with the idea of prenatal genetic testing and some articulated that, during their subsequent pregnancies, they had taken into consideration the implications of having the tests for the ways in which their family viewed their child with Down syndrome.

> *(For subsequent pregnancy) I did nothing. No tests. Yeah. I felt - I mean I had ultrasounds. But um, after having Sam, I felt like, you know, I've walked through that fire already. And it did not matter what the results would be. I would have the child. So, there was no reason to go through the anxiety. What was gonna be was gonna be. And I also felt in a way I would be betraying Sam. I don't know if you can understand. Because I love and I accept Sam and I think if - for me, if I were to have a test to find out if the baby had Down syndrome, in some way, would be, not a disservice - it just would be, umm - betraying him. Not fully embracing and accepting him for who he is. (Leah)*

> *Because I was happy with Krissy . . . I was just - I was happy. I didn't feel the need to have another normal child. . . . But now I do have one! . . . We didn't get the amnio - How could we? How would Krissy feel? How would we feel that we have a child with Down syndrome and then if we have another one - to get rid of it? (Jane)*

However, as mentioned earlier, not all mothers in this study opted out of prenatal testing in subsequent pregnancies. Two mothers in this group discussed their choice to find out prenatally whether or not their child would have Down syndrome in ambivalent terms. One mother, who was pregnant at the time of the interview, expressed deeply conflicted feelings about her decision to have prenatal testing during her current pregnancy and described the impact that this had on her pregnancy experience. She became very emotional as she discussed her decision to have prenatal testing after having a child with Down syndrome and articulated her belief that, in the act of opting to have the tests, she was “devaluing” or “negating the value’ of her daughter with Down syndrome:

> *I’m pregnant again and I did do CVS. . . . I didn’t want to get too attached to this pregnancy, cause I probably would have terminated if I was going to have another child with a developmental disability. . . . I wonder if I would have terminated then. I wonder - like, I don’t know. Where would I have drawn the line, like, oh that’s OK, but this isn’t? That’s such murky territory. . . . It was very hard for me to do the testing because, in some ways -it was really hard. It - it was a lot harder than I thought it was going to be. I can’t determine why - it was just like this gut, visual, emotional, wordless thing (crying) . . . I hate telling you. Because I felt like I was devaluing - I was negating the value of my daughter. Like, I was valuing her differently. No - on a purely, like, pragmatic- and I wanna say practically - I don’t know that emotionally - I don’t know if I would do it. I’d probably do it. I mean, I probably could . . . I just felt like I was negating my daughter. I was saying - you’re not good enough. And she’s more than good enough. I still have a lot of working through and I think I’ll probably be working through this my whole life. (Donna)*

Donna’s account of her experience with prenatal genetic testing during her subsequent pregnancy sheds light on an important finding in this study which relates to the ways in which these mothers contended with the idea of being nondisabled women who raise children with disabilities. As noted before, all mothers in this study were themselves nondisabled and most asserted that they had little contact with individuals with disabilities prior to the birth of their children with Down syndrome. These mothers were faced with the task of confronting institutional assumptions about disability and difference from their position as women *without* disabilities or from the stance of women whose bodies carried the ideologies that they challenged. The stories of the mothers in this study inform questions related to the ways in which they struggled with constructing their identities as mothers *and* as nondisabled mothers of children with disabilities. Donna’s description of her deeply conflicted feelings concerning her choice to have prenatal genetic testing and of the negative emotions she experiences whenever she contemplates what she “might have done” if she had received a diagnosis of Down syndrome, paint a picture of the ways in which she grappled with the competing discourses of the push for “normalcy,” and her own resistance to notions of the otherness of children with Down syndrome.

D. “Moments of Brilliance; Moments of Darkness:” Interpreting the Meaning of Motherhood

The mothers in this study talked about their expectations of motherhood and their beliefs about what is involved in parenting a child as well as whether these have changed as a result of their experiences with their children. Every mother in this group discussed the stressors that they experienced in their daily lives as mothers. However, they attributed much of the stress that they experience to parenting rather than parenting a child with Down syndrome. In elaborating on the most stressful aspects of their parenting lives, many mothers enumerated things like: juggling the demands of work with the demands of parenting, being too busy, and not having enough time to themselves. These were perceived as part of the territory of being a parent. In addition to these daily stressors, many mothers raised some additional challenges which they perceived as specific to the experience of raising a child with a disability. In this category, they mentioned things like: having more doctor appointments, having numerous therapists visit the home as part of early intervention, having to be more vigilant of their child, and having to protect their child from negative experiences. However, it is worth noting that when mothers identified specific stressors related to having a child with Down syndrome, these too were perceived by most as aspects of parenting. Many mothers expressed their understanding of parenting as presenting a range of expectations, demands and challenges, and articulated a belief that difficult, unpleasant, or stressful moments are simply inherent in the experience of raising any child. The expressed perceptions of motherhood of these mothers and their interpretations of even their most difficult moments as aspects of parenting, shed light on their resistance to being positioned as anything other than "typical" mothers and on their alternative definitions of normative motherhood. This is illustrated in the examples below:

> *I also feel that there are issues that are there with (children with Down syndrome). Health issues or whatever . . . but it's just, those issues are to me, they more reflect that being a parent can be work - it can create work. And I think if anybody has a child, and doesn't expect that there's going to be work,*

> *they're going to be very (unclear) about the whole thing - about what raising a child is all about. What the whole purpose is for raising children. It's just kind of inherent that you have a child, you going to be changing diapers, you're going to be dealing with smelly poops, you're going to - you're going to be dealing with these things. . . . And if you think that you just going to escape these things, have this perfect picture Gerber baby, then those are the people who are being foolish. (Andrea)*

> *I don't like the stress. . . . But it's also typical - what family, what typical family doesn't feel stress getting out of the house in the morning? What typical family, what typical mom doesn't feel any frustration with her kid? . . . Any parent - to think that having a child is not going to be arduous, complicated and make you learn new skills - I mean what the heck. People who have kids, or have a first child are gonna have to learn new skills . . . none of us know what we're going in for . . . it's degrees of arduousness or complicatedness. . . . They're parents. They are in for it, like anyone! (Maggie)*

Some mothers also added that, although having a child with Down syndrome had brought challenges, the experience was not particularly different than their experiences with their other children or step-children, who also presented challenges, placed demands upon them, or required adjustment on the part of the family members:

> *Is it more of a challenge sometimes? Yeah. Because sometimes I have to think outside of the box but you know, I say to myself - who's to say that I didn't have to think outside the box with (my other child)? I have two step kids going into a*

> *marriage and they are with us most of the time. There was a lot of thinking outside the box there too. (Victoria)*

These mothers also reflected on the meaning of motherhood in the context of a societal focus on perfection. Similar to the ways in which these mothers discussed their understanding of the meaning of disability as residing in the environment, they also situated their experiences of motherhood within the context of a social devaluation of their motherhood experience and a strong societal pressure to have “perfect’ babies. These mothers expressed beliefs that their children with Down syndrome are not viewed by society as meeting the criteria for perfection. Rejecting the ideology of perfect children, these mothers positioned motherhood in general as presenting difficulties and “risks.” This is seen in the excerpts below:

> *People want to do everything they can to ensure that they have the perfect baby. But I think that what’s being lost is that people don’t understand that becoming a parent is a huge risk in itself. Having a child is a huge risk. (Karina)*

> *We’re just in a place where people think there has to be the perfect child. And I think that she doesn’t fit the mold of what the perfect child is supposed to look like. (Victoria)*

Consistent with Bamberg’s (2004) assertion that, when positioned in master narratives, individuals are agentic in producing counter-narratives that assign new meaning to interpersonal and psychic phenomenon, the findings in this section reveal that the mothers in this study engaged in interpreting what is entailed in raising a child as well as in redefining the meaning of motherhood. Their positioning of themselves as “just moms" and their interpretations of their experiences of parenting a child with Down syndrome as not being particularly distinctive from parenting per se, reveal the ways in which these mothers reframed the meaning of "child' and motherhood and, thus, reinstated their identities as mothers.

III. Performing Identity in the Context of Education

Snapshots: Paula's Story

I wasn't still legally divorced. My husband left in June and I met Anya's dad in July, but by September I was pregnant. I was very shocked when I found out I was pregnant. It was like, Ok, what do I do? Because I am pro-choice - I spoke with (the father) and he was very arrogant in his attitude. . . . He felt - why don't you go ahead and have an abortion? . . . I think he should have asked me -what would you like to do? And I said, you know what? This is my body and I'm going to do what is right for me.

When I went to my doctor, she wanted me to have an amniocentesis because I was forty-one . . . I am very uncomfortable about needles. . . . So I just decide that I don't want to have the amniocentesis. . . . And I say, you know what? I understand that I am taking some risk here. Why should I make myself miserable finding if something is wrong?

I had Anya by myself in the hospital. Nobody was there with me . . . I think one the nurses, she realized right away that something was wrong . . . They wanted to take her right away to the nursery. They had a suspicion based on her features.

So, the day after, the pediatrician came in and mentioned that there was a suspicion that Anya had Down syndrome. . . . And of course at the beginning, you are like, you know, surprised. Like, oh my God. . . . Right after that you feel like you want to cry. You feel like you want to cry but when you look around and you see you don't have anyone to cry with. So, I said, okay, I'm here by myself and I have to deal with this. . . . You have all these feelings like, okay, I failed. I'm sorry but I failed, but what can I do? So you go through all these feelings - a mixture of feelings. You see your child and you say: "Okay, I'll take care of you. Don't worry about it and nothing's going to happen to you." So many feelings that you go through - the good feelings, the bad feelings and the different feelings. You feel guilty.

I think that for the most part, people were shocked. "I'm sorry." That's the reaction. "Oh, I'm sorry." . . . I guess people don't know what to say. People react like that and so that's what you get: "I'm sorry."

I've heard ("God gives special babies to special parents") a lot. I think it's stupid. . . . It's just a silly statement. . . . Some people said: "Did you know that you were going to have a child with Down syndrome?" And I say: "No, I did not." "Oh. Didn't you have a . . .?" And I say, "No. But what's the difference?" Some people ask you that. I just think it's a very silly question or inappropriate question. What do you want me to do if I find out? Did you want me to have an abortion? That's what you wanted? And I'm pro-choice, but it's a silly question.

As soon as I have her, I remember spending hours and hours and hours learning about Down syndrome . . . Internet. I went to the internet and found the Down Syndrome Society and started reading a lot. . . . I also read about a thesis about another doctor, a bilingual doctor, and her thesis is based on children with disabilities being exposed to a second language. Would be beneficial to them. Because her therapist advised me not to speak with her in Spanish. I don't believe them. I speak with her primarily in English. But I am - I speak in Spanish too. We watch channels in Spanish. . . . I'm teaching her words . . . she knows all the greetings now.

A lot of things went through my mind. I remember one of my feelings was like, now I won't even be able to meet anyone ever again because who is going to want to be with someone with a child with Down syndrome? . . . I felt like I would be very isolated from the world - like nobody is going to want to be with me . . . I didn't know if she would be walking, talking, if she would be in pampers for the rest of her life.

(Today) I think my life is perfectly fine. I went back to school and I finished my degree. And now I am going to go back to school, for a master's degree. She has not been an impediment in any way, you know, to do the things that I needed to do. There are things I want to do in my life, and now, it's a matter of money. Not a matter of having a child with a disability. So, I really don't think my daughter has been an obstacle in any kind of way. I mean if I have to say something about having a child with Down syndrome, she probably has been a strength, you know, for me to do the things that I want to do.

My babysitter was pregnant this summer, and I asked a question that so many people ask when you're pregnant: What do you prefer, a boy or a girl? . . . And people say to you: "Oh, I don't know but as long as the child is healthy. Or, as long as the child has ten fingers and ten toes. That's all I want." I say – "Well, you know something? It doesn't really matter, you know, because it's going to be your child . . ."

You start looking at the world with a different perspective, with a different eye. . . . If you are pregnant and you are going to have a child, you have to think that many things can happen. Even when your child has ten fingers and ten toes. . . . Everybody wants a Hitler-type of, you know, a particular type of personality. Everybody looking the same. That's what Hitler wanted. He didn't want anyone with illness. He didn't want the Jewish. He didn't want, you know, the darker skin. . . . But everybody has meaning in the world. It's about finding a place for them in the community that we live . . . It bothers me because what are you going to do if you don't have a perfect child? Have you thought about that? How about – you don't have the perfect child. What are you going to do? Are you going to put the child in the garbage? I don't want it – my child has four toes!

She's in first grade . . . She's in a self-contained class. . . . When they first told me that she will go (to self-contained class), I have also mixed feelings, because I think I want her to go to mainstream. . . . But then they suggested for her to be in self-contained. And then I figured that maybe that would be a better option.

Kids can be very mean . . . Kids can be very mean and cruel. And I guess, in a way to kind of protect her from, you know, kids who would not understand her disability. I debated myself and maybe I felt that self-contained was a better option . . . I say, well, maybe she will be more kind of protected in self-contained.

(School administrators) felt like she was, her level of understanding wasn't for a regular mainstream class. They said they could provide her with a good educational system in the self-contained class . . . And I have to say, the school has really been an excellent school.

Anya is a very social person . . . I always call other kids to come over because I don't mind to have kids in my house. You know, so they come and they play. And she interacts with them well.

(There's a) girl with Down syndrome, she goes to the high school, but she has a very introverted personality. . . This is what I observed last year - she goes to mainstream classes but this child has lunch every single day by herself. Every single day. And I did talk to all of my students – I never say that I have a child with Down syndrome – but I always tell them: You guys, this is our community. There is a person with Down syndrome and she is always by herself. I know that you all like to be with your friends, why don't you socialize with her?" My question is, the parents – are they really doing a favor to this girl, having her in mainstream? . . . I feel very sad that she is so lonely. . . . Kids are cruel.

> She is my daughter, and - I want to see her interacting in regular, mainstream classes . . . (But) again, I do feel like for her, it is better now, where she is. I do feel that is a better way until I see with my own eyes that it will be better for her in regular classes . . . The ideal thing is smaller classes. I don't know how many children they have per class in mainstream - twenty-something. So, I think it's just too many children in one class. Because I went into teaching myself. And I see what it is to be in a classroom. Because I do have kids, once in a while, kids with disabilities. And kids are cruel. They don't understand and they want everyone to be perfect.

Paula's story is highlighted in the snapshots section above because it reveals many complexities with regards to the ways in which mothers of children with Down syndrome come to understand issues of acceptance and the ways that these are linked to their views about the education of their children. Like the other mothers in this study, Paula resisted discourses that emphasized burden among families of children with disabilities and positioned herself as a mother engaged in raising her daughter. Unlike most of the other mothers in the study, Paula was a single parent and, in her narrative, she emphasized that much of her daily stress was a result of being a single parent and of economically related factors. Paula's narrative was distinctive in her expressed understanding of the ways in which society views children with disabilities and about the implications of these for herself and her daughter. Furthermore, Paula's articulation of her belief that children with disabilities are not accepted in society and that this would translate to a lack of acceptance in a general education classroom represent a critical theme in the reasoning of the group of mothers in this study who expressed their preferences for self-contained classroom settings. Paula’s assertions that inclusive education is not necessarily a good idea for children with disabilities because of the possibility of peer rejection reveal important aspects in the reasoning of mothers. While there was variability in the perceptions of the mothers in this study, it is important to note that Paula’s concerns about the social isolation of children with Down syndrome in inclusive school settings were generally shared by all. In Paula’s case, however, these views are particularly noteworthy, not only because of their impact on her parenting decisions, but also because she spoke from the stance of a teacher (Paula teaches Spanish at an elementary school).

In this section, I discuss those aspects of the data that relate to the ways in which the constructed meaning of disability as well as negotiated selves of the mothers in this study were performed through their activities related to the education of their children. Aspects of the narratives that pertain to the ways in which mothers understood various schooling options for their children, their beliefs about the benefits of particular classroom settings or kinds of educational programs, and their advocacy for the programs that they believe would be most beneficial or appropriate for their children are discussed in the context of the constructed notion of the otherness of children with Down syndrome. The mothers in this study discussed their beliefs and their perceptions of the range of schooling options available to their children. With regards to the group of mothers whose children were over the age of 3, I discuss aspects of the findings that shed light on the decision making processes that led to the children attending particular schooling programs and on mothers’ perceptions of the primary benefits or drawbacks of both inclusive and self-contained education. With regards to the group of mothers whose children were younger than the age of 3, I discuss aspects of the findings related to their beliefs about inclusive and self-contained education and their preferences for the kind of schooling that they envision for their own children with Down syndrome.

A. "The Land of Misfit Toys:" Classrooms as Places of Belonging

When mothers discussed their children's classroom placement, they focused to a great extent on issues related to "fitting in" or "belonging." An important finding in this study was that when mothers discussed the nature of classrooms or their preferences for either inclusive or segregated education, they often expressed beliefs about where their children would be most accepted by others or where their children "belong." Among those mothers who supported inclusive education or those whose children were already attending general education classrooms, inclusive classrooms were viewed as the natural environment for their children and, for some, placement in this kind of classroom was viewed as indicating societal acceptance of their children. Some mothers discussed their understanding about school inclusion as a civil rights issue or a matter of access to mainstream society:

> *I guess it represents - my daughter being included in day-to-day life. That she is not being segregated. That she's not being singled out. And that she is being accepted for who she is. Or at least an attempt to try to accept her for who she is. She should not have to earn her right to be in this class. It her right. But the insecurities within me make it hard. (Andrea)*

> *I want her to be as integrated as possible. And we would like her to obviously learn as much as she can. Somehow, to me though, it's become less about what I need her to be able to do academically, and more about just her right to be included. She has a right to be with children her own age in a mainstream classroom. She has the right to access the same educational curriculum as everybody else. Doesn't mean that she will be able to participate at grade level at that stuff. (Adele)*

Similar to the findings of Erwin and Soodak (1995), the mothers in this study often discussed inclusion in terms of issues related to social justice, equal opportunity, and fundamental civil liberties. In discussing particular classroom settings, mothers raised issues related to classroom membership as well as broader issues of full membership in society. Many of the mothers in the study who supported inclusive education or advocated for inclusion for their children expressed beliefs that this kind of education would prepare their children to belong in society, both the present time and in the future. For these mothers, the advantages of inclusive education went beyond immediate benefits, their reasoning included considerations of educational programs that would best prepare their children to participate in society as adults, give them the tools for success in future vocational settings, or allow them to access the "real world."

> *In terms of inclusion - she's got to learn to fit into the real world. And deal with real world problems. And if she's in an inclusive setting, those are things that hopefully she will gain some experience and either figure out for herself. . . . She's got to relate to everybody, not just her quote unquote disabled peers. And if she's in self-contained then it's just - there's that whole segregation thing again.*

> *You know it's just like - okay here are all the quote unquote normal kids here and here are all the - you know. What they used to call it in my school - the kids who ride the short bus to school. They're over here and never the twain shall meet. Those are some of the social issues I worry about. (Josephine)*

> *I want Leila to be with her peers, you know, whether they have Down syndrome or not. . . . For you to be a Down's child and not to be able to talk to your peers, or for you to be a normal child who is mainstreamed and to not have an inclusion child in your class, you're missing out. I hate that I use that word normal, but, you're missing out. . . . I feel that the experiences will enrich her and as they get older people become involved in different things. And her experiences based on me and based on the school will enrich her . . . Making her a more, well-rounded individual – I think it's very important for her to be out there in the world, using her skill, because that's what it's all about. It's not teaching you a skill and putting you in a limiting setting or a very specialized setting because then you're only going to know how to use that there. You need to be out in the world. You need to be able to negotiate. . . . Inclusion for my daughter represents - it represents her vehicle towards her independence in life. (Mary)*

Mothers whose children were attending self-contained settings or those who expressed a preference and support for segregated classrooms were *also* inclined to discuss classrooms as places of belonging. Similar to the ways in which mothers discussed their support for inclusive education in terms of belongingness, this group of mothers also tended to focus on the issue of "fitting in" or on considerations of where their children would "belong." Furthermore, similar to the ways that mothers who favored inclusion spoke about inclusive classrooms as representing membership to society, mothers who were wary of inclusive education discussed self-contained classrooms as places of unconditional acceptance and as providing opportunities for membership to a group:

> *(In self-contained classroom) everyone is just like him. . . . They can do their own thing, they can go to the movies together, they can have dances. . . . In a perfect world that wouldn't be, but I'm being realistic. (Leah)*
>
> *Maybe it's my own security blanket that he has to be in a Special Ed Room. . . . I don't want him to go into something and then get kicked out. I want him to know there's always going to be that classroom where people understand him and don't expect him to be perfect in a way that they might in a typical class. (Karina).*
>
> *I feel he would be most accepted in a Specialized Environment - within the group . . . I feel that people will understand him. (Yolanda)*

Mothers' beliefs about the nature of self-contained classrooms as places of acceptance and social belonging are elucidated in this mother's use of the phrase: "land of misfit toys" as a metaphor for self-contained classrooms:

> *I think in a self-contained classroom with other kids, it's sort of like the land of misfit toys where everybody is in it together. If you look at all the disabled kids together, it's sort of like the land of misfit toys . . . It doesn't rise to the top as much or it doesn't become noticeable or you could write it off as a quirk. (Maria)*

Issues related to belongingness for people with disabilities, whether in classroom or in society, were frequently articulated reasons for mothers' preference of particular educational programs. However, those mothers who advocated for inclusive classrooms also gave other reasons for their support of this kind of education including: access to academically challenging curricula, access to a range of resources, and opportunities for their children to model from typically developing peers. Additionally, mothers discussed the benefits of inclusion for children *without* disabilities. Many mothers, including those who believed that that self-contained classrooms were best for their own children, expressed an understanding that inclusion benefits all children and ultimately, society as a whole. This is seen in the following excerpts:

> *I think the benefits are probably first and foremost, socially for your child as well as the children that are being exposed to a child with disabilities. . . . If people don't experience somebody with disabilities firsthand, they're less understanding about it and they're less sympathetic about it and they're less interested - less concerned about it. But if it's to the degree that other normal, quote- unquote, kids can be exposed to kids with disabilities - maybe they'd see them more as normal. And you know to see them as being kids and that's - I think to me that would be a really great thing. . . . Her presence in a pre-school setting will affect her peers who will therefore be more sensitive individuals as they grow older, more so than my generation or the generation before us. And I think the more exposure that other kids have to kids with disabilities makes them more accepting. (Maria)*

> *Inclusion is for the benefit of everybody there. . . . Everybody can gain from it. (Yolanda)*

B. "Especially for Special Needs:" Classrooms as Places for the Enactment of Otherness

The findings discussed here pertain to a particular type of reasoning demonstrated by mothers who expressed their preferences for self-contained classrooms. Among this group, some articulated that self-contained classrooms would be the most beneficial educational setting for their children because here specialized services can be delivered by professionals using special equipment or special techniques. Their explanations point to perceptions of self-contained classrooms as desirable places for the education of their children with Down syndrome because of the availability of physical resources and of professionals who have the qualifications to educate children with disabilities:

> *They have a whole sensory room that they've created there. They have a lot of therapists on staff there. (Anne)*

Some mothers focused on the idea that, in separate, self-contained classrooms taught by special education teachers, their children would be educated by those who are "trained especially for special needs," or those who have personal qualities that are particularly needed for educating their children with Down syndrome. More specifically with regards to this, some mothers expressed beliefs that special education teachers may possess more patience, understanding, and empathy in addition to having specialized training and that general education teachers may lack not only the training but also the willingness to teach their children with Down syndrome. This is seen in the following excerpts:

> *I know in a specialized environment - I know that the teachers and the teacher's assistants are all trained especially for special needs and so I know that they*

> *would have the patience and the understanding, the training and the ability. (Yolanda)*
>
> *(In a self-contained class) I guess I was picturing the teacher would understand that she doesn't know, she can't really express herself as well. . . . (My daughter) wouldn't be able to express herself as she would want to, and be frustrated, and that's why . . . I assume that being a Special Ed. teacher she'd know, or have training to know. . . . I have high expectations for Special Ed teachers. (Jane)*
>
> *(In an inclusion class) the teacher would not have the background and would not be able to teach him the way he would need to be taught. (Ivonne)*

These statements indicate that some mothers supported the idea of segregated classrooms or school settings for their children with Down syndrome because of perceptions that it is only in these settings that the educational needs of their children can be addressed. Mothers expressed the idea that, in self-contained classrooms, children with "special needs" can be educated by those who are able to understand the *differences* of these children. It is worth noting that many of the same mothers who strongly resisted notions of otherness in their conceptualizations of disability, in their interpretations of their motherhood experiences, *and* in their descriptions of their children with Down syndrome, when confronted with important education related decisions, succumbed to ideological notions of a child with Down syndrome as other. When making decisions concerning schooling placement, they seemed to focus on those needs of their children with Down syndrome that rendered them different from children without disabilities rather than on those that could be considered common to the education of all children and was an unanticipated and important finding in this study. In attempting to understand the discrepancies between these mothers' interpretations of raising children with Down syndrome as not being distinctive from raising children in general and their educational preferences for settings that addressed the "special needs" of children with Down syndrome, it is necessary to examine the institutional rhetoric that they encountered at the time during which their children were transitioning to educational settings. To that end, in this section, I included findings related to these mothers' encounters with institutional discourses about the education of children with Down syndrome.

Institutional resistance to inclusive education

When their children with Down syndrome were born, the mothers in this study encountered medical and interpersonal discourses that centered on the otherness of children with Down syndrome. Their stories highlight the ways in which they resisted the master narratives on disability and actively participated in constructing the meaning of their own experiences. Approximately 3 years later when their children were ready for pre-school, these mothers became engaged once again in negotiating the meaning of Down syndrome. Similar to the ways in which interpretations of the birth and diagnosis of their children with Down syndrome were embedded in the context of medical discourses on disability, this time the meaning of Down syndrome was embedded in the context of the rhetoric of Special Education.

The narratives indicate that to a great extent, mothers encountered institutional resistance to the idea of placing their children in inclusive settings. Many mothers recalled that, when their children were transitioning to preschool, the Child Study Team (CST) identified the most appropriate placement for their children to be a self-contained classroom or what is termed “the preschool disabled class” in many school districts. A few mothers in the study reported that they had themselves advocated for self-contained placement in separate, specialized facilities for children with developmental disabilities and that their school districts had complied with their request because they also considered this kind of placement to be the most appropriate for their children. Others expressed that they had initially wanted to explore the possibility of inclusive education, however, CST professionals at their school district had informed them that they “did not offer” this kind of educational setting, that they “did not have inclusive preschools,” or that their professional recommendations were for a smaller, self-contained classroom for their children with Down syndrome. This is seen in the accounts of these mothers:

> *They didn’t have (an inclusive preschool) available. No. What they said was that, for preschool they have their self-contained preschool class. That’s their preschool program. And I knew myself that, you know, that’s not least restrictive environment, but we figured that, just get her into the school system first, we would do a year in that placement, just to get her acclimated to being in the school environment and then deal with it. Looking back, maybe I should have started fighting sooner. (Adele)*

> *Her teacher said she felt she wasn’t ready for (inclusive education). . . . For kindergarten - it wasn’t presented to us. No, no. It wasn’t. (Jane)*

> *At the time they were only offering self-contained. They said: “We don’t offer (inclusion).” I had expressed my overall goal that I want inclusion for her. But I*

> *did not say: "You don't have the program so you need to provide it elsewhere." I did not know the magnitude of my rights. (Andrea)*

The excerpts above shed light on some of the reasons that were reportedly given to these mothers by officials at their school districts for recommending segregated educational settings. Mothers reported that, in addition to asserting that the district does not "offer" inclusion, other reasons provided to them in support of recommendations for self-contained classrooms included: smaller class size, their children lacking the "readiness" for inclusion, or that the cognitive capabilities of their children were not at the same level as those of more typically developing children in general education classrooms. Some mothers recounted that, although they had initially hoped that their children would attend inclusive programs, they had changed their minds when professionals convincingly presented the benefits of specialized places. They recalled that self-contained classrooms had emerged as the more appropriate and, indeed, the more attractive educational setting after they had met with the educational team at their children's IEP (Individualized Education Plan) meeting:

> *This is just sort of what was presented to me and it sounded good with all the therapy options. . . . And I was so impressed with the number of therapists that they had there that I thought that, you know, this will be good for him while he's still little. (Anne)*

> *I first wanted her to just go to main stream classes, you know regular classes. But then they suggested for her to be in self-contained. And then I kind of figured that maybe that would be a better option. (The Child study team recommended) self-*

> *contained because they felt like she was - her level of understanding wasn't for a regular main stream class. So they said that they could provide her with, you know, with a good educational system in the self-contained class. And I mean, I have to say that I really -the school has been an excellent school. (Paula)*

> *The social worker said, at the placement meeting, "We have a new program. It's a self-contained class." . . . They did a great job of selling this program, the self-contained program . . . I bought it. She convinced me. I felt she was really doing the best for me. I thought, the social worker is doing what she thinks is best. You're thinking you're getting a good deal. I thought, I'm getting this great program. Fabulous. I thought this must be right - the best. (Andrea)*

Among those mothers whose children were in inclusive classroom settings, most reported that they had themselves advocated for this particular option and some reported that they had actively "fought' for this placement or were in the process or negotiating this with their school district. Mothers whose children were in inclusive classrooms stated that they were happy with their children's progress, however, they recalled that discussions about considering inclusive placement had not been raised by their school districts and, in some cases, had been initially resisted by the district. For 3 mothers in the study, the struggle to gain access to inclusive settings for their children was ongoing and unresolved at the time of the interview. They reported that they had questioned their CST's recommendations for a self-contained setting for their children and were in the process of negotiating this with their school districts. Overall, it is worth noting that, in this study, there are no accounts of school districts initiating a dialogue on considering inclusive placement for the children involved nor did school officials recommend inclusive education unless this discussion was initiated by the families.

The findings in this section are relevant because they reveal a disparity between educational law and educational practice. In order to examine this further, it is necessary to put these findings in the context of legislation such as the Individuals with Disabilities Education Improvement Act (IDEIA), which mandates that children with disabilities be educated with their typically developing peers to the extent possible in the least restrictive environment with the provision of necessary supports. The least restrictive environment is identified as a continuum of educational settings that can be considered, ranging from the general education classroom (maximum integration), moving down the continuum to segregated classroom, and finally, to residential placements (minimum integration). Thus, while educational law does not require that all children with disabilities be educated in general education classrooms, it explicitly identifies the general education classroom as the *starting point* for considerations about classroom placement and as the setting that provides maximum opportunities for integration. Furthermore, regulations specify that, if an inclusive placement is not recommended by districts and a student is placed in a self-contained classroom, such a decision must be accompanied by a justification, i.e., the recommendation for such a placement must be supported by reasoning that indicate that the student is unable to benefit from inclusive placement despite the provision of supports and accommodations. These regulations also apply to children with disabilities who are of preschool age; IDEIA mandates a free and appropriate public education to children with disabilities beginning at the age of 3 years.

In light of the existence of educational laws which specify that inclusive classrooms should be the first consideration with regards to placement or the starting point in the continuum of least restrictive environments for children with disabilities, the findings in this section are particularly alarming. The stories of the mothers in this study point not only to a disparity between educational law and educational practice, but in some cases, also to efforts by school district professionals to steer parents toward self-contained settings. School professionals' "selling" of self-contained classroom settings and segregated education as the most attractive alternative was influential in convincing some of the mothers in this study that this kind of education was "best" for their children. However, as noted earlier, not all mothers in the group accepted the ideology of separate, specialized education. Set against the backdrop of institutional resistance to inclusive education, a prominent theme that emerged in the stories of many mothers pertains to their roles as educational advocates for their children. These mothers challenged the recommendations of school professionals and pursued access to inclusive education for their children. They spoke about this kind of advocacy as important aspects in their parenting of their children with Down syndrome. For some, this was understood as one way in which parenting a child with Down syndrome may be distinct from being a parent in general.

> *(I am) an advocate so that I can get a proper education for Molly. Every step has been a struggle. You have to prove everything. You have to be really educated to know your rights. (Andrea)*

The narratives indicate that discourses on disability which position children with Down syndrome in a separate category of child and mothers of children with Down syndrome in a separate category of motherhood resurfaced in the lived experiences of these mothers through their encounters with institutions of education. School professionals steered parents towards segregated classroom settings by focusing on the differences of children with disabilities and by presenting self-contained classrooms as the place where these different learning styles can be addressed by specialized techniques and specially trained teachers. In the context of institutional resistance to inclusive education for children with Down syndrome, some mothers in this study yielded to master-narratives on disability and difference and to beliefs about self-contained classrooms as the "best" places for the education of children with Down syndrome. Among this group some, like Adele, believed that agreeing with the recommendations of those in positions of power was a way of "getting in" to the system and having access to services; others, like Andrea described that, at the time, they had "bought" the idea because it was presented to them in an appealing manner and had became "convinced" that segregated classrooms were indeed the best for their children. Although their children began preschool in self-contained classrooms based on the recommendations of the CST, both Adele and Andrea reported that they became increasingly dissatisfied with the decisions that had been made and, at the time of the interviews, both were engaged in negotiating a move to more inclusive classroom settings for their children. Notably, both reported that they were encountering continued resistance from their school districts regarding this transition. Their accounts reveal that mothers' resistance to the otherness of children with Down syndrome competed with institutional discourses that perpetuated notions of separate categories of children. The constructed identities of the mothers in this study enacted in the ways in which they viewed, supported, resisted, or advocated for particular kinds of educational programs for their children were deeply embedded in dominant discourses of difference, stigma and the otherness of children with Down syndrome.

C. “Will She Get Invited to Birthday Parties?”: Inclusive Classrooms as Places of Exclusion

A consistent finding in this study pertains to mothers’ beliefs about inclusive education settings as places of rejection or exclusion of children with disabilities. Many mothers raised concerns about whether or not their children would be accepted or valued by others and, more specifically, most expressed these concerns in the context of their children’s school or classroom. Although there was variability in individual mothers’ perceptions about different kinds of schooling programs, a common theme in their stories pertained to whether or not their children with Down syndrome would be accepted by their peers, included in daily childhood activities, or viewed as members of their classrooms. These kinds of concerns were expressed by both groups of mothers, i.e., those who expressed their preferences for segregated settings *and* those who had advocated for inclusive classrooms or whose children were presently attending general education classrooms. For some mothers, issues regarding peer acceptance were key factors in their lack of enthusiasm for inclusive education or their support for self-contained settings for their children:

> *It would be a very hard thing for me to do. To let him go into an inclusive setting. I don’t want him to be laughed at. Or made fun of, because he’s different. My biggest concern about an inclusive setting down the road, as he gets older . I want him to have friends. . . . I think young children are very sweet and kind, but you*

> *know, kids are cruel. Human nature is cruel. And as he gets older, I want him to have friends. That is what really scares me about an inclusive setting. . . . In the middle school years, in the high school years, socialization is a huge component of the child's school day. And I don't think he would be invited to all the parties. You know, the teenage parties. I don't want him to be a joke, or like a class pet. I want him to be taken seriously. I want him to feel accepted and part of the group and I don't - it's a nice thought that it could happen, but in all honesty, I don't see it happening. . . . In an inclusive setting, at that age. It's just not realistic to me. (Leah)*

> *We want him to be accepted by his peers and we don't want him to be teased. And we don't want him to be the odd man out. I think that's what scared me and stuns - I mean every parent wants their child to fit in and to be accepted. And it's like, the thought of that breaks my heart - like Leo not being invited to parties and feeling left out. And I feel sorry and that makes me want to cry just thinking about. (Karina)*

The beliefs of mothers who supported inclusive education were not particularly different from those expressed above. Even among those who actively advocated for access to inclusive education for their children, social isolation was viewed as one potential outcome of this particular classroom placement. However, their concerns about peer rejection or exclusion in inclusive settings co-existed with their overall beliefs that inclusive education was the most appropriate path for their children. Among this group of mothers, inclusive education was seen as the more beneficial program and the possibility of peer rejection or exclusion was discussed in terms of an unavoidable aspect of this kind of education. This is illustrated below:

> *I'd like to think that people won't ridicule her but I'm not sure whether she would really fully be socially accepted. . . . I'm talking socially not educationally. So I worry. You know it's heart-breaking for me as a mother to think that if there would be a sleepover party as a teenager that she's not invited. You know people are nice to her on the playground but she's not really good enough to go to the movies with friends. And as a mother that really hurts my feelings. I dread the day that her feelings get hurt, which is coming. You know it's going to come. So I worry about that. (Rose)*

Although these mothers had concerns about negative social outcomes in inclusive classrooms, they also expressed beliefs about positive social outcomes for their children in inclusive classroom settings. These were articulated in terms of "role-modeling" or the benefits of imitating typically developing peers for children with Down syndrome. Many believed that opportunities to interact with more typically developing peers would facilitate the development of social skills among their own children. As noted in an earlier section, mothers also articulated the social benefits of inclusive education for children without disabilities, which included opportunities for other children to experience diversity and opportunities to learn about acceptance. Despite these benefits, concerns over peer rejection infused these mothers' narratives and were among the most frequently raised issues with regards to their perceptions of inclusive education. Some mothers acknowledged that their fears may be unfounded; others were more convinced that the social acceptance of children with Down syndrome in inclusive classrooms is an "unrealistic" expectation and that the potential for negative social outcomes were such that inclusive education could not seriously be considered an option. The nature of mothers' beliefs about inclusive education and the intensity of their fears about the negative social outcomes of school inclusion is captured in Maria's words:

> *I think the fears are sort of, socially as well as academically. Being made fun of, being sort of like, there's always somebody in the classroom that's - you know, the kid that's made fun of. Often times it's just the nature of children. Somebody who's sort of, you know, not in with the cool. . . . They're kids. They care about that. They want to be included. They want to part of it. They wanted to be invited to the birthday party. They don't want to be left out. (I read) an article in the Wall Street Journal talking about Special Ed. Classrooms and they said that somebody doesn't commit suicide because they don't know how to do Math. They commit suicide because they have no friends. And that's why I think the social aspect of it. (Maria)*

Maria's concerns are illustrative of the nature of her fears about inclusive education for her daughter with Down syndrome. Her reference to the newspaper article which stated that "someone doesn't commit suicide because they do not know how to do math; they commit suicide because they have no friends" reveals that, for Maria, the idea of inclusive education evokes deeply negative images. This suggests that, similar to the ways in which mothers' initial reactions to their children's diagnosis of Down syndrome were tied to their expectations of the lives they imagined they would have, here too, the present was held hostage by an imagined future. For Maria, the negative outcomes of inclusive education were such that they rendered it an all but inconceivable option.

Although Maria's concerns were expressed in more extreme terms than those of most mothers in this study, it is important to note that, in general, her perceptions about inclusive education as a place of exclusion were not unique to her, but rather were shared by most. Thus, mothers' voiced concerns about inclusive school settings as places where children with differences are likely to be isolated, rejected, or ignored by peers emerged as one of the most consistent findings in this study. In understanding the preferences for self-contained classrooms among those mothers who strongly resisted dominant discourses on disability, the findings in this section provide valuable insights into the ways in which decisions related to the education of children with Down syndrome are embedded in dominant discourses of stigma, difference, and the otherness of children with Down syndrome. With regards to inclusive education, the beliefs of the mothers in this study were inextricably linked with the ways in which they understood the meaning of having a child with Down syndrome in a sociocultural context.

CHAPTER 4

DISCUSSION AND CONCLUSION

Overview

In this study, I have elucidated the contextualized meaning of having a child with Down syndrome and the profoundly social nature of human experiences and identity. By eliciting narratives from 19 mothers of children with Down syndrome and by giving voice to their interpretations of mothering a child with a disability, I have demonstrated that the meaning of this experience cannot be understood without a critical examination of the cultural beliefs and institutional discourses within which it exists. The findings of this study lend support to a theoretical framework firmly grounded in sociocultural psychology as well to the works of scholars who have conceptualized the self as inseparable from human activity. The findings inform the research questions identified and, as such, indicate that a theoretical shift is needed in understanding the familial experience of raising a child with Down syndrome. Moving away from assumptions of negative outcomes for these families, their experiences should be understood as embedded within oppressive discourses or master narratives on disability that are enacted through continually shifting dynamics of power and privilege. The results of this study challenge conceptualizations of disability as biologically determined and residing within individual bodies and call into question the implications of these for parenting a child with Down syndrome as well as for educating a child with Down syndrome. The narratives highlight the ways in which notions of the otherness of children with Down syndrome perpetuated in interpersonal and institutional discourses were resisted by the mothers in this study. Ultimately, the stories of these mothers elucidate the ways in which they engaged in meaning-making and came to redefine the experience of having a child with Down syndrome and of motherhood itself. In this chapter, I discuss the major findings in the study and link them to the theoretical underpinnings of this work. I also discuss the specific implications of the findings of this study for future research as well as for professional practice and public policy.

Discussion of Findings

The findings of this study lend support to sociocultural perspectives on disability and to the works of scholars who have emphasized the socially constructed and contextualized nature of the experience of disability (e.g., Bogdan & Taylor, 1994; Hahn, 1997; Kliewer, 1998; Taylor, 2000). The narratives point to the existence of negative societal attitudes surrounding the birth of a child with Down syndrome and to dominant discourses on disability that center on stigma, burden, and damage. Mothers in this study spoke extensively about their negotiations of the meaning of their children's diagnosis of Down syndrome in interpersonal and institutional discourses. Their stories about their interactions with members of the medical community at the time that their child's diagnosis was conveyed to them indicate that stereotypical representations of Down syndrome as well as notions of persistent hardship among families of children with Down syndrome continue to exist in medical discourse and practice. Their accounts reveal that in conveying a diagnosis of Down syndrome, physicians may use the language of bereavement and loss, demonstrate negative affect, or otherwise act in ways that imply a diminished value of children with Down syndrome. Some mothers in this study recounted that their doctors provided outdated or inaccurate information, emphasized negative outcomes for the family, or used terms like "mongoloid" and "vegetable" in discussing a diagnosis of Down syndrome. It is clear that the language, attitudes, and actions of medical professionals had an impact upon the ways in which a diagnosis of Down syndrome was interpreted by the mothers in this study. Expressions of sympathy or regret from medical professionals were perceived by mothers as unhelpful and these were often counterproductive for them. In addition to encountering medical discourses that centered on assumptions of negative outcomes for families of children with Down syndrome, many mothers in this study also perceived their physicians as holding the belief that that it is better to avoid negative outcomes for the family through the use of the technologies of prenatal genetic testing and through the selective abortion of fetuses with Down syndrome. The findings indicate that mothers' decisions to forgo prenatal genetic testing or to carry their pregnancies to term after a positive diagnosis of Down syndrome was sometimes met with disbelief, disapproval, or dismay by doctors or genetic counselors and that some mothers experienced pressure from their physicians to reconsider their decisions. Subtle or overt coercion from physicians to consider terminating their pregnancies after a prenatal diagnosis of Down syndrome was reportedly among the more stressful or negative aspects of some of these mothers' early pregnancy experiences. The mothers in this study were deeply affected by what they perceived to be the message from the medical community - that a child with Down syndrome is of lesser value than a *normal* child.

The stories of the mothers in this study indicate that the interpretations of Down syndrome that were initially provided by physicians were steeped in the medical paradigm of disability, which views disability as biologically determined, universally defined, and contained in individual bodies or minds. This aspect of the findings support the works of scholars who have asserted that medical discourses on disability are based on the belief that disability necessarily results in a diminished quality of life for individuals and their families as well as belief about prenatal genetic testing as unequivocally good because it prevents “tragedy” and “suffering” (e.g., Asch, 1989; Saxton, 2000). Consistent with the assertions of these scholars, the interpretations of Down syndrome provided to mothers in this study by most physician failed to acknowledge the variability in outcomes for individuals with Down syndrome and their families and the embeddedness of the experience of disability in a sociocultural context.

The narratives reveal that discourses centering on notions of “tragedy” and “devastation” which surround the birth of a child with Down syndrome are not limited to the medical community. In describing the reactions of members of their family, friends, and acquaintances to the news of their children’s diagnosis, many mothers recalled that, although people were generally supportive and caring, they had also reacted with expressions of sympathy or extreme sadness. It is interesting to note that, in addition to overt expressions of sympathy and sadness, it was not uncommon for people to respond to the news of a child’s having Down syndrome by stating that mothers of children with disabilities are “special” people chosen to have a “special” child, by lauding the bravery of the mothers, or by identifying themselves as lacking the qualities required to be parents of a “special” child. Although these kinds of comments were perceived by mothers as well-meaning, they were simultaneously perceived by most as clearly conveying a societal belief that being a mother of a child with Down syndrome is a largely undesirable experience. Additionally, the narratives reveal that it is commonplace for mothers of children with Down syndrome to be questioned regarding whether they had opted to have an amniocentesis or why they had chosen to forgo it. The frequency with which mothers in this sample had encountered questions about whether or not they had undergone prenatal genetic testing as well as whether or not they planned to continue their pregnancies after a prenatal diagnosis of Down syndrome suggests that mothers of children with Down syndrome are often expected to justify their choices to have their children.

The findings of this study with regards to mothers’ experiences with prenatal genetic testing are resonant of the works of many scholars who have asserted that, although advances in reproductive technologies are presented as expanding available choices, in reality they may present only an illusion of choice and may in fact limit some other choices (e.g., Rothman, 1993). As prenatal genetic testing becomes increasingly advanced and routinized, there is also an increased expectation among the medical community that women will avail of these technologies as well as a belief that doing so is the most natural course of action (Cuckle, 1998; Rapp, 2000). Furthermore, it is indicated that many medical practitioners, genetic counselors, and people in general hold expectations that women should make the “rational” choice to terminate a pregnancy after a prenatal diagnosis of Down syndrome and women who choose to continue a pregnancy after a prenatal diagnosis are often viewed as responsible for the outcomes and attributed with the blame for it (Marteau & Drake, 1995; Rapp, 2000). In this study, mothers who had received a prenatal diagnosis of Down syndrome believed that they were viewed by others, including members of the medical community, as making incorrect choices and some experienced pressure from medical professionals as well as members of their family to consider terminating their pregnancies. Those who had opted to forgo prenatal testing perceived medical practitioners and genetics counselors as expressing disbelief or disapproval of their decisions. These findings lend evidence to Rothman's (1993) assertion that the technology of prenatal testing, packaged in the language of options, becomes restrictive; the "choices" that are offered are embedded in a push to make the 'right" choices and, as such, themselves become limiting and value-laden with regards to the meaning of having a child with Down syndrome.

The findings of this study reveal the ways in which mothers of children with Down syndrome are positioned in social and institutional discourse. Positioning theory explains that "an important feature of social behavior is the collaborative construction of social reality and the mutual upholding of particular interpretations of the world" (Harre & Moghaddam, 2003, p. 3). Through the act of positioning in discourse and activity, power dynamics are articulated, enacted, and resisted and claims are made about the nature of relationships and the meaning of events. The findings of this study elucidate that in discourses that emphasized the undesirability of parenting a child with a disability and upheld socially constructed interpretations about children with disabilities as burdensome, the mothers in this study and their children with Down syndrome become positioned as "other." Children with Down syndrome became positioned as having lesser value than children without disabilities through interpersonal and institutional discourses centering on notions of sympathy, loss, tragedy, and devastation as well as through expressed beliefs that it is better to avoid the birth of children with disabilities through the use of prenatal genetic testing. Furthermore, the otherness of children with Down syndrome and of the mothers who nurture them was upheld in the rhetoric of *special children*, *special needs*, and *special mothers*. The findings of this study reveal that in hegemonic discourses, children with Down syndrome are identified as occupying a separate category of childhood and their mothers are positioned outside the constructed category of normative motherhood.

A broad finding in this study pertains to the ways in which the mothers engaged in meaning-making and came to redefine the experience of having a child with Down syndrome and of motherhood itself. Consistent with one of the grounding theoretical assumptions in this study that individuals are not passive in the act of meaning-making (Harre & Gillet, 1994; Holland 1997), the mothers in this study were agentic and actively participated in negotiating the meaning of having a child with Down syndrome and constructing their identities as mothers. Lending support to the work of scholars who have asserted that positioning is not merely a means for enacting identities within social contexts but also a tool for resisting perceived power differentials in hegemonic discourses (e.g., Harre & Langenhove, 1999), the findings of this study are indicative of the ways in which dominant discourses were resisted and the fluid and contextualized meanings of disability and motherhood were collaboratively negotiated by mothers. The narratives point to the prevalence of negative assumptions about outcomes for families of children with Down syndrome, however, these mothers had very different interpretations of their familial experiences. One of the more significant findings in this study pertains to these mothers' resistance to dominant discourses on their lived experiences as mothers. Most of them emphatically rejected notions of suffering, hardship, and burden as characterizing their families' experiences. Instead they described the quality of their own lives and those of their families in much the same terms as one might expect from mothers of children without disabilities. Not only did the mothers in this study reject notions of suffering and hardship as characterizing their familial experience, they also consciously resisted notions of otherness, both in their descriptions of their children with Down syndrome as well as in their representations of themselves as mothers.

The narratives are also indicative of transformations in the ways that the mothers in this study came to make sense of their experiences through collaborative meaning making. They acknowledged the presence of challenges and difficulties in raising a child with a disability, however, they attributed these to the experience of motherhood. Thus, it is worth noting that, although these mothers identified stressors related to having a child with Down syndrome, they interpreted these stressors as being related to parenting rather than to the parenting of a child with a disability. Furthermore, the findings point to transformations in these mothers' understandings of what life is like for families of children with Down syndrome. The mothers in this sample rejected the notion that their experience of motherhood was a negative one and most described it by highlighting both the difficulties and the positive aspects of raising their children. In their descriptions of their present lives, the negative language and metaphors that they had used in describing their initial reactions to the diagnosis were largely absent. Instead, they represented their lives in terms such as "active," "busy," "stressful," "fulfilling," "wonderful," and "content." Their emphasis on the ordinariness of their daily parenting experiences and their highlighting of both the everyday stressors and the everyday joys of raising their children reveal the transformations in their understanding of the meaning of having a child with Down syndrome. These mothers' perceptions of themselves as "just being a mom" and their interpretations of the experience of parenting a child with Down syndrome as not being particularly distinctive from parenting per se, reveal that these mothers rejected notions of the otherness of children with Down syndrome and of families like their own. These findings support Bamberg's (2004) assertion that, when positioned in master narratives, individuals are agentic in producing counter-narratives that assign new meaning to interpersonal and psychic phenomenon. Furthermore, consistent with the findings of other studies that have elucidated the ways in which parents resist and deconstruct the dominant discourse on being the parent of a child with a disability (Goddard et al., 2000; Landsman, 1999), the women in this study reframed the meanings of "child" and motherhood and, thus, reinstated their identities as mothers.

The findings lend support to theoretical works that conceptualize the experience of disability as embedded in shifting social and political contexts (e.g., Davis, 1997; Hahn, 1988; Danforth & Navarro, 1998). In this study, mothers' understanding of the meaning of their children's diagnosis of Down syndrome shifted from interpretations that focused on its biological impact to those that focused on its social implications. Their narratives reveal that, for these mothers, issues of social inclusion, acceptance, and rejection were predominant concerns. In discussing their concerns as mothers who raise children with Down syndrome, they almost always raised issues related to social acceptance and access to the mainstream. Their perceptions of what is involved in raising a child with Down syndrome included negotiating the social world on behalf of their children, protecting their children from the possibility of teasing and rejection by peers, and "fighting" for access to mainstream settings for their children. Additionally, for these mothers having a child with Down syndrome involved their negotiations of their own access to the constructed category of motherhood. For these mothers, the meaning of having a child with Down syndrome was understood as linked with a cultural devaluing of children with disabilities as well as a diminished societal view of mothers like themselves. Their stories indicate that mothers of children with Down syndrome locate disability not only in their child but also in the social and political environment. This sheds light on a central aim of this study which seeks to examine mothers' experiences of having a child with Down syndrome within a sociocultural context. These findings reveal that the experience of having a child with Down syndrome is embedded within dominant discourses that position both individuals with Down syndrome and their families as "other" and, as such, it is inextricably linked with the social meanings ascribed to constructs like disability and motherhood.

The findings of this study inform its research questions pertaining to the nature of the self and lend support to a theoretical framework grounded in the notion of identity as inseparable from human activity. Consistent with the works of scholars who espouse the notion of mental life as dynamic activity or the idea of self in action (e.g., Harre & Gillet, 1994; Holland, 1997), this study reveals the ways in which the identities of mothers of children with Down syndrome are performed through everyday discourse and activities related to parenting. Operating within contexts, the mothers in this study participated in constructing meaning through engagement in purposeful activity. To a great extent, they discussed their perceptions of themselves as mothers of children with Down syndrome *and* as mothers in general in terms of the activities in which they engaged. Framing their process of identity construction in the context of their own nondisability status, it is important to acknowledge that these mothers contended with the idea of being nondisabled women who raise children with disabilities. The mothers in this study, who had hitherto been largely uninvolved in activities related to disability rights or disability awareness before the birth of their children, when faced with the task of confronting institutional assumptions about disability and difference engaged in constructing their identities as mothers *and* as nondisabled mothers of children with disabilities in discourse and activities through which they grappled with competing discourses of institutional push for “normalcy” and their own resistance to notions of the otherness of children with Down syndrome. Their active engagement in disability advocacy, organizing parent-to-parent support networks, or taking a leadership role and in educating those around them can be viewed as avenues through which these mothers enacted resistance to ideologies of burdened families and perfect children. This is resonant of the works of scholars who have highlighted a pattern of civic activism and leadership in disability related work among parents of children with disabilities which begins as a response to what is perceived as a failure in society to meet the needs of children with disabilities and their families (Darling, 1988; Wickham-Searl, 1992). Drawing from their own experiences, the mothers in this study took on roles in public work related to disability; their transitions to becoming educators, organizers, and activists were derived from their personal processes of meaning-making and, in turn, influenced the meaning that they assigned to disability and to their constructed identities as mothers. From the perspective of Cultural Historical Activity Theory and consistent with the works of scholars who view the self as embedded in human activity (Leontiev, 1983) or as activity itself (Stetsenko & Arievich, 1997), the identities of these mothers can be understood as their active engagement in disability related work, in negotiating social acceptance or access to physical spaces for their children, and their efforts at redefining the meaning of disability and motherhood.

The identities of the mothers in this study can be further examined through the lens of the master narratives of normative motherhood and of “special” children. As discussed earlier, the majority of the mothers in this study emphatically resisted the discourses of burden, tragedy, and damage and, as such, rejected the idea that raising a child with Down syndrome is distinct from raising a child. Perhaps even more emphatically, they resisted the notion that their experiences of motherhood were significantly different than those that are generally understood as normative motherhood. In their choices of daily activities, in their accounts of the ways that they lived their lives, and in their representations of their children, these mothers actively sought to challenge dominant discourses of otherness and to reinstate themselves as mothers “just like everyone else.” However, while there was commonality in the ways that the mothers in this study resisted notions of otherness in their definitions of their children with Down syndrome and in their perceptions of themselves as mothers, for some, resistance to otherness became difficult in the context of their children’s schooling. With regards to schooling decisions, the mothers in the study differed, with one group expressing a preference for inclusive education and another, their preference for self-contained classrooms or segregated, specialized education. Their perception and beliefs about inclusive education and their advocacy for particular schooling programs is a lens through which their constructed identities can be examined. Among some mothers, resistance to discourses on disability and difference manifested in a struggle to access inclusive education for their children with Down syndrome; among others, institutional discourses that emphasized the otherness of children with Down syndrome became influential in these mothers acceptance that specialized places of education would be “best” for their children. Mothers who engaged in activities to gain access to inclusive education spoke about inclusive classrooms in terms of places where their children “belonged,” places where their children would have access to the same things as everybody else, and places that would prepare their children to participate in mainstream society. Mothers who indicated a preference for self-contained classrooms or segregated school programs discussed their children’s schooling in terms of access to specialized equipment or professionals who were trained to meet the different needs of their children, safe places where their children would be accepted despite their differences; or places where their children with Down syndrome could be with others who are also different like them. These findings reveal that the identities of the mothers were enacted in activities through which they resisted the otherness of children with Down syndrome as well as in activities through which they were unable to resist institutional labels of difference and the ideology that the education of these children is best undertaken in specialized places and through significantly different means.

In attempting to understand the reasons for the acceptance of self-contained placement as most appropriate for their children, among mothers who emphatically rejected dominant discourses that positioned their children with Down syndrome as “other”, important insights can be gained from this study’s findings concerning institutional resistance to the idea of inclusive education for children with Down syndrome. Although the original research aims of this study did not include questions about educational institutions’ support for inclusive placement of children with Down syndrome, an unexpected and relevant finding that emerged in this study pertains to mothers’ perceptions of the extent to which education professionals resisted the placement of their children with Down syndrome in inclusive classroom settings. I included a discussion of this finding, despite the fact that it was not identified as an area of inquiry in this study because it is critical in informing the central aim of this study, i.e., to examine the situated nature of the experiences and identities of mothers of children with Down syndrome. Many of the mothers in this study related accounts of having been informed by education professionals that placement in an inclusive preschool classroom was simply not an option for their children or, in the case of kindergarten-age children, that inclusive education was not the recommended program. In discussing their recommendations for self-contained placements, school districts reportedly provided reasons that included that the district does not have inclusive preschools, that the child was not considered to be cognitively or socially “ready’ for inclusive education, and that a smaller, specialized setting would best meet the child’s educational needs. Some of the mothers in this study recalled that they had initially hoped to have a dialogue with professionals at their school district about inclusive education or that they had originally wanted to explore this type of educational program for their children, however, they reported that segregated settings were presented to them by school professionals as the more appealing, more specialized, and more beneficial program for their children with Down syndrome. In the “selling” of these segregated programs, school officials emphasized that this kind of education would be best suited to meet the different needs of their children with Down syndrome through the use of specialized equipment, specially trained professionals and so on. Some mothers, who had originally envisioned an inclusive classroom setting for their children, came to believe that self-contained classrooms would be better based on the advice of education professionals who presented this option to them as the “best” choice. It is interesting to note some mothers were simply informed that their school district does not “offer” inclusive preschool placement. Some mothers did not question this official information because they were not aware that, under educational law, their child was entitled to a placement in the least restrictive environment at the preschool level and that the district was required to, at the very least, consider such a setting and, if appropriate for the child, to provide it. Others were aware of this, but said that they had not wished to challenge professionals at the school district or alienate them or stated that they had accepted the district’s recommendations for segregated placement because they viewed it as a way of “getting in” and accessing services with the idea that they would challenge the placement decision at a later stage. Mothers in the study were not usually informed by school districts about the full range of placement options available to their child by law and *none* of the narratives contained accounts in which school professionals initiated a dialogue about considering inclusive education. Mothers whose children were attending inclusive classrooms at the time of the interviews related that they had advocated for such a placement and that inclusion had not been the initial recommendation of the Child Study Team. Among this group, some made references to an ongoing “fight” or a struggle to gain access to inclusive classroom placement for their children. Two of the mothers in this group who wanted their children to transfer from a self-contained to an inclusive setting reported that school administrators in their districts were not supportive of this idea.

These findings point to the existence of institutional resistance to the practice of inclusive education for students with Down syndrome. Similar to their experiences with medical professionals at the time of the birth and diagnosis of their children, mothers’ interactions with education professionals were embedded in master narratives that positioned children with Down syndrome as “other.” When confronted with labels of difference in educational settings, some mothers resisted notions of otherness, just as they had done during the weeks following the birth or diagnosis of their child with Down syndrome. Their alternative interpretations of Down syndrome and their constructed identities were enacted through their rejection of Special Education dogma and their “fight” to gain access to the inclusive settings. However, some mothers in the study accepted master narratives regarding the education of their children for a range of reasons discussed above. These mothers who had resisted dominant discourses on disability and had actively engaged in redefining the meaning of having a child with Down syndrome became overwhelmed by the rhetoric of special education. Unable to counter institutional discourses about the education of children with Down syndrome, some in this group came to accept segregated education programs as “best” for their children.

An understanding of the performed identities of the mothers in this study is further informed by findings that pertain to their beliefs about classrooms as places of belongingness or exclusion. In discussing their children’s education or classroom placement, most mothers raised their beliefs about where their children “belong” or where they would “fit in” best. It is worth noting that both groups of mothers (i.e., those who supported inclusive education and those who believed that self-contained classrooms are more appropriate for their children) discussed classrooms in terms of belongingness. Among those who supported or advocated for inclusive education or among those mothers whose children with Down syndrome were already in general education classrooms, there was an expressed perception of inclusive education as the vehicle for ultimately belonging in society or as providing tools in preparation for living in mainstream society. These mothers also spoke about inclusive education as a “right” and of placement in inclusive classrooms as indications that their children were being accepted in society. Similarly, belongingness was also a critical theme in the reasoning of the group of mothers who expressed preference for self-contained classroom settings. These mothers focused on issues related to fitting in and on considerations of places where their children with Down syndrome would be most accepted by peers and by teachers. Although both groups of mothers discussed classroom settings as avenues for membership to groups, for mothers who expressed preference for inclusion, inclusive classrooms represented membership to society, while for those who were wary of inclusive education, self-contained classrooms were seen as places of unconditional acceptance and membership in a group of similar people.

Finally, an important finding in this study pertained to mothers’ beliefs about inclusive education settings as places where children with differences are excluded, rejected, or ignored by peers. While there was much variability in the perceived experiences of the mothers in this study, there was consistency in the data with regards to their beliefs about the social outcomes of a diagnosis of Down syndrome for children. In discussing their concerns about peer acceptance of their children, most expressed strong beliefs about inclusive education as having greater potential for the social isolation of their children with Down syndrome. Once again, I emphasize that this belief was held by both groups of mothers, i.e., those who expressed preferences for segregated setting *and* those who advocated for inclusive classrooms or whose children were in inclusive classroom. Their voiced concerns over peer rejection or the isolation of their children provided valuable insights into the ways in which they understood the meaning of Down syndrome. For these mothers, disability resided, not only in their child, but also in the environment, and their experiences of raising a child with Down syndrome were steeped in constructed notions of normative motherhood.

Conclusion

The findings of this study strongly indicate that the ways in which a child's diagnosis of Down syndrome is perceived by mothers is contextually bound and has as much to do with the sociocultural constructions of disability and normalcy as with the biological realities that accompany it. The narratives point to the prevalence of negative expectations for families of children with Down syndrome and, yet, these mothers told very different stories of families like their own. For the mothers in this study, Down syndrome was seen as residing, not just in their child, but also in the fabric of the daily interchanges and activities that took place in the context of the family's social environment. The findings of this study are consistent with the work of scholars who reject conceptualizations of disability as a universally fixed category, asserting instead that the experience of disability is best understood as a socially constructed phenomenon (Bogdan & Taylor, 1994; Danforth & Navarro, 1998; Kliewer, 1998; Taylor, 2000). In revealing that issues of social acceptance and peer rejection are among the predominant concerns of mothers of children with Down syndrome, the findings of this study shed light on the deeply contextualized nature of the experience of having a child with Down syndrome and elucidate that mothers of children with Down syndrome locate disability not only in their children but also in the environment.

These narratives lend support to Davis' (1997) assertion that "the 'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the "problem" of the disabled person" (p. 9). Situated in constructed meanings of disability in society and in master narratives on normative motherhood, the selves of the mothers in this study are revealed as performed within the constraints of a sociocultural context as well as actively negotiated in discourse and activity. Ultimately, by highlighting these mothers' resistance to dominant discourses on their lived experiences and their alternative interpretations of their lives, the findings of this study contribute to the broader discussion on the meaning of disability in society and challenge the constructed categories of normative motherhood and desired child.

Limitations of the Study

In considering the findings of this study, it is necessary to recognize its limitations. First, the sample size was small and the mothers in this sample constituted a relatively homogenous group in terms of ethnicity and socioeconomic background. Although there was some diversity among the mothers in terms of socioeconomic status, ethnicity, religion, and family structure, the majority of the mothers in this study hailed from White, suburban, middle-class families. In addition, the study may also have been subject to selection bias. During the process of recruitment, I explained to potential participants that this would be a study about the experiences of mothers of children with Down syndrome and that this was an opportunity for mothers to tell their stories from their own perspectives. It is possible that mothers who had certain kinds of experiences after the birth and diagnosis of their child may have volunteered to participate in the study. It is also worth noting that all mothers in the sample had at least a college education, and this is likely to have influenced their interpretations of the medical discourse as well as their individual abilities to seek alternative meanings in response to their children's diagnosis. For these reasons, it is difficult to generalize these findings to other groups of mothers of children with Down syndrome.

An additional limitation of this study pertains to the absence of fathers' perspectives. For this study, I undertook an examination of the unique experiences of mothers in an attempt to elucidate the ways in which the identities of women who become mothers of children with Down syndrome are performed within the context of master narratives on motherhood and cultural constructions of desired children. The role of fathers' contributions to the familial experience of having a child with Down syndrome was explored only to the extent that the mothers themselves discussed it, and fathers' views were present only through the perspectives of the mothers in the study. It is acknowledged that a deeper understanding of this familial experience can be gained by including perspectives of fathers of children with Down syndrome. Future research should include the perspectives of mothers and fathers of children with Down syndrome from a wider range of backgrounds in order to gain a deeper understanding of this familial experience.

Future Perspectives: Implications for Further Research, Professional Practice, and Public Policy.

The findings of this study strongly suggested that a theoretical shift is needed in understanding the familial experience of raising a child with Down syndrome. By lending support to perspectives on disability as a culturally embedded and relative category, this study has implications for professional practice and public policy. Moving away from assumptions of negative outcomes for families of children with Down syndrome, medical and clinical professionals need to acknowledge the embeddedness of their experiences within oppressive discourses or master narratives on disability and make a paradigm shift toward a more contextualized understanding of what it means to have a child with a disability. Medical and mental health practitioners need to problematize conceptualizations of disability as biologically fixed and residing within individual bodies and consider the implications of such conceptualizations for the familial experiences of parenting a child with Down syndrome as well as for educating a child with Down syndrome. Those who are oriented in the medical model on disability should be educated about the social paradigms on disability and direct experience with individuals with disabilities and their families should be a necessary aspect of the training of all medical professionals and Genetic Counselors. Further research should explore whether Disability Studies programs for medical students and doctors could positively influence their interactions with mothers following a diagnosis of Down syndrome. In terms of clinical practice, it is clearly indicated in this study that mothers of children with Down syndrome need access to balanced viewpoints and current information regarding outcomes for children with Down syndrome and their families. Medical practitioners should be held accountable for providing inaccurate or outdated information concerning Down syndrome, for conveying personal biases with regards to what is entailed in raising a child with Down syndrome, and for coerciveness in advising mothers who receive prenatal diagnoses of Down syndrome to terminate their pregnancies. Furthermore, families who receive a positive diagnosis of Down syndrome either prenatally or after the birth of their children should be offered the opportunity to meet other families of children with disabilities and or to access their perspectives about their lived experiences. The mothers in this study actively sought balanced information concerning what is involved in raising a child with Down syndrome, including the views of other families of children with disabilities and, indeed, many emphasized that they would have welcomed opportunities to connect with such families and to hear their perspectives.

This study's findings have implications for the education of children with Down syndrome and for the practice of inclusive schooling. Like medical practitioners, those involved in the education of children with Down syndrome also need to make a shift from traditional Special Education dogma to critical Special Education practices which call into question intuitional discourses that perpetuate the segregation of students with disabilities. School districts need to evaluate the extent to which "generic" recommendations for segregated placement for children with Down syndrome are made by educators, based on an unquestioned belief that specialized equipment, specialized teachers, and small, separate classrooms are "best" for children with Down syndrome. Furthermore, school districts should be closely scrutinized and assessed with regards to the extent to which they are in accordance with laws that mandate the education of students with disabilities in the least restrictive environment. School administrators need to be held accountable for failing to inform parents about the range of educational settings available as well as for providing information that is inconsistent with IDEIA regulations. It is also indicated that education and training concerning successful inclusive education practices should target, not only special education teachers, but also general education teachers. To this end, college programs in teachers' education need to include substantial preparation in the philosophy and practice of inclusive education for *all* future educators. In schools, curricula that are aimed at addressing the social integration of children with disabilities with their typically developing peers in general education classrooms should be included as part of inclusive education goals. Finally, the findings of this study indicate that there is a need for parent education and outreach programs that are aimed at helping parents to understand the benefits of inclusive education to children’s overall development as well as at providing information about laws and regulations regarding the education of students with disabilities.

Afterword: Locating the Researcher

In this dissertation, I have sought to understand the experiences of mothers of children with Down syndrome. While this is its specific aim, in a broader sense, the study is concerned with the ways in which individuals construct meaning through engagement in discourse and purposeful activity. In attempting to understand the enacted identities of the mothers in this study, I framed their lived experiences in the sociocultural and political contexts within which they existed. However, given that this dissertation is firmly grounded in an underlying premise that knowledge is situated and that experiences are embedded in contexts, I believe that it may also be necessary to reveal the context of the researcher. In this section, I locate myself in my work and frame the knowledge generated in this study in the context of my own construction of the meaning of acts and events.

My interest in families of children with disabilities precedes my commencing this dissertation. It emerged through my professional work as a therapist working with adults with developmental disabilities and their families and strengthened during the time that I was a graduate student studying Special Education. During these years, I wore many hats: therapist, educator, advocate, and academic. Although my roles were varied and my commitment to advocating for individuals with disabilities was genuine, my conceptualization of the phenomenon of disability remained relatively unchanged during this time. My professional and academic efforts were aimed at the effects of disability for individuals and families. My gaze focused on the disability itself; the sociocultural environments within which individuals with disabilities lived were left largely unexamined.

In 2002, I began a doctoral program in Developmental Psychology at the Graduate Center, CUNY, and, that same year, my daughter (and second child) was born. She was diagnosed as having Down syndrome. This event thrust me into yet another role in my relationship with individuals with disabilities – that of a parent. My newly acquired “insider” status provided, among other things, access to multiple viewpoints and a new lens for viewing the phenomenon of disability. From the vantage point afforded by my new role, my academic and professional interest in families of children with disabilities took new dimensions. In my attempts to understand this familial experience, I became simultaneously the observer and the observed! Having hitherto focused on disability itself and its impact on individuals and families, I now became aware that interpretations of having a child with a disability are varied, negotiated, constructed, and inextricably linked with its cultural meaning. In the context of oppressive interpersonal and institutional discourses that were steeped in themes of burden and grief, I struggled to represent my family in alternative terms and to define myself as a mother. My own process of meaning-making fueled a new inquiry into the lived experiences of mothers of children with Down syndrome - and this time, my gaze focused on the sociocultural conditions that sustained and perpetuated negative interpretations of disability and positioned families of children with disabilities as “other.” Thus, for this dissertation, knowledge originated from the lives of mothers; the research questions that I identified were guided by my own stories and by those of numerous other mothers of children with Down syndrome with whom I came into contact. In conceptualizing the study and in generating research questions, I focused largely on those areas of inquiry which I believed would be most relevant and meaningful to mothers of children with Down syndrome and those which would speak to their contextualized and situated experiences. In this and in every sense, mothers of children with Down syndrome have been the "grounds for knowledge" (Harding, 1993) in this study and the starting point from which critical questions emerged.

While questions related to the starting point for knowledge are important ones, other questions concern the audience of one's work. According to Alford (1998), for any scholarly work, there is a direct audience, which includes the readers, academic colleagues, and other scholars and an indirect audience, which exists in the mind of the writer, and includes "those ancestors to whom she is giving homage as well as those antagonists whose arguments she is challenging" (p. 33). It should be acknowledged that the focus of inquiry in this study as well as its methodologies were influenced to an extent by its indirect audiences, which include those families, both past and present, whose stories have been told by those in positions of power and those oppressive discourses that have sustained pervasive cultural belief that being the parent of a child with a disability is a negative experience.

The issue of whether any research is value-free is a pertinent one and, therefore, it is often relevant to understand the lens that was used in the production of knowledge. Ferguson, Ferguson, and Taylor (1989) assert that whenever we, as researchers, become involved in helping other people tell their stories, we inevitably become involved in telling *our* stories of *their* stories; we present our interpretations of their interpretations of events. In this study, there are multiple layers of perspectives and multiple interpretations. My intention was to highlight the interpretations of mothers of children with Down syndrome by giving voice to the mothers who participated in the study.

However, it should be acknowledged that their voices may have been filtered through the lens of my own perceptions. Families of children with disabilities have always been scrutinized; their stories have been told from the perspectives of those who have not lived similar lives. To the extent that the voices of the mothers in this study may have become filtered, it is through the lens of my perspectives as a mother of a child with Down syndrome.

Ultimately, this dissertation is about enacted identities and negotiated selves. In embarking upon the task of understanding the experiences of mothers of children with Down syndrome, I hoped to elucidate that, through the stories that we tell, we engage in meaning-making about our psychic realities through our activities we perform ourselves. If, indeed, the activities in which an individual engages *is* the self (Stetsenko & Arievich, 2004), then surely the act of writing this particular dissertation can be understood as the negotiated and performed identity of the author.

Appendix A: Interview Protocol

1. Questions relating to the birth and diagnosis of the child.

   - Tell me about your child . . . (include description of family)
   - Tell me the story of when you were pregnant with _____. (Include: was this the first pregnancy? What preparations were made for child? How did you anticipate motherhood?)
   - Were you aware of _____'s diagnosis while you were pregnant? (Include in detail: why and how did you find out? Describe the testing experience. If there was genetic counseling, what was that experience like? How was the diagnosis presented? What was your reaction? What was the reaction of partner, others?
   - Describe the birth of your child. (If there was no prenatal diagnosis, ask: when did you first become aware of the diagnosis? Who informed the parents, how, what <u>language</u> was used by professionals etc.?
   - What was your initial response? What were responses of spouse/partner, family, friends/acquaintances, hospital staff, etc.? What language was used, what affect was displayed? When people visited you, how did they act . . . did you receive cards, letters, visits?
   - Use Q-sort
   - Addition to Q-sort: Ask mother to create 3 cards of the most significant (positive or negative) responses of others . . . why were these so significant/ what does this mean to you?
   - What did you know about Down syndrome prior to the birth of your child? What did you believe people with Down syndrome were like/how they develop or how much they can achieve? What image was evoked at the time you were first informed that your child has it?
   - What literature/information was provided to you related to the disability? What "advice" did you receive? Did medical staff provide information related to resources? Did you receive contact information for other families who have children with _____ (disability) as a resource?

2. Questions related to how mothers view their present lives and social relationships.

   - Tell me about yourself and your relationship with your child now . . . what are you like as a parent today . . .
   - What is your life like these days? (Describe daily issues, routines, and social patterns).
   - Has your life changed? How?
   - Have your social relationships changed?
   - How do others respond to the knowledge of your child's having Down syndrome?
   - What is the nature of the peer interactions/friendships of your child?

- What kinds of friendships and relationships do you expect your child will develop in her community or school?
- How would you describe the present quality of your life of your family?
- What do you think are some of the difficulties associated with child with Down syndrome at this point in time?
- Have there been positive outcomes as a result of your experience?
- What have you learned about yourself or about the world through this experience?
- How do you believe that others view your child? What do you think that other people believe it is like to have a child with a disability? Do you agree with them?

3. Questions related to how mothers envision the future for their child and how they believe the disability will impact upon their lives.

- Are you familiar with the laws and educational policies related to disabilities in this country? What do these mean for your child? How do you feel this impacts your child's life at this time and in the future?
- What do you anticipate in terms of _____'s education? What do you believe would be an ideal situation?
- What does the idea of inclusive education mean to you?
- What kind of preschool/school does your child attend (if child is of school/preschool age)? Was this your preferred placement choice? Why/why not?
- What kind of preschool or school do you anticipate your child attending? (If child is younger than preschool age). Elaborate.
- How do you envision _______'s future? What is your ideal vision?
- If you met a woman who had just had a baby with ______ today, what message would you want to convey to her? Imagine you could design a card for her, what would you say in it? (Give her a blank card and ask if she would write a message to a new mother of a child with Down syndrome).

THANK YOU FOR PARTICIPATING . . .

Appendix B: Q-sort Cards (Samples)

- I’m so sorry.
- Did you have an amniocentesis?
- Why bring a child into this world, if it will suffer.
- God gives special babies to special parents.
- I don’t know how you do it. I could never handle it.
- Your baby has chosen the best family to be born into.
- You are the best parents to raise a special child. Your child is so lucky to have you as parents.
- Down’s children are so sweet and affectionate.
- Children with disabilities put a lot of stress on a marriage.
- Is it really fair to your other children to have a child with Down syndrome?
- Congratulations!
- This child will bring you more happiness and joy than you can imagine.
- Are you going to continue with the pregnancy?
- You don’t need the extra burden of a handicapped child

Appendix C: Consent Form

Consent form.

My name is Priya Lalvani and I am a doctoral candidate in the Developmental Psychology program at the Graduate Center of the City University of New York (CUNY) and the principal investigator in this research project. This is a study that will explore what it means to mothers to have a child with Down syndrome and what the social experience is like for them. There is very little research in this area. The goal of my project is to gain a better understanding of what it means to have a child with Down syndrome from the viewpoint of mothers as well as to examine what disability really means to people in our society.

I would like to interview you about your pregnancy, the birth of your child and other aspects of your experiences as a mother of a child with Down syndrome. The interview may take about one to two hours. With your permission, I would like to audio-tape this interview so that I may be able to record the information and details accurately. The tapes will be heard only by me and my advisors. All information gathered in the interview will be kept strictly confidential and only my advisor and I will have access to it. If the results of this study are published, the names of the people who participated in it and any identifying information will be concealed in the publication.

The risks associated with participating in this research are minimal. It is possible that a wide range of emotions, both positive and negative could be evoked during the interview. Many people find that talking is helpful. However, if you feel uneasy during the interview, you may refuse to answer any specific questions and may choose to end the interview or your participation in the study at any time. If you feel you would like to talk to someone after the interviews are finished, I will provide you with a list of resources that include qualified therapists whom you can contact, as well as information about local support groups for parents.

Your participation in this study will benefit others by generating knowledge about mothers' experiences of having a child with Down syndrome and will contribute to a better understanding of families of children with Down syndrome. As a token of appreciation for your time and involvement, you will receive a list of resources and a gift for your child.

If you would like a copy of this completed study, please let me know and I will send you one in the future. If you have any questions about this research, you can call me at (973) 744-1076 or email me at PriyaLalvani@msn.com, or my advisor Anna Stetsenko at (212) 817-8715 or email her at astetsenko@gc.cuny.edu. If you have any questions about your rights as a participant in this study, you can contact Kay Powell, IRB administrator at The Graduate Center at (212) 817-7525 or kpowell@gc.cuny.edu.

Thank you for taking part in this project. I will give you a copy of this form to take home.

I agree to take part in this project and to have the interviews audio-taped.

______________________________	______________________________
Participant's signature date	Investigator's signature date

Table 1

Codes Related to the Constructed Meaning of Disability

	Code	Description	Paraphrased Example from Narratives
A1	Initial interpretation of diagnosis	Accounts of initial reactions to their child's diagnosis, accounts of early perceptions of what life would be like for themselves and their family, descriptions of initial image of child with Down syndrome	*It was like the earth opened up and swallowed me into a pit.*
A2	The medical discourse on families of children with disabilities	Recollections of the way that their child's diagnosis was conveyed by medical professionals, perceptions of the language and actions of doctors, information and recommendations provided by medical or clinical professionals.	*I have some bad news - Your baby has Down syndrome. I'm so sorry.*
A3	Becoming positioned through discourse and activity	Accounts of verbal or non-verbal social interchanges with regards to their child's diagnosis of Down syndrome.	*You must be a saint to choose to raise a child like that - I could never do it.*
A4	Positioning the self through discourse and activity	Stories about mothers' responses to people's reactions, attempts at shaping people's perceptions or at conveying alternative interpretations of the diagnosis, seeking contact with other individuals with disabilities or their families.	*I said to people - don't be sorry. I'm not.* *I told the nurse - I just needed to meet another child with Down syndrome. If I could just see another child with Down syndrome, I would understand what it means.*
A5	Contextualize understanding of disability	Mothers' reflections on what disability means in society, beliefs about the social implications of Down syndrome.	*I don't get sad about my daughter. I get sad about the way the world views her and values her.*

Table 2

Codes Related to the Constructing the Self

Code		Description	Paraphrased Example
B1	Resistance to a discourse of otherness	Expressions of disagreement with the notion that children with Down syndrome are different in a significant way, rejection of the notion that their parenting experience are significantly different than those of other parents or that they have exceptional qualities as mothers.	*We're not special parents - We're just normal like everyone else.*
B2	Alternative Interpretations of families of children with Down syndrome	Descriptions of daily life as a mother; descriptions of family life; perceptions of quality of life of family; resistance to the discourse of "devastation," grief, and unmitigated hardship among families of children with Down syndrome.	*(a) I have a busy life, but my life is satisfying. I would not change it.* *(b) People think it's all work and that we have no fun. I disagree. We have lots of fun.*
B3	Enacting identity	Accounts of participation in activities related to disability awareness or disability advocacy, efforts to gain access to mainstream settings for their child, accounts of particular courses of action taken for their families	*(a) I fought for inclusion from the time she was a little girl.* *(b) For my subsequent pregnancy, I did no prenatal tests.*
B4	Interpretations of motherhood and the meaning of child"	Reflections on the nature of motherhood and what it entails, reflections of the nature of normative childhood.	*It's not supposed to be perfect - being a mom is hard whether or not your child has Down syndrome.*

Table 3

Codes Related to the Meaning of Inclusive Education

	Code	Description	Paraphrased Example
C1	Classroom as places of belonging	Descriptions of either inclusive or self-contained classrooms as the place where their child “belongs,” would be most accepted or would “fit in,” beliefs about access to inclusive classroom as a matter of “rights.”	*I want him to always have a place where people understand him and don’t expect him to be perfect in a way that they might in a typical class.*
C2	Classroom as places for the enactment of otherness	Beliefs about self-contained classrooms as places where the “exceptional” needs of the child can be addressed, descriptions of inclusive classrooms or general education teachers as lacking in the area of addressing “special” needs.	*In a specialized environment, I know that the teachers and the teacher’s assistants are all trained especially for special needs and so I know that they would have the patience and the understanding, the training and the ability.*
C3	Inclusive classrooms as places of exclusion	Reflections about the extent to which children with Down syndrome are socially accepted in inclusive settings, concerns about rejection or teasing, concerns about whether their child will have friends or socially integrated in a general education classroom.	*In an inclusion classroom, I’d like to think that people won’t ridicule her, but I’m not sure whether she would be socially accepted.*

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