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Living Liminality: Maternal Subjectivity in the Context of Raising Children With Autism

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Abstract

Autism is a severe developmental disorder that begins at birth or within the first few years of life. Research shows that mothers do the bulk of the parenting work in raising children with special needs, including autism. Despite the prevalence of autism, a dearth of literature considers, as central, the maternal experience in raising a child with special needs. This qualitative study focuses on the disorder of autism with the objective of elucidating how the context of autism shapes maternal meaning-making and subjectivity. Additionally, this dissertation examines how mothers of children with autism construct or reconstruct their meanings of motherhood as a result of their maternal experiences.

Grounded theory methods were employed in order to develop theory from the conceptualization of the data. The investigation consisted of in-depth audio taped interviews with 15 mothers of a child diagnosed with autism and participant observation in monthly parent support groups in the metropolitan Atlanta area.

Results showed that the experiences of raising a child in the current sociohistorical context of autism give rise to distinct maternal practices and perceptual processes that, over time, shape maternal subjectivity. More specifically, the context of autism is shaped by the experience of liminality, that is, the experience of existing between conditions that is characterized by the dislocation of established contexts, structures and systems and ongoing uncertainty regarding the future. For the subjects involved in this study, the experience of living liminality facilitated the development of distinct orienting contexts for making-meaning and navigating intrapersonal and interpersonal experiences that, in turn, manifested in a reappraisal and reconstruction of maternal subjectivity.

These findings have implications for professionals and practitioners who work with mothers and families whose lives are shaped by autism. Recognition of mothers' meaning-making and coping can influence the efficacy of treatment approaches for mothers raising children on the spectrum, in addition to family therapy approaches, and child-based educational and therapeutic efforts. By making these experiences evident, this study contributes to the body of feminist psychological literature that challenges and extends mainstream conceptualizations of mothers, motherhood, and maternal development.

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CONTEXT OF RAISING CHILDREN WITH AUTISM

Jennifer K. Bateman

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LIVING LIMINALITY: MATERNAL SUBJECTIVITY IN THE
CONTEXT OF RAISING CHILDREN WITH AUTISM

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Jennifer K. Bateman

DEDICATION

I dedicate this dissertation to Claudia and Andrew Lynn for your endless support and encouragement well beyond the bounds of this research endeavor. The unceasing love, kindness, and generosity that you have shown to me and your confidence in me, as a mother, has been fundamental in making meaning of my own maternal journey. The grace, patience, and support that you demonstrate, as parents and grandparents, has helped me to embrace the challenges and blessings of raising a special needs child and has provided me with a clear vision of the type of mother I hope to be.

This dissertation is also dedicated to Canyon. Your light has transformed me in every possible way. You have shown me the ways in which I need to grow and have forever altered my worldviews. My journey as your mother has made me a more engaged, present, contented and fulfilled person than I ever would have been. The blessings that you have brought to my life have changed me as a mother and person, indelibly.

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ABSTRACT

LIVING LIMINALITY: MATERNAL SUBJECTIVITY IN THE CONTEXT OF RAISING CHILDREN WITH AUTISM

Jennifer K. Bateman

Diana Slaughter-Defoe

Autism is a severe developmental disorder that begins at birth or within the first few years of life. Research shows that mothers do the bulk of the parenting work in raising children with special needs, including autism. Despite the prevalence of autism, a dearth of literature considers, as central, the maternal experience in raising a child with special needs. This qualitative study focuses on the disorder of autism with the objective of elucidating how the context of autism shapes maternal meaning-making and subjectivity. Additionally, this dissertation examines how mothers of children with autism construct or reconstruct their meanings of motherhood as a result of their maternal experiences.

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Results showed that the experiences of raising a child in the current sociohistorical context of autism give rise to distinct maternal practices and perceptual processes that, over time, shape maternal subjectivity. More specifically, the context of autism is shaped

by the experience of liminality, that is, the experience of existing between conditions that is characterized by the dislocation of established contexts, structures and systems and ongoing uncertainty regarding the future. For the subjects involved in this study, the experience of living liminality facilitated the development of distinct orienting contexts for making-meaning and navigating intrapersonal and interpersonal experiences that, in turn, manifested in a reappraisal and reconstruction of maternal subjectivity.

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CHAPTER I: BACKGROUND

Statement of the Problem

This qualitative study explores the ways in which mothering a child with autism shapes maternal subjectivity. Two years ago, when my son was diagnosed with autism, I was inducted into a club in which I never sought membership. Like most members, I would do almost anything to leave this club. Yet I rely, practically and emotionally, on the shared knowledge, perspectives and experiences that I garner from the other reluctant members.

I have often heard parents of children on the spectrum describe an immense sense of isolation—noting that parents of typically developing children, friends and even relatives cannot understand what they are going through. Likewise, parents of children with autism frequently note that they can no longer relate to the experiences, priorities, and concerns of those in their former social networks. In parent support groups, autism conferences, and other autism-based communities of practice, parents of children on the spectrum discuss these and other aspects of a shared reality. In such contexts, they often remark that these communities help them feel that they are not alone in the challenges associated with raising children on the spectrum. Their comments demonstrate that the sense of isolation does not necessarily stem from the sense of being alone in the struggle. Rather, parents who participate in such communities find that parenting in the context of autism changes them, as parents and as people, wholly and indelibly. Hence, the oft-described sense of isolation arises from the realization that this transformed way of

knowing and being makes us, as parents of autistic children, both unrelatable and unable to relate to many aspects of mainstream familial culture.

I often struggle to describe my experiences of mother care and the related interpretive processes to others. I search for the language to convey my shift to an outside reality, to articulate this unnamed social location. Although deficient, I have relied on terms and phrases such as “alternate reality” to describe my different maternal journey. I experience this alternate reality as situated alongside that of the world of normative parenting. Although distinctly dislocated, my view of the mainstream is wide and clear—clearer now than it ever was as an insider. Paul West (1969) conveys this perspective in *Words for a Deaf Daughter*, “Until I knew I had to bring the world to you,” he writes, “I don’t think I knew or saw the world at all” (p.17).

Despite its pedestrian connotation, I continue to employ the alternate reality metaphor—explaining to others that the most significant distinction between these disparate realities is my vantage point. Mainstream cycles and systems persist. The sun still rises in the east. Once applicable cultural ideologies stream in mellifluous waves through my lucent atmosphere, constantly basking me in a sunny pool of “what could have been.” And every morning, as the warm light envelope filters through my window-paned glass, I try to soak up its energy and allow its flush to frame my path as I once had. But it’s different here, now, in this realm. Despite their ubiquitous presence, these theories, standards, norms and values no longer illuminate my possibilities. Theirs is not the light that guides my maternal journey; theirs is not the force that fuels my maternal practices and behaviors.

I am not alone in this nonnormative maternal journey. Although others would likely describe their processes and experiences in different terms, there is nonetheless a “we.” We are the inductees in the club that we never asked to join. We are the inhabitants of this alternate reality. There are many ways of knowing and being in this realm, many voices. Yet we share the experience of navigating a nameless reality—negotiating unattainable and inapplicable cultural standards, managing the unceasing care of children with autism, and in doing so creating unnamed maternal thinking and work (Ruddick, 1989). Many of us call ourselves “autism moms” with the word *autism* intentionally preceding the word *moms* because the experience of mothering a child with autism necessarily defines and transforms the person. And although so many mothers are affected by this experience, little is known about the context of this reality and the ways in which mothers, themselves, are shaped. It is my personal experience that has led me, through this study, to begin to query the maternal experience of mothers who are raising children with autism. How do autism moms describe their experience? How do they make meaning of their journey?

Study Rationale

Mothers as Subjects

As I began to critically reflect on my experiences, I looked for support in the literature on maternal experiences in the context of raising children with special needs, and specifically in autism. The decision to focus the proposed research on mothers, as opposed to parents, was guided by research that shows that mothers do the bulk of the parenting work in raising children with special needs (Kingston, 1997).

My literature search led me to an array of texts on a variety of childhood disabilities and learning disorders, including autism. While such texts are written from a range of parent and professional perspectives, they are nearly all child-centered (Kingston, 2007). This significant body of literature is extremely useful in delineating common characteristics, challenges and solutions with regard to the needs of children affected by various conditions. Likewise, there is a multitude of literature on an array of therapies, teaching methods, diets, and other topics related to improving the quality of children's lives (Kingston, 2007). However, I was disappointed to find a dearth of literature that considers, as central, the maternal experience in raising a child with special needs. Whereas many large-scale quantitative studies have situated mothers of children with special needs as subjects, the vast majority of these analyses focus on stress and depression in this population (e.g., Fitzgerald, Matthews, Birkbeck, & O'Connor, 2000; Hoare, Harris, Jackson, & Kerley, 1998; Joesch & Smith, 1997; Olsson & Hwang, 2003; Ryde-Brandt, 1991; Veisson, 1999; Erickson, Hauser-Cram, Krauss, Upshur & Shonkoff, 1999). Whereas such research consistently demonstrates that mothers of children with special needs have higher levels of stress and depression than fathers of special needs children (Kingston, 2007), than both mothers and fathers of children with other disabilities (Greenberg, Seltzer, Krauss, Chou & Hong, 2004) and than mothers of typically developing children (Duarte, Bordin, Yazigi, & Mooney, 2005), these statistical findings are seldom analyzed in depth.

I was similarly disappointed to find the voices of mothers of children with special needs largely absent in the literature on maternal identity (Kingston, 2007). Rather, the

literature on the transition to motherhood (e.g., Barba & Selder, 1995), maternal identity development (e.g., Kegan, 1982; Rubin, 1984), and maternal role attainment (MRA) (e.g., Rubin, 1967; Mercer, 2004) is framed by normative contexts of parenting such as raising children without disabilities. The few studies that extend their analyses of maternal identity to the context of raising children with special needs generally group a range of childhood disabilities and learning disorders such as Down syndrome, autism, attention deficit disorder, schizophrenia, and more. (Kingston, 2007; Landsman, 1999). Incorporating subjects who parent children with a range of disabilities and disorders is extremely valuable in elucidating common challenges, strategies, processes, and experiences and highlighting major differences. However, each of these disabilities is distinct in cause, biology, symptoms, treatments, etc.—differences that likely lead to differences in maternal experiences. The present study focuses exclusively on the disorder of autism with the objective of elucidating how the context of autism shapes specific maternal experiences.

The Context of Autism

Autism is a severe developmental disorder that begins at birth (early onset) or within the first few years of life (regressive). Most children with the disorder are not recognized by appearance as having autism. Rather, the disorder manifests in a range of puzzling and disturbing behaviors that are profoundly different than the behaviors of typical children. Autism is a spectrum of psychological conditions that is characterized by the following core symptoms: significant problems with social interactions and relationships, delays and impairments with communication, severely restricted interests,

and stereotyped and repetitive behaviors (Jepson, 2007). The severity of symptoms and specific manifestations of these core symptoms varies greatly between individuals—a characteristic of the disorder that is represented by a statement commonly repeated by parents and practitioners: “When you meet a child with autism, you’ve met *one* child with autism.”

The American Academy of Pediatrics, in their most current study of autism rates, found that one out of 91 children in the United States, or roughly 1% of children, is on the spectrum (Kogan, Blumberg, Schieve, Boyle, Perrin, Ghandour, Singh, Strickland, Trevathan, & van Dyck, P., 2009). The rate is four times higher for boys than girls, with one in 58 affected. These staggering statistics make autism the fastest growing developmental disability. In fact, more children will be diagnosed with autism this year than cancer, diabetes, Down syndrome and AIDS combined (“Autism Facts & Statistics,” n.d.; Jepson, 2007).

Despite these statistics, autism research receives less than 5% of the funding distributed among the most prevalent childhood disorders (Jepson, 2007). The history of insufficient federal funding for autism research has impeded progress with regard to building a cohesive understanding of the causes, biology and treatment of this disorder. This lack of comprehensive knowledge has contributed to divisions within the autism community. This division plays out among parents, practitioners and supporters on many fronts including the cause of the disorder (e.g., genetics, environmental, vaccines, etc.), treatment options (e.g., biomedical treatments, behavioral therapies, etc.), and the most effective types of therapy (e.g., applied behavioral analysis, play therapy, etc.). Perhaps

the most significant rift occurs along the lines of one's ideological stance toward the disorder—that is, whether autism is preventable, curable, and that children should be recovered, or whether autism, as with other human variations, should be embraced. This ideological division contributes, in part, to the well-publicized debate about the autism research agenda. Some believe that the majority of the autism research dollars should be attributed to prevention and treatment research. Conversely, those who believe that autism is neither curable nor preventable feel the research money should be focused on identifying avenues for improving the quality of life for those with autism.

Competing viewpoints and contradictory information regarding the cause, biology and treatment of autism exacerbate families' labyrinthine quests for services. Many families become familiar early on with the ambiguity and instability that so often characterizes the autism journey. Despite parents' recognition of their child's delays and their ensuing treatment-seeking, autism frequently goes undiagnosed for years (Kingston, 2007). For parents, this ambiguity translates to years of worry and distress without adequate supports (Quine & Pahl, 1987). Delays in obtaining diagnoses also translate to years of missed opportunities for early intervention (Kingston, 2007). Ironically, it is this very point—that early intervention holds the greatest promise for positive developmental outcomes—upon which most experts agree. Eventually obtaining a diagnosis often results in a multitude of complex emotions for families: profound sadness upon receiving a devastating diagnosis, resentment arising from knowing something was wrong yet not having one's concerns validated, and overwhelming anger regarding the lost opportunity for years of much-needed intervention while simultaneously being told that early

intervention holds the most promise for positive developmental outcomes (Quine & Pahl, 1987; Kingston, 2007).

Kingston (2007) found that, after receiving a diagnosis, some parents experienced a profound sense of emptiness. These parents described being at a loss about where to turn for information and services. Interestingly, other parents described a sense of relief upon obtaining a diagnosis. After years of negotiating an unnamed reality, the diagnosis provided confirmation of parents' beliefs about their child's health. For these parents, not knowing what was wrong manifested in blaming themselves for their child's challenging behaviors and not being able to educate themselves on the existing services and treatment options.

Snell and Rosen (1997) describe the period in which families first come to understand that their child is going to require nonnormative medical, physical and/or educational services as the "initiation to special needs." The researchers found that, regardless of the child's disability, each family experienced a period of instability and uncertainty during this process. However, the intensity, duration and associated challenges varied significantly according to the "types of initiation to special needs" (p. 429). In the case of Down syndrome, a disability that is recognized immediately upon birth, families experience a sudden initiation. Conversely, in the case of autism, families come to discover their child's disability over an extended period of time. For these families, the initiation period is marked by the ambiguity of "knowing something was wrong, yet not knowing what it was or what the long-term effects might be" (p. 429).

As with the initiation to special needs experience, Snell and Rosen (1997) found that “everyday reminders” played a key role in shaping how families made meaning of the challenging events in their lives. The authors define everyday reminders as the “common events occurring throughout the lives of . . . families that highlighted their child’s ‘differentness’ and had to be managed in some way” (p.430). For example, taking a child with autism to a playground and negotiating their struggle to interact appropriately with peers is an everyday reminder of a child’s differentness. Similar to the initiation process, everyday reminders can vary according to the type of disability as well as among families affected by the same disability. Attending to intragroup differences, such as the experiences of initiation to special needs and everyday reminders in the context of autism, is particularly important in light of the varying onset, biology, outcomes and symptomology of the disorder.

The objective in providing this overview of autism is to demonstrate how the context of autism is distinct from the other childhood disorders with which it is often grouped in research. The experience of raising a child with autism differs qualitatively from that of other childhood disabilities. Research that clusters subjects across disabilities (e.g. Kingston, 2007; Snell & Rosen, 1997; Landsman, 1999; Dumas, Wolf, Fisman, & Culligan, 1991) has facilitated greater understanding of the differences and similarities of parents’ experiences in negotiating the challenges of various disabilities. However, the perceptual and behavioral processes that are unique to parents who raise children with autism, and the intragroup differences among the families affected by this disorder, have not been adequately explored. Variables such as delayed diagnoses, labyrinthine quests for

care, competing and contradictory information, and long-term uncertainty with regard to children's outcomes are some of the contextual elements that likely shape the maternal journey within the context of autism. These elements in addition to the presently unrecorded and unnamed aspects of the maternal journey may explain why mothers of children on the spectrum are frequently found to suffer more stress and depression than mothers of children with other disabilities including Down syndrome and behavior disorders (Dumas et al., 1991; Sanders & Morgan, 1997). The present research seeks to contextualize statistics such as these by providing an in-depth analysis of mothers' experiences within the context of autism. An explicit focus on autism will begin to elucidate the nuanced ways that this specific disability shapes maternal subjectivity.

Nonnormative Maternal Narratives

Feminist research has provided a vital lens for reappraising dominant cultural ideologies such as historically androcentric theories of motherhood. For example, feminist scholars have argued that the dominant ideal of the "good mother" in western society imposes an impossibly narrow set of requirements and expectations on women (Bassin, Honey & Kaplan, 1994; Kruger, 2003; Trad, 1990). This rigidly circumscribed ideology dictates that women should find complete contentment and fulfillment in the role of "the ever-bountiful, ever-giving, self-sacrificing mother" (Bassin et al., 1994, p.2). Rich (1976) refers to the manifestation of this narrow ideology as the "institutionalization of motherhood," stating that "this institution—the foundation of human society as we know it—allowed me only certain views, certain expectations" (p.39). As Rich illustrates, the good mother prevailing ideology does not adequately reflect the wide range of

mothers' ways of knowing and being. Moreover, the bounded construction and pervasiveness of this ideal serves to undermine women's ability to fully actualize their possible selves¹ as mothers. Juhasz (2003) describes the ways in which the good mother imposes the subjugation of women's diverse subjectivities, stating that the

plethora of subject positions can be especially difficult to maintain because the cultural consensus, usually well internalized by individual women, is that there is only one identity: Mother. This mother is usually the fantasy Mother at that: the great and wonderful selfless and all-loving capital M Mother, with her utter devotion and dedication to the child. Historically, motherhood means self-sacrifice, self-abnegation, selflessness. With a definition like that, the very possibility of subjectivity becomes problematic. (p.405)

Feminist reappraisals of the dominant ideology of motherhood have challenged the ways in which the good mother is necessarily equated with the suppression of women's diverse subjectivities asserting that psychological well-being is linked to the maintenance of diverse subject positions (Nicholson, 1999). While this feminist reconceptualization offers a more sufficient framework for understanding mothers' ways of knowing and being than traditionally limiting ideologies, this framework does not adequately underpin my maternal experience.

For me, adaptive coping and psychological well-being has necessitated accepting the realities of autism and allowing these realities to permeate and transform my self-knowledge—wholly and indelibly. To maintain my diverse subject positions is to maintain subjectivities that have been framed by dominant cultural standards—standards that are no longer applicable to my reality. Moreover, the maintenance of diverse and

¹ Cross and Markus (1991) describe the concept of 'possible selves' as an important component of self-knowledge that acts as "personalized representations of one's self in future states" (p. 230). This aspect of self-knowledge is a psychological resource throughout adult development that is influential in encouraging/ inspiring and supporting/ defending the self.

autonomous subject positions has meant enduring the psychological toll of shifting between ideological frameworks (Jones & Shorter-Gooden, 2003). Of the pain I have experienced in the past three years, it is that of teetering constantly between what is and what could have been that is the most unbearable. As such, thriving psychologically has entailed the abandonment of dominant ideologies and the “personalized representations of [my] self” that these ideologies have shaped (Cross & Markus, 1991, p.230).

Lesser (2005), an educator and author in the arena of emotional intelligence, calls this process the “choiceless choice,” that is, the complete giving up of “the life that had been, in order to make room for the life that is.” She asserts that holistic well-being means “making that choice, over and over again—to accept what is, and to release what was” and describes this process as “patient, surrendered, and openly embracing what is before [you] every day” (Lesser, 2005, p. 68). The widespread ownership and use of the term “autism mom” among mothers raising children on the spectrum speaks to this choiceless choice. For those of us that employ this term, it is more than just a label. Perhaps it is the reflection of the shared, unnamed understanding that adaptive coping may mean allowing the “surrendered . . . openly embracing” transformation of the mother by the disorder (Lesser, 2005, p.68).

Research Questions

I have put forth my narrative as a counterdiscourse to theories of motherhood that are framed exclusively by dominant ideologies and to begin to extend conceptualizations of motherhood to incorporate the realities of those who mother in nonnormative contexts. Many feminist researchers have written that “finding one’s voice” is a fundamental

process in their research (Reinharz, 1992, p. 16). I recognize and situate as central the dynamic process whereby finding my voice is crucial to the research process and the research is crucial to the process of finding my voice. Klein (1983) suggests that while we cannot speak for others, we can and must speak *out* for others. I recognize that my voice frames the direction of this research, however, I undertake this research as an exploration of the *many* voices of mothers who raise children with autism and the ways in which they make meaning of their experiences.

The aim of this study is to examine how the experience of mothering a child or children with autism shapes mothers. In doing so, I pose the following research questions:

1. How do mothers make meaning of their experiences of raising a child or children with autism?
 - a. What are the interpretive processes by which a mother makes meaning of her child's nonnormative development?
2. How does mothering a child or children with autism shape maternal subjectivity?
3. How do mothers construct or reconstruct motherhood in the context of raising a child with autism?

Hypotheses

These research questions are undergirded by the following hypotheses:

1. The experience mothering a child with autism gives rise to distinctive psychosocial processes that ultimately shape one's maternal subjectivity.

2. Nonnormative maternal narratives may serve as counternarratives to traditional theories of motherhood. Recording and naming these realities can extend current conceptualizations to more adequately reflect the range of maternal experiences.

CHAPTER II: LITERATURE REVIEW

In this chapter I provide a discussion of main bodies of literature that inform and shape the theoretical approach and research design of the present study. This research invokes two main conceptual frameworks with many intersecting principles: feminist theory and life course theory. In locating my study, I will first provide a brief historical overview of the conceptualizations of mothers in the psychological literature, and specifically, characterizations of mothers of children with autism. I will then review the two major conceptual arguments beginning with a discussion of feminist theory and then life course theory. Finally, I will discuss the various bodies of literature within these frameworks that inform my study.

Theoretical Framework

Mothers in Psychological Research

Feminists have argued that the social sciences have historically overlooked and distorted the study of women in a systematic manner that results favorably to men (Riger, 2002). According to Marecek, Kimmel, Crawford, and Hare-Mustin (2003, p.5) the inclusion of the variables of sex and gender in social science research can be characterized according to a shift, in time frames and conceptualizations, from 1) a deficit-oriented framework that situates “woman-as-problem,” to 2) the study of female-male differences and similarities, and most recently to 3) the feminist study of women’s lives. Within the field of psychology, the first method for studying women was to situate them as lacking. Although a great deal of early research focused exclusively on male participants, the studies that included women in the sample concluded that women were

by nature inferior. For example, summarizing his 19th century research that focused on individual differences, Sir Francis Galton stated that “women tend in all their capacities to be inferior to men” (Lewin & Wild, 1991, p.582).

Despite the conclusion that women were inferior, most early research neglected to even examine comparisons between male and female participants (Schwabacher, 1972). Furthermore, research on women conducted prior to the 1970s was consigned as peripheral to the main body of psychology (Denmark & Paludi, 2008). Prior to the second wave of feminism, the approach to studying women was underpinned by the assumptions of profound differences (Maracek et al., 2003). This consensus in psychology continued to foster a societal structure that supported male superiority and control (Denmark & Paludi, 2008).

The status and characterizations of women in psychological research prior to the feminist study of women’s lives parallels the problematic conceptualizations of mothers in the literature. In western society, motherhood has been long regarded as the definitive and natural role of women (Kruger, 2003; Llewelyn & Osborne, 1990). The ideals and expectations associated with motherhood have been so narrowly and rigidly defined that scholars commonly refer to this ideology as “the fantasy of the perfect mother” (Kruger, 2003; Chodorow & Contratto, 1982; Price, 1988) and “the myth of motherhood” (Kruger, 2003; Braverman, 1989; Glenn, 1994; Thurer, 1994). According to these rigidly idealized and romanticized constructions of the good/normal/healthy mother, women are expected and required to find contentment and fulfillment in the role of “the ever-bountiful, ever-giving, self-sacrificing mother” (Bassin et al., 1994). These rigidly circumscribed ideals

have functioned historically to silence women whose experiences of motherhood fall outside of this narrow conceptualization and to simultaneously situate as lacking those who voice resistance to the dominant discourse.

The conceptualization of mothers of special needs children in the psychological literature exemplifies this perspective. For example, the portrayal of mothers of children with autism as the cause of their child's disability is perhaps one of the most powerful and debilitating deficit-oriented characterizations of mothers in psychology. Kanner, an Austrian psychiatrist and physician whose work formed the foundation of child and adolescent psychiatry in the U.S. and worldwide, first identified autism in a 1943 paper. In a 1949 paper, Kanner suggested autism may be related to a "genuine lack of maternal warmth" and noted that children were exposed from

the beginning to parental coldness, obsessiveness, and a mechanical type of attention to material needs only.... They were left neatly in refrigerators which did not defrost. Their withdrawal seems to be an act of turning away from such a situation to seek comfort in solitude. (p.416)

In a 1960 interview, Kanner bluntly described parents of autistic children as "just happening to defrost enough to produce a child" ("Medicine," 1960).

Bettelheim, a widely known Austrian-born American developmental psychologist, extended Kanner's proposition contending that unemotional and cold mothering was the very cause of childhood autism. Bettelheim's "refrigerator mother" theory posited that autism had no organic basis, but rather was mainly the result of upbringing by mothers who did not want their children to live, either consciously or unconsciously, which in turn caused them to restrain contact with them and fail to establish an emotional connection. Bettelheim's influence, and the Freudian framework in which it was situated, prevailed as

dominant in both professional paradigms and popular culture for many years (Severson, Aune, & Jodlowski, 2007; McDonnell, 1991). As McDonnell (1991) explains,

Bettelheim . . . has been read far more widely than any mother who has written on autism. In fact, when the mothers of autistic children did speak, they ran the risk of being discounted, “explained away,” by the very theory they sought to resist; as Bettelheim said, the mother hardly can be believed, nor should she be involved in a rehabilitative program with the child, since she is the “very person” who has “kept him from developing normally in the first place.” (p. 59)

The prevailing medical belief that autism resulted from inadequate mothering caused mothers of children on the spectrum enormous self-blame, guilt, and self-doubt for decades. Despite the fact that the refrigerator mother theory has been discredited (Rimland, 1964), the influence of a mother-blame perspective persists. In fact, present day proponents of the psychogenic theory of autism continue to maintain that the condition is a result of poor parenting. The example of autism epitomizes the deficit-oriented characterization of mothers in the psychological literature. The psychological literature on mothers of children with autism, as McDonnell (1991) states, “both silences the mother and assumes that she is all-powerful, capable of doing enormous harm to her child but incapable of understanding and addressing her child’s conditions” (p.59).

A sociohistorical view of mothers of children with autism undergirds the proposed study in that mothers’ experiences of raising children with autism are inseparable from current and historical contexts (Enns, 2004). As such, this contextual approach recognizes that historical mother-blame perspectives have shaped, in part, the current context of mothering a child with autism. This contextual approach as it is invoked in the proposed study will be discussed in greater detail in the following section.

Feminist Theory

There is no single unified feminist theory. Rather, an array of feminist theories offer many different but overlapping perspectives (Enns & Sinacore, 2001). In the application of a feminist theoretical framework to the proposed research, I invoke the following central feminist concepts.

Contextual and socially constructed. This study employs a postmodern feminist perspective that views reality as embedded in social and historical contexts and reproduced through power relations (Enns, 2004). Within this framework, dimensions such as race, class, gender, ability and sexuality are not static or fixed. Rather, the meanings of these dimensions vary across social, historical and global contexts (Weber, 1998). These contexts help define social differences, thus giving them meaning. Ability, like gender, ethnicity, age, and sexual orientation has little meaning in and of itself. Rather, the social context in which the dimension of ability is perceived, experienced, understood, and defined is what makes it salient. The salience of autism, therefore, is determined by how much of a difference it actually make in peoples' lives at a given time and what it means to those influenced by the experience (Denmark & Paludi, 2008).

As Denmark and Paludi (2008) note, “feminist researchers are concerned with the particulars of women’s experiences—how and why women come to act, think and feel the way that they do” (p.7). The application of feminist theory to the present study makes evident that the experience of mothering a child with autism and the salience of that experience must be considered in concert with the social and historical contexts in which it is embedded. As such, attending to contextual influences in the present study

necessitates a critical examination of the stereotyped beliefs, and cultural proscriptions that shape the way mothers act, think and feel (Lott, 2008).

To grasp the significance of race, class, gender, sexuality, and ability in society, the meaning of these dimensions must be examined at the social structural (macro) level of community and social institutions *and* at the social psychological (micro) level of individuals' everyday lives. Central to such an analysis is the explication of the linkages between "broad societal level structures, trends and events and the ways in which people in different social locations live their lives" (Weber, 1998, p. 21). In addition to consideration of how macrosystemic social structural trends shape mothers' everyday lives, feminist theory attends to the individual and group efforts to influence community and societal structures, trends and events (Riger, 2002). As Weber (1998) notes, consideration of such efforts includes an examination of "daily acts of resistance [which] can range from the individual psychological process of rejecting negative group images and affirming positive group images to group activities designed to produce social change" (p.22).

It is important to note that occupying a subordinate position in the systems of race, class, gender, ability, and sexuality does not necessarily mean that one lacks psychosocial resources (Comas-Diaz & Greene, 1994). Rather, resistance to inequality can serve as a psychosocial resource that can facilitate collective struggles and intrapersonal journeys toward well-being. A feminist perspective challenges deficit-oriented perspectives that frame mothers of children with disabilities as weak human beings who are passively accepting and even deserving of their situation. Thus, an

analysis of the ways in which the contextual linkages between social structural processes and mothers' everyday lives supports or constrains their psychosocial development is central to the question of how raising a child with autism shapes maternal subjectivity.

Non-Western paradigms. Feminist theory is underpinned by a commitment to multiple truths (Chisholm & Greene, 2008). The dominant culture defines facets of human existence, such as race, class, gender, sexuality, and ability as fixed, biological traits rather than social constructs. This view of human variation situates the categories within these dimensions—White and Black (or non-White), men and women, heterosexual and homosexual, able and disabled—as polar opposites. Moreover, social rankings such as “good and bad, worthy and unworthy, right and wrong” are attributed to these categories (Lorber, 1994). As Weber (1998) explains, when these characteristics of human existence are

treated as discrete variables, individuals are typically assigned a single location along each dimension, which is defined by a set of presumably mutually exclusive and exhaustive categories. This practice cannot grasp the relational character, the historical specificity, or the conflicting meanings that arise in everyday life. (p.18)

Feminist perspectives present an alternative view to schemas that situate aspects of human variation in binary, dichotomous categories. Comas-Diaz (2001) contends that the incorporation of non-Western paradigms and imperatives, such as interdependence, the reality of external social systems, and both/and frameworks, will advance knowledge about human differences and the ways they are interrelated. Stevenson (2003) argues that a Eurocentric either/or worldview provides a limited understanding of human functioning. A both/and model challenges either/or worldview by conceptualizing human behavior as circular rather than linear. A both/and model assumes that complex ways of

knowing and being are synthesized and co-exist simultaneously, rather than in contrast. Feminist perspectives provide a framework for examining mothers' multiple truths by critically examining how dominant imperatives shape mothers' psychosocial processes through the application of non-Western cultural alternatives. The application of a both/and model to this study will help elucidate the complex ways that mothers of children with autism experience self-blame and guilt yet simultaneously resist models that impose such perspectives; and how mothers harbor relentless feelings of self-doubt yet actively and competently lead research and treatment efforts for their children.

Mothers as subjects. For the past forty years feminist researchers have challenged the rigid conceptualizations of mothers in academic and popular literature (Kruger, 2003). In challenging this view of mothers, feminist researchers have collected and documented alternate voices of mothers including those who had previously been forgotten, ignored, ridiculed and devalued. Feminist theory contends that situating mothers as subjects—as individuals with their own needs, interests, and feelings—is central to the ongoing fight against the devaluation of women. Kruger (2003) argues that feminist psychologists must continue to explore and understand the diverse ways in which women experience motherhood. “The mother’s subjectivity,” states Bassin et al. (1994), “her ability to reflect on and speak of her experience, has become an important ingredient in altering myths and changing social reality” (p. 2).

The present research carries forth the challenge of documenting alternative voices of mothers by extending a feminist conceptual framework to a special needs population. Much of the research on raising special needs children continues to neglect and devalue

the role and experience of mothers. For example, research on raising special needs children often identifies “parents” as the subjects of study when a closer look reveals that the vast majority of are, in fact, mothers (Kingston, 2007). Despite the fact that mothers continue to carry the bulk of parenting work in raising special needs children, very few studies situate mothers at center stage (Kingston, 2007). A failure to name mothers as subjects in this body of literature has contributed to the misrepresentation of the conditions and forces that lead to the fact that mothers are still doing the majority of the work and continues to facilitate mechanisms that reproduce silencing. By situating mothers of special needs children and their experiences of motherhood at center stage, this research stands in contrast to studies that neglect to name the experiences of this population. In doing so, this research adheres to the feminist notion that women’s narratives of motherhood serve as an important starting point for altering myths and transforming social reality (Kruger, 2003).

The personal is political. Central to feminist theory is the emphasis on practical politics (Knapp, 2000). Highlighting practical politics as it relates to mothers’ stories of raising special needs children ties back to necessity of considering contextual influences. Kruger (2003) asserts that merely relaying mothers’ stories will not facilitate transformation. Harding (2001) echoes Kruger’s concern, warning against remaining “preoccupied with women’s voices, important as these nevertheless are, and fail[ing] to examine the cultural discourses through which women’s experiences are framed and continuously reframed” (p.518). Hence, contextual analyses can illuminate the ways that stories are embedded in material and ideological conditions and socially situated. Hence,

the analysis of mothers' narratives involves attending to the extent to which narratives support or contest dominant social structures and practices as well as analyzing the socio-economic and cultural context in which the narrator is constructing her story (Collins, 1994).

Feminist reappraisals of the larger literature on motherhood have challenged the dominant ideologies and the habitual silencing of mothers in the 20th century psychological literature by documenting the alternative voices of mothers. However, the feminist study of mothers raising special needs children is in its nascent stage. The present research reflects and extends a feminist consciousness in the study of mothering by exploring mothers' experiences of raising children with autism. These ignored, forgotten and devalued voices further the process of testing and extending the insights of the feminist scholarship on motherhood—"work that tends to be based on middle class assumptions concerning childcare in optimal conditions and on predictable growth within a reliable natural and social order" (McDonnell, 1991, p. 59).

Life Course Theory

In addition to feminist theory, this study is underpinned by life course theory—a multidisciplinary framework that situates individuals' lives within a complex interrelationship between social structures, and the influence of time, place, and history. Life course theory draws from the social sciences and humanities in its interlacing of methodologies (O'Rand, 1998). As Black, Holditch-Davis and Miles (2009) note, "continuity and change, social structures, and the relationships among time, place and lives as contexts for developmental processes are foci of life course research" (p.39). Life

course theory is particularly relevant as a framework for the proposed study based on the paradigmatic development over the past two decades that resulted in heightened recognition of the significance of the physical body (Elder, 1996) and the nature of mind and body as inseparable (Magnussen & Torestad, 1993) in life course studies. A framework that recognizes, as central, the biological and psychosocial responses of humans in contexts of health and illness offers important insights into the role of autism in shaping unique parenting circumstances and thereby influencing maternal development.

Fundamental to life course theory is the notion that human development occurs in a reasonably ordered fashion with regard to patterns that are shaped by age, social structures, and historical contexts (Elder & Johnson, 2003). Additionally, life course theory is underpinned by five key concepts: 1) time and place; 2) life-span development; 3) timing; 4) agency; and 5) linked lives.

Time and place. As with feminist theory, a key principle in life course theory is that human development is shaped by sociohistorical contexts. In this regard, the experiences of raising a child with autism today are very different than they were ten years ago—a shift that becomes apparent when speaking to parents of adolescents or adult children with autism versus speaking to parents of toddlers with autism. Likewise, the experience of raising a child with autism ten years from now, when the cause of the disorder, symptoms, treatments, supports, outcomes and other fundamental aspects are better understood, will shape maternal development in extremely different ways. The research presented in this paper sought to examine the experience of raising a child with

autism in the current “time” and “place”—a context in which many facets of the disorder remain shrouded in uncertainty. As there exists no monolithic social world, mothers’ different “times” and “places” shape a diverse array of psychological and social realities.

Life span development. The second key concept of life course theory is that of life span development. Life span development posits that meaningful biological, social, and psychological development continues throughout the life course (Elder, Johnson, & Crosnoe, 2003). Scholars in the fields of human development and psychology have suggested that, rather than a linear conceptualization, psychosocial development is more accurately represented as a spiraling or widening process that leads to an increase in adaptive functioning (Spencer, 1995; Kegan, 1982; Rubin, 1984). This principle is key to framing motherhood as a significant and ongoing period of development in women’s lives (Barba & Selder, 1995). Becoming a mother involves a shift from a present, known reality to a new, unknown reality—a transition that is exacerbated by the intense unknowns that accompany raising a child with autism. Like other major developmental life events, the transition to motherhood requires reframing goals and adjusting behaviors in order to achieve a new self-conception (Mercer, 2004; Barba and Selder, 1995). A life course perspective informs the proposed research in that it speaks to the fundamental assumption that maternal subjectivity will be influenced by the transition to motherhood. Furthermore, life span development recognizes that new experiences encountered throughout the life course are shaped by earlier situations and their associated meanings (Marshall & Mueller, 2003). This concept suggests that maternal development in the

context of raising children with autism will be shaped by mothers' previous relationships, prior experiences of and understandings of motherhood, and other related situations.

Time. Timing, the third foundational principle of life course theory, refers specifically to the chronological sequencing of events across the life span. While life events are not rigidly sequenced, there exists a reasonable order to biological events. If such events are experienced out-of-order, physical, psychological and social consequences will differ from the outcomes that would be experienced within the expected order. The notion of biological timing is particularly salient to the experience of raising a child with autism in that it frames as significant a range of relevant issues including parenting a child who does not develop in a normative manner, the experience of raising a typically developing child and then experiencing the abrupt developmental decline that is characteristic of regressive autism, and/or coping with and making meaning of a child's possible or actual lifelong dependence on others. According to life course theory, the ways in which mothers and those in their social networks manage out-of-order events is shaped by women's own development and preexisting psychological and behavioral patterns (Black et al., 2009).

Agency. The notion of agency reflects the view that individuals make decisions that govern the shape of their lives. As stated by Black et al. (2009), these "decisions are influenced by one's temporal orientations to the situation, with some decisions requiring intense focus on the present and others influenced by long-term goals." The notion of agency is particularly relevant to parenting in the current sociohistorical context of autism—a context that is characterized by more questions than answers. As such, mothers

everyday make life-altering decisions for their children, their families and themselves with limited insight into the outcomes of those decisions. In this regard, the concept of agency in relation to the present study brings into focus the influence on maternal subjectivity of having to make significant decisions in circumstances shrouded by the unknown.

Linked lives. Also central to life course theory is the perspective that lives are socially linked and shaped by sociohistorical influences (Marshall & Mueller, 2003). Linked lives refers to the interdependence of relationships beyond that of families, thus including friends, coworkers, and community members who offer a “distinct orienting context” (Marshall & Mueller, 2003, p. 11). Social linkages shape the ways people understand and make meaning of life events (Giele & Elder, 1998). However, there exists wide variation in the extent to which individuals integrate relationships, norms and systems and the process of integration may be interrupted and sporadic. The lives of mothers and their children are distinctly linked, each continually shaping one another in the process of development. However, the experience of raising a child with autism—a disorder that is characterized by social and communication impairments, frequently complicated by additional health concerns, and framed by the unexpected and unknown—adds complexities to the development and nature of linkages.

Interlaced with the five key life course perspectives are the concepts of trajectory, transition and turning point. Trajectories refer to the “paths of change in developmental processes” (van Geert, 1994, p.31) and speak to long-term perspectives on the life course including parenting, career, and marriage. Transitions are gradual changes that are related

to the acquisition or relinquishment of new states or roles and include processes such as becoming a mother or changing careers (Hagestad, 2003). Turning points involve sudden and significant change from one state to another that result in substantial adjustments (Cairns & Rodkin, 1998). A child's diagnosis with autism often serves as a turning point in mothers' lives and influences substantial shifts in the mothering trajectory. These interrelated human development phenomena are central to the life course perspective employed in the present study because they shed light on the influence of navigating processes and specifically, the impact of change and one's subsequent adaptation to change on maternal subjectivity.

Life course theory informs this study by addressing the developmental relevance of social pathways on maternal development. This conceptual framework brings into focus the ongoing adjustments, coping and meaning making that happens as mothers navigate unanticipated shifts in their maternal journeys. This framework is particularly useful in that it illuminates the impact of liminality, that is, of being "neither here nor there," "betwixt and between all fixed points of classification" on maternal subjectivity (Turner, 1969, p.232). The role of liminality is central to a mother's experience of raising a child with autism because it highlights the influence of uncertainty on maternal development.

In the following section of this literature review, I will discuss the various bodies of interdisciplinary literature that inform the proposed study.

Traditional and Counter Conceptualizations of Mothers and Motherhood

Western culture establishes standards and norms that define the “ideal” mother and child. However, the “often brutal realities of life” give rise to childbearing and childrearing experiences that fall well outside this rigidly circumscribed ideal (Layne, 1999, p. 1). The interdisciplinary essays in Layne’s (1999) “Transformative Motherhood” convey some of the diverse experiences of mothers whose lives do not correspond to the mainstream ideals including, for example, surrogate and foster mothers, mothers of children with disabilities, and women who experience pregnancy loss. While each of these childbearing and childrearing contexts is unique in its hardship and struggles, one theme that emerged across the essays was that the process of meeting the challenges posed by contexts of nonnormative mothering facilitated mothers’ reappraisals of their own motherhood and their conceptualizations of motherhood as an ideology.

Few maternal realities challenge the prevailing ideals of mothering as the experience of having a child with special needs (Kingston, 2007). Kittay (1999; 2002) a philosophy scholar whose daughter was born with a severe learning disability calls into question some of the most fundamental conceptualizations of motherhood. In this society, the role of the mother is focused on the objective of fostering her children’s independence—a theme that is echoed throughout most feminist writings on motherhood. The focus for mothers with disabled children, Kittay charges, is not on fostering independence but rather on “enabling development” (1999, p.21). The process of enabling development is not guided by the achievement of a single characteristic, such as independence. Rather, realizing accomplishment within this alternative framework means

that a mother needs to know that she is doing is the best that she could do to promote her child's development. This process, argues Kittay, hinges on access to knowledge, educational, financial, and medical resources. While Kittay does not carry this theory through to an exploration of maternal subjectivity, her charges challenge one of Western society's most widely accepted ideologies regarding the role of the mother.

McDonnell (1991) similarly challenges society's fundamental assumptions of mothering. In *Maternal Thinking*, Ruddick (1989) provides a systematic account of mothering as a social practice characterized by unique types of thinking. This distinctive type of thinking manifests in response to the three core childrearing demands: preserving the child's life, guiding her growth, and fostering the development of an adult who is acceptable by society's standards. According to Ruddick, the very definition of a mother is the sustained engagement in these processes. McDonnell (1991) charges that Ruddick's framework is founded on assumptions of normative development. McDonnell sheds light on the often taken-for-granted context of the normative mothering experience:

The givens of the situation in most cases of mothering thus start with what we choose to call the "humanity," the human condition of the child. We see ourselves responded to, our love for the child reflected back in myriad ways. Frequently it is the child who guides the mother, who sets the pace and indicates when she is ready to learn. (p.61)

What does maternal thinking, therefore, look like in response to contexts framed by profoundly different child development experiences? Although engaged in maternal work, does a "mother" cease to be because her care does not translate into ideal outcomes? In *The Siege: The First Eight Years of an Autistic Child*, Park (1982) asks, "What is one to think, feel and do when confronted by a two-year-old—one's own—who

makes no exploration or approach, who expresses neither hostility nor anger, and who wants nothing?" (p.88) How is "mother" defined in contexts such as these—contexts where one's engagement in the social practices that define "mother" are both impossible and inapplicable? Like many mothers of autistic children, Park decides that she must launch a "siege" on her daughter's development. "The world we would tempt her into," states Park,

was the world of risk, failure, and frustration, of unfulfilled desire, of pain as well as activity and love . . . Confronted with a tiny child's refusal of life, all existential hesitations evaporate. We had no choice. We would use every stratagem we could invent to assail her fortress, to beguile, entice, seduce her into the human condition. (Park, 1982, p.12)

The assertion that mothers and maternal thinking are defined in response to the child's demands begs the question of what is a mother and what does maternal thinking look like under the profoundly different demands of enabling development? Ruddick (1989) recognizes that she writes from her own privileged experience and that her work is framed by the prevailing understanding of predictable and reliable "natural" development and in addressing her assumptions, calls for scholarly attention to alternative maternal contexts.

To mother a child who, as Park (1982) describes, does not imitate the world, explore her surroundings, or demand anything from it, imparts a profound displacement of a mother's sense of reality (McDonnell, 1991). McDonnell argues that mothering a child with autism, a circumstance in which the assured growth, development and ultimate acceptability of the child can by no means be assumed, gives way to a mother's deepest challenge "in the way that she must confront her own values and her least questioned

assumptions about the nature of “reality” itself” (p.59). In reconstructing one’s deepest convictions, mothers of children with autism must also reconstruct their subjectivities. These mothers, writes McDonnell, “seize their own interpretive strategies, and record a reality which perhaps never has been recorded before” (p. 60).

The narratives of mothers of special needs children, like Kittay and Park, whose experiences of parenting special needs children serve as counterdiscourses to the prevailing assumptions of motherhood and as a means to broaden and extend notions of maternal thinking, point to a range of key issues that are rarely acknowledged and seldom researched. These narratives beg the following questions: What are the psychological processes by which a mother makes meaning of a child’s profoundly different way of being? What does the process of reconstructing one’s convictions in the face of a dislocated reality and a disruptive new awareness look like? How do mothers recreate motherhood in the face of nonnormative mothering experiences? How does this process translate to a reconstructed maternal subjectivity? It is these very issues that I address in the present study. In doing so, I have sought to extend the feminist analysis of alternative maternal realities to motherhood in the context of autism in order to challenge rigid conceptualizations of mothers, motherhood and maternal development that are framed by the dominant discourse.

Nonnormative Maternal Narratives

Kittay’s (1999) aforementioned theory of enabling development, presented as a counterdiscourse to the mainstream ideology that equates motherhood with the objective of fostering a child’s independence, points to some of the central aspects of maternal

subjectivity in the context of raising a child with a disability. In order to enable development, Kittay argues, a mother must know that she is doing all that she can do, which in turn means having access to knowledge as well as medical, financial and educational resources. Kingston's (2007) interview-based research on the experiences of 18 mothers raising a child with a learning disability corroborates Kittay's theory. Kingston reported that many of her subjects found that helping their children was their way of coping and that an inability to influence outcomes inhibited coping. "The only time I felt angry," stated one mother, "was when I didn't have anything that I could hold on to. Once I got the [therapy] manual and there was something I could actually do to help this child, then I was fine" (p. 73).

For those whose maternal experiences align with an enabling development perspective, affordances and constraints with access to resources suggests diversity with regard to maternal subjectivity. Specifically, what is the impact on maternal subjectivity when one seeks to enable development through various avenues yet lacks the resources to do so? Does one resist, abandon or reframe this perspective in the face of limited resources? And perhaps the most disconcerting question: What is the impact on maternal subjectivity when a mother does all that she can do but cannot affect her child's development? What is the impact on the mother of unceasing effort without accomplishment? A passage taken from Edward's "Motheroath" eloquently embodies this question:

We stand there you and I, body to body. And wait, I believe it is the end. I know this holocaust will take not only you and me, but all the world, all children, all trees and songs, all promises. The sirens have sounded and I believe . . . I hold you and can do nothing. Nothing to give you tomorrow, nothing to save you,

nothing to protect what might be. There is no gesture of defiance, no gallant last battle. Just you and I in this room with the wind and rain against the window . . . I hold your pulsing wrist to my lips, feel again your struggle to be born, and know that I must promise you the only thing I have left. If we live through this night, dear child of my body, if we survive these moments of ultimate madness, I will do what I can to shift the balance . . . And if, in the end, we lose, I will look at you, straight at you, and say I tried. (1984, p.25)

While some feminist research has begun to reconstruct the traditional conceptualizations of motherhood, very few analyses exist that explicate the unique and specific interpretive processes of mothers of children with disabilities, and how these processes translate to maternal subjectivity (Kingston, 2007). Evidence of these unique psychological processes are present in research and literature with alternative investigative foci such as studies of stress (e.g., Davis & Carter, 2008) and coping processes (e.g., Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008) among parents of autistic children. Yet a lack of explicit attention to these processes and outcomes—to mothers' experiences of "surviving the ultimate madness" or to mother's experiences of giving everything and only being able to say "I tried"—paints a wholly inadequate picture of alternative maternal journeys (Edwards, 1984, p.25).

In addition to the highlighting the heartwrenching experience of a mother who is "able to do nothing to give [her child] tomorrow," Edwards' passage is relevant to a discussion of maternal subjectivity in that it points to the sense of sole responsibility that is so common among mothers of special needs children. "*I hold you and can do nothing,*" she writes. "*I will do what I can to shift the balance [emphasis added],*" she avows. Research clarifies this enormous sense of responsibility confirming that mothers,

historically and presently, carry the bulk of the work caring for children with disabilities (Kingston, 2007).

The persistence of the gender divide that impacts mothers' sense of complete responsibility for their child's developmental possibilities has important implications for maternal subjectivity. Greenspan (1998), whose daughter has special needs, contends that the sense of sole responsibility is "a recipe for feeling inadequate" (p.42). Most mothers—that is, mothers of typically developing children as well as mothers of children with disabilities—internalize society's standards of mother care. In attempting to realize these expectations, mothers suffer pain and hardship. The resulting sense of inadequacy is exacerbated in contexts where a child's developmental outcomes are not known or assured, where all a mother can do is everything she can do in order to foster the unnervingly vague "best possible outcomes." And while this process of attempting to promote a child's developmental well-being appears as though it mirrors that of the normative parental journey, the difference is profound. It is a mother's soliloquy. It is a mother's call and her solitary response. To the universe of possibilities she may plead, "Will my child ever speak?" and in response to the looming silence she proclaims "I will do everything that I can do, all that is humanly possible, to hear the sound of my child's voice."

Greenspan (1998) finds that the inability to meet society's expectations and the resulting sense of inadequacy creates a "self-enforced silencing," among many mothers of special needs children (p.43). In order to maintain the image of good mothering, mothers keep one's pain and exhaustion private through self-silencing, censorship, and

“disappearing” (p.44). Todd and Jones’ (2003) research on parents of adolescents with learning disabilities support Greenspan’s findings. While Todd and Jones set out to investigate both mothers’ and fathers’ experiences with professionals, the researchers found that the majority of those who engaged with professionals were mothers and therefore, they decided to focus on the maternal findings. “This is not to marginalize the experiences of fathers,” note the authors, “but a recognition that it was typically mothers who had had a longer-standing participation with professionals” (p. 242). The researchers found that notions of good mothering impacted mothers’ self-perceptions and in turn, their relationships with professionals. The subjects described themselves, first and foremost, as advocates for their children and they were adamant that what they were doing was what all good mothers would do. Moreover the mothers, who were concerned about being perceived as selfish, were reluctant to discuss their own needs with professionals.

These studies suggest mothers of special needs children struggle to meet society’s ideals of mother care and, in doing so, may be employing processes that undermine their well-being. Self-silencing as a mechanism for upholding a “good mother” image in the face of impossible expectations is disturbing for many reasons. Self-silencing in this circumstance serves to maintain, rather than undermine, the “good mother myth” and in doing so allows the extraordinary family work that mothers of special needs children do to remain undervalued and invisible. In the context of the present study, mothers’ self-silencing highlights the need to address the impact of such mechanisms on maternal well-being, and to address how such mechanisms add to the “social and psychological costs

borne by women” (Tarrant, 2002, p.2). While current research (e.g., Greenspan, 1998; Todd & Jones, 2003) recognizes the existence of processes like self-silencing, the research objectives lead the authors to focus on alternative findings. The present research seeks to extend current analyses by exploring the impact of these mechanisms on maternal subjectivity.

Reconstructing Maternal Subjectivity

Tarrant’s (2002) research on the experience of fourteen Australian mothers of children with autism is an important addition to the academic study of mothers of special needs children because it challenges oversimplified hypotheses and analyses that suggest mothers’ hardship and struggle leads, necessarily and exclusively, to poor outcomes. The subjects in Tarrant’s research echo the concerns raised in other studies (e.g., Read, 1991) regarding the lack of support in raising a children with disabilities, insufficient educational and medical services, unaddressed needs, community ignorance, and poorly informed professionals. Interestingly, Tarrant describes an evolving process of hardship, struggle and adjustment—a “maternal metamorphosis” whereby mothers learn to “trust maternal intuition” and gradually experience increased self-confidence (p. 80). By no means do Tarrant’s findings negate or supersede research that finds mothers’ of special needs children frequently feel stressed (Read, 1991) and inadequate (Greenspan, 1998). While an either/or framework would situate self-confidence and a sense of inadequacy as diametrically opposed, a both/and framework allows us to see how these could be intertwined. In response to inadequate and competing expert opinion and the sense that

“the only thing I can do is everything I can do,” mothers may turn inward—actively employing and learning to rely on an internal compass to guide their decisions.

Having a treatment direction alone, or having a treatment direction that is also leading to certain outcomes, may lead to mother’s increased self-confidence and further reliance on self-knowledge (Kingston, 2007). And while this pathway is one example of a reappraisal process, research that shows that mothers experience a range of psychosocial experiences points to the need to further explore the interplay of such experiences and their relationship to maternal subjectivity.

Landsman’s (1999) interview-based research is one of the few studies that focuses specifically on explicating the linkages between mothers’ psychosocial experiences in the context of raising a special needs child and maternal subjectivity. Landsman uses the rhetoric of “the gift”—that is, the notion that “God gives special children to special parents”—as a framework for her analysis of how mothers reappraise conventional understandings of motherhood and, in doing so, reconstruct their maternal subjectivity (p. 134). Landsman explores the cultural meaning that is conveyed by the notion that God gives special children to special parents. Specifically, she asks,

what might account for both the widespread dismissal of this notion by mothers who have been raising young children with disabilities for some time, and the fact that these same mothers nevertheless continue to represent themselves as the recipients of blessings and gifts? (p.134)

In her exploration of maternal subjectivity among 60 mothers of children with disabilities, Landsman’s finds that her subjects reconstruct the meanings of motherhood in Western culture, as well as the interrelated ideologies of the body, disability, and personhood, in order to claim the full value of their own motherhood. Landsman’s

subjects describe a personal transformation—a shift in perception of self and worldview in which they come to see themselves as recipients of a gift. This transformation sits in contrast to mainstream social constructs like mother-blame that frame mothers as “producers or purchasers of defective merchandise” by redefining the child as the giver of the gift. In reclaiming the language of the gift and redefining their children not as a product or a gift from God, but the giver of a gift, mothers reinstate the personhood of their children, elevate their social worth, and reclaim the value of their full motherhood. Landsman’s analysis of the transformative experiences of mothering a child with a disability presents the rhetoric of the gift as a counterdiscourse to mainstream conceptualizations of maternal responsibility and blame. However, this model does not negate or simplify the complex emotional experiences involved in raising a child with special needs. Rather, Landsman’s both/and model is perhaps most useful in recognizing the complexity of mothers’ psychological journeys. Attending to these complexities, Landsman describes how

A mother can . . . simultaneously see that she is (morally) better off for having the gift and still wish for, and work toward, her child’s cure; she can, and does, often wish that she never received the gift . . . the rhetoric of the child as the giver of the gift of unconditional love helps account for and unify the “apparently conflicting stories of sorrow and hope, of pain and enrichment” told by mothers of children with disabilities. (p.152)

A fundamental concept in Landsman’s analysis and a central construct in disability research is the conception of personhood in Western culture. Many feminist analyses focus on the concept of personhood within the domain of reproduction, challenging *when* in the gestational process personhood begins. Landsman extends this discussion to include the notion of personhood within domain of mothering and raises

important questions about *to whom* personhood is assigned in Western culture.

Employing a both/and framework, Landsman argues that rather than two distinct categories—“nonpersons” or “persons”—there exists gradations of personhood when considering the birth of children with disabilities. Landsman states,

The same woman whose body held a “person” in the womb during pregnancy may later find herself the (diminished) mother of “less than full person” upon giving birth to a baby identified with a defect or upon her child’s subsequent diagnosis of disability. (p.135)

In Western culture, the worth of mothers is linked with the value of children (McMahon, 1995). McMahon contends that prior to World War II, the worth of mothers was associated with their roles as protectors of innocence. However, a sociocultural shift in latter half of the twentieth century has reduced the moral worth of motherhood to a connection with valued children. Because a mother’s moral worth is linked to valued children,

The cultural expectation of, and exclusive maternal responsibility for, attaining perfection in fetal outcome links the diminished personhood of the “defective” child with disabilities to an experience of diminished motherhood for the woman who nurtures it. (McMahon, 1995, p.135)

As such, mothers of children with special needs are not viewed as equitable in value to mothers of normal children. How then, is the birth of children with disabilities made sense of in modern Western society? As Landsman (1999) argues, mothers of special needs children are either viewed as “bad” mothers whose irresponsible decisions and actions caused their child’s disability, or they are viewed as “special” mothers who were pre-selected by God to rear children with disabilities. The mother-blame perspective as it relates to mothering children with disabilities is grounded in the assumption of human

control over nature. That is, it is the individual's responsibility to implement expert medical advice and it is believed that compliance with such advice will allow a mother protection from nonnormative outcomes. Landsman's subjects' narratives echo this perspective and substantiate previous findings (e.g., Press, Browner, Tran, Morton, & LeMaster, 1998) that during their pregnancy most women view having a disabled child as something that happens to "other" people. Therefore, in addition to shock and grief, learning that their child has a disability brings about a profound sense of injustice. After all, these mothers had done "everything right" (Landsman, 1999, p.139). A statement by one of Landsman's subjects, a mother of a daughter with cerebral palsy, embodies this viewpoint. She states,

Here I am, you know, fruits and vegetables, don't drink, don't smoke, you know, walk and get my exercise and . . . prenatal care the whole time I was pregnant and stuff and people treat you like you're some like little teenager who was out doing drugs and have this kid with all these problems and good for you. (p. 140)

The narrative of another mother in Landsman's study, whose two sons are diagnosed with pervasive developmental disorders (a disorder on the autism spectrum), makes clear that the possibilities for maternal responsibility and blame extend beyond prenatal care and encompass a woman's lifelong morality. "I made the right choices with my life when I was a teenager," she contends,

And I saw people all around me, you know, in the 70s or so, all the teenage girls . . . pregnant; it was like why do you want to ruin your life? I've met a lot of people, you know, throughout my life that, you know—I thought of, but I didn't do drugs—but I told them, I said, you can be anything you want to be. You just go find out how to do it, and do it. And I've always believed that. And so, here I had to come smack up in my life of I made the right choices and yet I still have to deal with stuff. So that was why I was so mad at God. (p. 138)

Although not explicitly analyzed in Landsman's research, this mother's narrative speaks to the way in which having a child with a disability challenges some mothers to reappraise their deepest convictions regarding the nature of privilege in their lives. The Western assumption of human control over nature and widespread faith in the medical model—a belief that is evidenced by these mothers' narratives—is embedded in a framework of privilege. Denmark and Paludi (2008) refer to the definition of privilege as “a special advantage, immunity or benefit granted to or enjoyed by an individual, class, or caste that people come to feel they have a right to hold” (p. 47). West (1994) describes privilege as an “underserved gift” (as cited in Denmark & Paludi, p.47). Social privilege confers many benefits that people often believe they have earned and deserve. It facilitates, for example,

the optimal development of an individual, increases access to societal opportunities, or simply makes life easier, but is not acquired by virtue of merit or personal effort. (Denmark & Paludi, 2008, p.47)

It is widely believed in the United States that if a woman “does everything right” and complies with expert medical advice, she will be afforded a healthy child. An alternative outcome—the birth of a child with a disability—undermines what many believe is their preemptive right. Hence, for many mothers, the sense that one deserves to have a child without a disability facilitates the feelings of profound betrayal and injustice that mothers with special needs children, including Landsman's subjects, often describe.

Wildman (1996) delineates key elements in the systemic determinants of privilege. Members of privileged groups establish societal norms by situating the characteristics and values of less dominant groups as defective, deviant and deficient.

Conflation of the privileged characteristics with societal norms functions to make invisible the systemic conferral of privilege and disadvantage, thereby legitimizing the myth of earned power and meritocracy (Denmark & Paludi, 2008). The constructs of maternal blame and responsibility in relation to mothering a child with a disability is an example of how the structural nature of privilege manifests in self-blame among members of disenfranchised groups. Throughout their narratives, Landsman's (1999) subjects refer to the image of the "bad" mother—a multifaceted stereotype that often incorporates some or all of the following elements: the unwed teenage mother, the drug-addicted mother, and the mother whose reprehensible acts of child abuse result in child disability. The narrative of one of Landsman's subjects exemplifies the embeddedness of the bad mother image and the undergirding construct of maternal blame in relation to a child's disability. In conveying her experience of interacting with her daughter's doctors, the mother states,

They talked down to me until I told them, wait a minute here. I pay my taxes, and I'm a good mother. I didn't put my child here. I didn't shake my child. I didn't neglect her to put her here. (p.140)

Ginsberg and Rapp (1995) use the term "stratified reproduction" to describe this phenomenon whereby "some reproductive futures are valued while others are despised" (p.3). Landsman (1999) shows how mothers of children with disabilities recognize this system of stratification as it relates to the valuation of their children. She contends, "By their association with either "perfect" or "imperfect" children, some mothers are assumed to be valued contributors to society, and others to be the deadbeat takers" (p. 140).

Landsman's research sheds light on how social constructs, like mother-blame, function to influence maternal subjectivity. The pathway between such processes that Landsman explicates is framed by "the situation of the mother of a child with disabilities who did in fact "do everything right" to control her pregnancy outcome" and the subsequent explanation given to these situations (p.141). What is missing from this analysis, however, is explicit attention to the way in which mothers' confront privilege and how this confrontation impacts maternal subjectivity. Specifically, how does the process of coming to acknowledge that disability is not merit-based affect maternal subjectivity? How do mothers negotiate and make meaning of this process? Denmark and Paludi (2008) argue that

We are all . . . responsible for acknowledging the presence of social privilege in our own lives, and the ways we benefit from it. It is impossible to grapple with the complexity of difference if we do not acknowledge the social context of privilege and disadvantage within which salient human differences are embedded. (p. 50)

Hence, does the process of grappling with disability facilitate the recognition of systems of privilege and disadvantage? Does the lens of disability illuminate that which has remained invisible?

In "Mothering an Autistic Child: Reclaiming the Voice of the Mother," McDonnell analyzes the Park's *The Seige*, a mother-authored autobiography about raising an autistic daughter. In this essay, McDonnell describes Park's experience of grappling with her daughter's disability as a gateway to her comprehension of the nature of privilege. The following passage in Park's autobiography is evidence of this experience:

Comfortable, well-educated members of the upper middle class ordinarily escape the experience of depersonalization, of utter helplessness in institutional hands, of reduction to the status of children to whom situations are mediated, not explained. Like so much that hurts, the experience is deeply educational. We know now in our skins that the most threatening of all attacks is the attack on personal worth, that the harshest of all deprivations is the deprivation of respect. We know now, I think, how the slum mother feels as the welfare worker comes round the corner. (Park, 1982, p.143)

While evidence of the process of grappling with the nature of privilege can be found amidst psychological research with alternative foci, in parents' autobiographies and essays, and even in popular literature, the hypothesis that the presence of a disability among one's child can facilitate a mother's confrontation of privilege—a process that, in turn, affects maternal subjectivity—has yet to be explicitly analyzed. Inherent in this hypothesis is the concept of “multiple identities,” that is, that individuals have more than one identity (Chisholm & Greene, 2008). Some identities and traits may situate individuals in privileged groups while others can simultaneously place them in disadvantaged groups (Frye, 1996). Likewise, some forms of privilege may lessen some forms of disadvantage. Similarly, membership in some disparaged groups may exacerbate the negative impact of concurrent membership in another disadvantaged group (e.g., a person of color with a disability, a poor woman with a disability, etc.). Because privilege functions differentially in different subjects' lives, the process of acknowledging social privilege and the scope and impact of this experience is a unique and individual process.

Mothers, like Park, who have benefited throughout their lives from multiple systems of privilege may have greater difficulty acknowledging and coming to terms with the many ways they have been unfairly privileged throughout their lives. For Park, the experience of raising a child with autism makes evident the nature of privilege,

facilitates an awareness of social injustice, and provides a gateway to empathy with other people. And yet, this process of awareness is just one of many interrelated reappraisal processes that Park experiences in the context of raising a child with a disability.

According to McDonnell (1991), Park's interpretive strategies and reappraisal processes manifest in a reconstruction of motherhood as a social activist position. "Because she could not change her child, Park set out to change the world," states McDonnell (p.73). In this spirit, McDonnell's essay closes with a description of the many contributions Park has made to advance professional knowledge of autism. McDonnell uses the term "identity-in-relationship" to describe the creation of a mother's identity through the relationship with a child—an identity that is also autonomous and "not dependent on her children for self-esteem" (p. 73). Park's maternal subjectivity is shaped by the raising of a child with a disability and the discovery of her deepest values. "As she encourages her child to become a 'self'," claims McDonnell, "Park herself becomes a deeper, more complex self" (p.73).

Snell and Rosen's (1997) findings substantiate research that shows that raising a child with a disability impacts one's perception of self in relation to others (Kingston, 2007; McDonnell, 1991; Landsman, 1999). In their investigation of parents who "master" the job of parenting children with special needs, the authors interviewed "veteran families" about the many challenges they faced and how they effectively negotiated these challenges. Snell and Rosen found that nearly all subjects (whose children were between six and 12 years old at the time of the study) described the experience of raising a special needs child resulting in significant shifts in thinking. These shifts in thinking were more

significant in scope than cognitive coping strategies and were usually experienced by parents as shifts in worldview—specifically, how they conceptualized themselves and their family in relationship to the systems outside of their family. Among the worldview shifts described by Snell and Rosen’s subjects were “a redefinition of ‘motherhood’ and ‘family,’ and a let[ting] go of the ‘American dream’ that hard work and clean living would prevent bad things from happening” (p.437). These worldview shifts manifested in new ways of relating to others including interactions and relationships with physicians, parents and in-laws. As the authors describe, “many of these shifts in thinking were painful and represented the letting go of life-long beliefs in ‘how things are supposed to be’” (p.437).

Snell and Rosen’s findings resonate with the previously discussed research regarding mothers’ reappraisal processes in terms of privilege and control of one’s outcomes. These data also draw attention to behavioral processes (e.g., parents relationships with authority figures) as outcomes and evidence of shifts in perception of self in relation to others. The authors’ findings contribute the mosaic of evidence demonstrating significant shifts in maternal subjectivity in the context of raising a child with a disability. The piecemeal evidence presented in this literature review makes evident the need for more comprehensive investigations of nonnormative maternal journeys. Furthermore, the dearth in the psychological literature on maternal experiences in the context of raising special needs children, and specifically to the impact of this experience on maternal subjectivity makes clear the need for further academic attention to these experiences. The present study seeks to bridge the gaps in the research reviewed

by explicating the linkages between mothers' experiences, their interpretive strategies and reappraisal processes, and the impact of these processes on maternal subjectivity while focusing on the context of autism.

CHAPTER III: RESEARCH METHODS

Grounded Theory

The experience of motherhood in the context of autism has received scant attention by scholars and as such, the voices of mothers of children with autism remain unrecorded and their experiences unnamed. Due to the dearth of literature on this topic, this study employed grounded theory methods in order to develop theory from the conceptualization of the data. According to Stern (1995), “the strongest case for the use of grounded theory is in investigations of relatively uncharted water,” a description that suits the present topic (p.30).

Grounded theory methods consist of systematic yet flexible guidelines for collecting and analyzing qualitative data in order to construct theories that are “grounded” in the data (Charmaz, 2006). I adhere to Charmaz’s (2006) view of grounded theory methods as a set of flexible principles and practices rather than a rigid methodological prescription. In grounded theory, data undergird the generation of theory. In the current study, data collection included in-depth, semi-structured interviews with 15 mothers of children with autism and participant observation in three different monthly parent support/share groups.

According to Glaser and Strauss, (1967; Glaser, 1978; Strauss, 1987), the defining components of grounded theory methods include:

- Simultaneous engagement in data collection and analysis
- Construction of analytic codes, concepts and categories from data

- Use of the constant comparative method to establish analytic distinctions and make comparisons at successive levels of analysis
- Advancement of the development of theory throughout data collection and data analysis
- Memo-writing in order to analyze one's ideas about codes and emerging categories
- Use of theoretical sampling in order to facilitate theory construction, rather than population representativeness
- Conducting the literature review following the development of one's independent analysis

With regard to conducting the literature review following the development of an independent analysis, I diverged from the classic view of grounded theory. Rather, I adhered to Henwood and Pidgeon's (2003) perspective of "theoretical agnosticism" in which researchers take a critical stance toward earlier theories. This view is compatible with Glaser's (1978) position of requiring existing concepts to earn their way into one's narrative (Charmaz, 2006). Despite having engaged the literature prior to undertaking data collection, I treated extant concepts as problematic, and critically investigated the extent to which the characteristics of these concepts were lived by my participants.

Participants

This investigation consisted primarily of in-depth audiotaped interviews with 15 mothers of a child or children diagnosed with autism, and participant observation in monthly parent support groups. Autism spectrum disorders (ASD) is a general category

of developmental disabilities that includes five different disorders, each with varying severities and patterns. Of the five disorders, which include autism, pervasive developmental disorder-not otherwise specified (PDD-NOS), Asperger syndrome, childhood disintegrative disorder (CDD) and Rett syndrome, autism is the most common. For a diagnosis of autism, a child must have a specified number of symptoms in the areas of social interaction, communication (including language delay), and a restricted range of behaviors, activities and interests. (“Characteristics of autism,” n.d.). Although no two children with autism are the same, I selected participants whose children are diagnosed with autism, rather than the other four disorders, because there is the greatest similarity in patterns of symptoms.

In order to gain an understanding of whether participants’ experiences varied according to the age of their children, I interviewed mothers with children of different ages. However, as previously discussed, the experience of raising a child with autism is shaped by the sociohistorical context. A significant shift has occurred over the past ten years with regard to the context of autism—a shift that includes an understanding of its prevalence, biology, treatments and therapies, popular portrayal, etc. This study is concerned the maternal experience of raising a child with autism in the current sociohistorical climate. Therefore, I limited participants to mothers whose children are of elementary age and younger.

Personal experience, anecdotal accounts, mothers’ autobiographical texts and research (Kingston, 2007; Landsman, 1999; Layne, 1999) have made clear that the time surrounding a child’s diagnosis of autism is often the most heartbreaking and devastating

experience in parents' lives. Out of concern for mothers' well-being during the difficult time of initiation to special needs (Snell and Rosen, 1997), I limited participants to mothers whose children were diagnosed at least one year prior to the interview. In order to investigate whether mothers' experiences of raising a child with autism varied according to duration of time since diagnosis, I selected participants who differ according to this criteria.

Initial sampling occurred through my current connections in the Atlanta area autism community. More specifically, initial interviewees were referred to me by three speech and occupational therapists that are well known and well respected in the metro area. In this phase, I sought interviewees who differed according to age, race, socioeconomic status, child's current age, and child's age of diagnosis.

In line with grounded theory logic, sampling subsequent to this initial phase was aimed at theory construction (Charmaz, 2006). Successive memo-writing led to the formation of theoretical categories. Sampling then followed categories that emerged as analytically intriguing yet thin. Seeking and gathering pertinent data explicated these categories and their properties. Theoretical sampling continued until categories were saturated and "they reflect[ed] qualities of [my] respondents' experiences and provide[d] a useful analytic handle for understanding them" (Charmaz, 2006, p.100). It is important to note that the sampling practices employed in this study followed grounded theory logic and centered on conceptual development rather than ensuring population representativeness (Glaser and Strauss, 1967).

Data Collection

Procedures

Participants were recruited through the snowball sampling technique whereby study participants suggested future interviewees from among their acquaintances. Theoretical sampling was employed in the latter stages of data collection and analysis in order to collect pertinent data to refine categories. I have not sought generalizability through my sampling procedure, but rather to achieve what Schofield (1990) describes as an “illuminating description of and perspective on a situation that is based on and consistent with detailed study of that situation” (p. 203); a perspective that is in line with grounded theory. In addressing my research questions and presenting my findings, I seek to discern socially constructed norms and relationships located in 15 mothers experiences of raising a child with autism. I have identified patterns across these stories with the aim of generating an emergent theory of maternal subjectivity.

Fifteen mothers of children with autism were interviewed over the course of three months. Participants ranged in age from 29 to 48 years old and all resided in the metropolitan Atlanta area. Mothers represented various races, ethnicities, sexual orientations, and socio-economic statuses. Although participants were not specifically queried with regard to these issues, participants generally shared such information over the course of the interview process. Participants’ children ranged in age from 3 to 13. Fourteen of the participants’ interviewed were mothers to boys on the spectrum and one participant was a mother to a girl on the spectrum. The greater number of interviewees

who are mothers to boys is generally representative of the ratio of boys to girls with autism at approximately 4:1 (“Autism Spectrum Disorders Overview,” n.d.).

Interviews. Data collection consisted primarily of interviews with mothers of children with autism. These in-depth, intensive interviews focused on eliciting mothers’ interpretations of their own maternal experiences. By concentrating on how these women were experiencing motherhood and making central their needs, feelings and interests, the interview process situated the mother as subject (Kruger, 2003). This perspective followed the feminist notion that “the mother’s subjectivity, her ability to reflect on and speak of her experience, has become an important ingredient in altering myths and changing social reality” (Bassin et al., 1994, p.2).

Interviews were semi-structured in nature and began with broad, open-ended questions. Intermediate questions followed the ideas and issues that emerged in response to these initial questions and focused on inviting more detailed reflections of participants’ experiences. I continuously asked the participant to articulate her intentions and meanings throughout the course of the interview. Clarifying these meanings was particularly important in light of the fact that interviewees were informed that I, too, am the parent of a child with autism. Hence, this shared experience could possibly have fostered the assumption on the participant and/or myself that meanings were automatically shared.

Following the recommendation of Charmaz (2006), I attempted to end the interview with questions that were slanted to facilitate positive responses. Closing the interview on a positive level was particularly important in light of the topic on which participants were asked to reflect. It is uncommon for mothers of children with special

needs children to be asked to share their maternal narratives (Kingston, 2007). As such, I correctly anticipated that the interview process would be an emotional experience for some participants. Feminist researchers have argued that giving voice to women and engendering the telling of stories, particularly stories that have previously been ignored and devalued, can be part of a social coping process—a process that is cathartic in the ideas that are developed and the meaning that is created during the interview experience (Kruger, 2003; Reinhartz, 1992). A semi-structured interview guide is provided in Appendix A.

Each interview was audiotaped and then transcribed. Interviews lasted between two and five hours and upon transcription, yielded 300 pages of data. Interviews primarily took place in participants' homes or local coffee shops and restaurants. Comfort and convenience to the interviewee, as well as the limitation of distractions (such as childcare responsibilities) was emphasized in negotiating the interview context.

Participant observation. In addition to interviews, data collection included participant observation at three monthly parent support/share groups. These group meetings included the Floortime Atlanta Parent Support Group, Talk About Curing Autism (TACA) Help and Support Group, and Mothers Achieving with Special-needs Kids (MASK). The following are the Floortime and TACA support group descriptions as provided by their respective websites:

Floortime Atlanta serves children with social, emotional, communicative, developmental and learning challenges, including autistic spectrum disorders such as autism and Asperger's disorder. We also work with parents and entire families to help them to understand their children, and to address the range of emotional and practical challenges they face in helping these children grow.

The Floortime Atlanta Parent Support Group is open to parents who are currently utilizing the Developmental, Individual-difference, Relationship-based (DIR) model/Floortime within their family, this group is designed to be a place to share ideas and support and to network with other parents who are experiencing the journey of raising their exceptional children using DIR/Floortime. (“Floortime Atlanta,” n.d.)

Talk About Curing Autism (TACA) provides information, resources, and support to families affected by autism. For families who have just received the autism diagnosis, TACA aims to speed up the cycle time from the autism diagnosis to effective treatments. TACA helps to strengthen the autism community by connecting families and the professionals who can help them, allowing them to share stories and information to help people with autism be the best they can be.

TACA’s monthly meetings feature educational speakers on important topics and allow family members to connect with one another and stay on top of the latest information in the autism world. (“Autism help and support groups,” n.d.)

Both Floortime and TACA parent support group meetings are open to mothers and fathers, however attendance at TACA meetings tends to be comprised primarily of mothers. Floortime meetings are geared towards a range of childhood disabilities yet attendance is comprised primarily of parents of children with a disorder on the autism spectrum. There is very little, if any, overlap between parents who attend Floortime and TACA meetings. This may be due, in part, to parents’ close alignment and adherence to either a behavioral or biomedical model. In fact, it is not uncommon to hear mothers who attend TACA meetings to refer to themselves as “biomedical moms.” Floortime is a behavioral therapy model. TACA promotes the knowledge of biomedical treatments and tends to align with an alternative behavioral approach: Applied Behavioral Analysis (ABA). Some parents, like myself, implement both biomedical treatments and a range of behavioral interventions. Yet it is important to note that for some parents and

practitioners, these models may represent conflicting perspectives on the cause, biology and treatment of autism.

Oxygen MASK. MASK is the most informal of the three parent support groups in that it is not undergirded by an organization or a specific ideology. Started by a local mother in September 2009, MASK was developed to specifically address the needs of mothers. Although the meetings are open to mothers of children with a range of disabilities, those who have attended have been exclusively mothers of children with an autism spectrum disorder. At least one of the mothers who attends MASK meetings also attends Floortime meetings. In the initial email sent out to potential attendees, the following description was provided:

As moms of children with special needs, we are so busy caring for, advocating for and researching for and loving our kids that we frequently forget to take care of our own needs. And if we don't take care of ourselves, eventually, we'll no longer have the mental or emotional strength to support our children and families. Oxygen MASK is a social/peer support group just for us. My hope is that we can provide one another not only with resources and ideas for our children, but also with much-needed social interaction, understanding ears and just plain fun. (A. Auerbach, personal communication, August 26, 2009)

All meetings vary in duration yet typically last between two and three hours.

Attendance at meetings also varies and tends to range between two and 20 individuals.

Floortime meetings are held in the evenings and take place at the Floortime Atlanta offices in metro-Atlanta. TACA meetings are held on Saturday mornings and take place at a therapy center located in the Atlanta suburbs. MASK meetings alternate between morning and evening and are held at metro-Atlanta coffee shops. All meetings are informal in structure and the content. The topics and issues discussed tend to arise from and follow the concerns of the attendees. Comprehensive field notes were collected

during the meetings and focused on mothers' accounts of how they are experienced motherhood in relation to the issues and topics that arose.

Data Analysis

Data collection and data analysis occur simultaneously over a nine-month period. I employed Atlas, a qualitative data analysis (QDA) computer software package to assist with the classification, sorting, and arrangement of my data.

Coding

As is consistent with grounded theory, the analysis of interviews and field notes began with qualitative coding. The use of emergent codes that arose from the data themselves formed the framework of my analysis. The coding process consisted of two main phases: initial coding followed by focused coding. In the initial phase, I began to scrutinize and mine the data for analytic import. Following Charmaz's (2006) recommendation, I asked the following questions of my data:

- What is this data a study of?
- What does the data suggest? Pronounce?
- From whose point of view?
- What theoretical category does this specific datum indicate? (p. 47)

I employed line-by-line and segment-by-segment coding for interview data. In coding the field notes, I employed incident-by-incident coding, making comparisons between anecdotes, conversations and observations. In the initial coding phase, I adopted and applied in vivo codes from the mothers' narratives in order to preserve respondents' meanings and to protect the views and actions that were characteristic of participants' worlds. Using in vivo codes and attempting to code with terms that reflect action helped me curb the inclination to apply preconceived or extant concepts thereby allowing me to

remain open to alternative analytic directions (Charmaz, 2006). As Charmaz (2006) suggests, I “tr[ie]d to remain open to seeing what [I] can learn while coding and where it can take [me]” (p.48). Throughout the data analysis process, I used constant comparative methods (Glaser and Strauss, 1967). In the initial coding phase, I compared data with data in order to elucidate what my participants view as problematic. I then began to treat those ideas and issues analytically by comparing issues within and across interviews and field notes in order to explicate similarities and contrasts. Codes were continually refined as distinctions develop.

Initial grounded theory coding generated analytic directions that I pursued in the subsequent phase of focused coding. It is important to note that my data analysis process was not linear and although certain categories became more salient as I engaged in focused coding, I continued to shift between new and earlier interviews in order to explore issues and ideas that I may have glossed over previously. My objective in focused coding was to test my most significant initial codes against extensive data in order to establish codes that were more “directed, selective, and conceptual” (Charmaz, 2006, p.57). As with earlier coding practices, I attempted to use codes that stick close to the data and reflect action. I compared data to data in order to develop focused codes, and then data to these codes in order to revise them. Throughout this analytic phase, I engaged in reflexivity—that is, continually questioning my own perspectives and practices in order to guard against imposing preexisting frameworks on the data. Focused coding, in conjunction with continual memo-writing, elevated my analysis from definition and description to a more abstract, conceptual level (Charmaz, 2006). In doing

so, focused coding made evident gaps in the data that I pursued through theoretical sampling.

Memo-Writing

I engaged in memo-writing throughout the data collection and concurrent data analysis process. I wrote approximately two to three memos a month over six months. In keeping with Glaser and Strauss's (1967) constant comparative methods, much of my memo-writing was concerned with making comparisons. I used early memos to develop my ideas regarding my initial codes, thereby helping to clarify and direct subsequent coding. These memos focused on making comparisons between data and data, and data and codes. In exploring and filling out my codes, I examined and attempted to describe what was going on in my interview accounts and meeting fieldnotes.

In later memos, I moved from descriptions of the data to analysis. Continuing to utilize constant comparative methods helped me to grapple with the emerging issues. As I explored common themes and patterns, certain codes emerged as having overriding significance and categories began to take shape. Advanced memo-writing also helped make apparent gaps in my knowledge. Thus, throughout the data analysis period, I engaged in theoretical sampling in order to address these emerging gaps and to help define the properties of my categories. The continual process of comparing codes of data and other codes, codes and categories, and categories and concepts raised the level of abstraction of ideas throughout the course of my memo-writing. In sum, memo-writing throughout the data collection and data analysis process helped me to actively engage my materials, to develop my ideas, and to modify my subsequent data gathering.

CHAPTER IV: THE CONTEXT OF AUTISM

Introduction of Results

This qualitative study examines the ways in which the experience of parenting a child with autism impacts mothers. In doing so, the following research questions are addressed:

1. How do mothers make meaning of their experiences of raising a child or children with autism?
 - a. What are the interpretive processes by which a mother makes meaning of her child's nonnormative development?
2. How does mothering a child or children with autism impact maternal subjectivity?
3. How do mothers construct or reconstruct motherhood in the context of raising a child with autism?

These research questions are undergirded by the following assumptions:

1. The experience of mothering a child with autism gives rise to distinctive psychosocial processes that ultimately shape one's maternal subjectivity.
2. Nonnormative maternal narratives may serve as counternarratives to traditional theories of motherhood. Recording and naming these realities can extend current conceptualizations to more adequately reflect the range of maternal experiences.

In order to address these questions, a semi-structured interview protocol was employed during in-depth audiotaped interviews with 15 mothers of children with autism. Each interview lasted approximately three to four hours and, after transcription, yielded approximately 300 pages of data. The continual process of comparing codes of data with

other codes, codes with categories, and categories with concepts throughout the course of my data analysis yielded themes and subthemes that are organized by the Results chapters with the following titles: 1) The Context of Autism, 2) Maternal Meaning-Making and Subjectivity.

Themes and subthemes within each chapter heading, inclusive of the present chapter 4, and chapters 5-6, are intentionally organized and ordered as such for three reasons. First, the categorization and organization of presented themes follow the shift in mothers' meaning making processes. That is, that the context of autism and the daily realities of this unique context give rise to distinct maternal practices and these perceptual and behavioral processes, over time, impact maternal subjectivity. In other words, the concrete experiences of mothering a child with autism facilitate reflection on those experiences on a personal basis. Over time, the interrelated, bidirectional processes of reflection and shifts in maternal practice give rise to specific discerning interpretations of this experience, that is, maternal subjectivity. In that the process of mothering a child with autism continues and one's experiences in this realm further shape development, maternal subjectivity is less of a static outcome and more aptly considered an enacted process.

Second, the categorization and organization of presented themes also follows a chronological order that progresses from mothers' discussions of and perspectives on children's early life experiences and mothers' perspectives on these experiences forward to present day experiences. The third reason for organizing this chapter as such is that the interview guide was also developed intentionally to employ this loose chronology and

thus, the findings presented parallel the structure of participants' stories. The hypothesis that the experience mothering a child with autism gives rise to distinctive psychosocial processes that ultimately shape one's maternal subjectivity framed the interview protocol which asked mothers to reflect on their experiences in an increasingly abstract way throughout way. Therefore, the presentation of findings follows a general shift from concrete to abstract, that is, from daily experiences to complex interpretive processes.

The focus of this chapter is on the context of autism. Three themes, and within these themes, two to nine subthemes are presented in this chapter. Table 1 delineates these results.

Table 4.1

Themes and Subthemes Related to the Context of Autism

Themes	Subthemes
Mothers' responses to early signs	Developmental variations and atypical trajectories Expressing concern and seeking professional guidance
The experience of the period of diagnosis	The diagnosis experience Mothers' initial reactions and early coping
The business of autism	Assessment and ambiguity Treatment seeking experiences Shifts in treatment trajectories The experience of simultaneous stressors The developmental window Extended mothering Relational stress A sense of sole responsibility Isolation

In relaying these findings, I seek to present the stories of 15 mothers of children with autism. I draw heavily on participants' own voices to convey themes using direct

interview quotes to highlight and personalize the data. Descriptions of the participants are provided to offer context and depth regarding the results. All names have been changed to protect participant identity. It is my hope that these participants are drawn out of the text to be more than a name and that their voices illuminate the unique contextual and perceptual processes that inform their stories.

Mothers' Responses to Early Signs

Developmental Variations and Atypical Trajectories

For each mother who participated in this study, the journey of raising a child with autism began with the recognition of atypical behaviors and development early in the child's life. Although there are similarities in these processes, each mother's awareness appears to follow a unique pathway.

Several mothers noted that their children displayed delayed development from birth. While these mothers often recognized atypical development, they were not overly alarmed because the delays were consistent with that child's developmental pattern since birth, or were not considerably different from developmental variation that naturally occurs among young children.

For other participants, it was the recognition of their child's atypically good behavior that triggered concern over time. Jennifer, a suburban mother to a six year-old named Davis, was surprised by her son's extremely calm nature—a nature that appeared to be in stark contrast with her elder, "very typical" daughter. "When he came along, he was completely opposite," stated Jennifer. "He slept perfect. He was very quiet. I felt like the only time he would really cry was when he was hungry." Michelle, the mother of a

ten year-old son named Benjamin, also noticed her child's easy-going temperament in his early life.

Even when he was ten months old I noticed . . . he's in his exersaucer and he was the best kid actually because he was quiet and he never had outbursts, I was very structured with his feeding and everything else and he was actually very independent. He, himself, was trying to hold his bottle. I had him off the bottle like that, went to holding a juice cup. He did a lot of things on his own.

Michelle's observations of her son's advanced development in this statement were similar to those of Tennielle, an urban working mother to a seven year-old son named Benji. "I noticed when he was about five months old that he was doing things that other kids weren't doing, but in a positive way," recounted Tennielle. She continued,

He was doing things like mimicking the alphabet . . . he would sing the alphabet tune. He would try to sing it and . . . it was weird because he was so young. He was doing some things that were exceptional at an early age.

Among the mothers who experienced atypically advanced behavior and development in their children, a pattern emerged whereby mothers noticed an apparent and sudden loss, regression or shift in her child's developmental trajectory within the first few years of her child's life. Margo, a mother of a six year-old daughter named Megan noted that although her daughter did not make significant eye contact,

[She] seemed to be developing typically as far as verbal. She was laughing at about five months old. She was babbling all the time and then it stopped, as I hear that happens a lot. [She lost it] soon after it began, I guess. Maybe she babbled for about a month and everybody was saying she's going to be such an early talker and then that stopped and then we sort of lost the eye contact and lost the engagement. I first became aware at about . . . I guess my earliest signs that something was a mess . . . was, I think our 15-month check-up. They're going down the checklist at the pediatrician's [office]. "How many words does she have?" She was definitely behind. She had no words. She had zero.

Tennielle, like Margo, noticed a sudden loss of advanced behaviors. Tennielle's observations of a sudden regression in her son's development increased her awareness of other odd behaviors. "Somewhere around month 14, he stopped doing those [exceptional] things," Tennielle recalled.

It was noticeable because they were so exceptional and I couldn't get him to do it anymore and it's like, that's weird. But in the back of my head . . . I didn't go crazy about it because I had already decided that I wouldn't be one of those crazy mothers that was obsessing over every single milestone. But I did notice. I think he was about 15 months when I also noticed that you could hug him but he wouldn't let you hug him for more than a second. Or, you know how you like to hold your baby and rock him, I couldn't do any of that with him.

Here, Tennielle speaks to the moment in which she noted in her son's developmental regression and the onset of other odd behaviors. "Prior to that," Tennielle said, "It was fine."

It was probably about the time that he started running. He would run nonstop constantly. We would be in the house and he would just run wall to wall and he hit the one hallway and just go back and then go back [again]. He would go down the steps, he would come back up the steps. I was like, "he's a boy" and I was just thinking [that] he was really active.

Kristen, a lawyer and mother of a six year-old son, whose son had been extremely calm in the first few years of life also noticed a sudden shift in her child's demeanor.

"When he was about two, all of a sudden he just started tantrumming," she stated.

It was terrible tantrums and it was when transitioning, especially when getting in and out of the car. Getting in and out of the car was the worst thing in the world to me. Once he was transitioned, he was okay, but until then I would literally have to man-handle him and he would get a nosebleed [because] he would be screaming so loud.

Expressing Concern and Seeking Professional Guidance

All of the women interviewed noticed some signs early in their children's lives that were suggestive of developmental delay. Retrospectively, mothers noted that these signs were much clearer and they were now able to assign greater significance to specific behaviors and moments of time. However, for all except one of the interviewees, these signs raised enough concern to seek professional opinion. Margo's story, however, demonstrates the perspective of an outlier in this regard. Margo described how her husband, who struggled with drug addiction, decided early in his daughter's life to "sign his termination of parental rights . . . because he didn't want to be a part of our life." For this mother, a preoccupation with the demise of her relationship blinded her to some of these early signs.

This didn't happen overnight with her father situation. This had been going on since her whole second year. He had been a complete disaster. So, where I should have been in there starting [treatment] . . . basically at 11 months, he was gone. I should have been in there working more with her and I was so preoccupied with my own stuff and looking for attorneys and going to meetings and writing letters and it was during this whole period that she was slipping away. This went on for six or seven months.

Aside from Margo, the remaining 14 mothers interviewed described how their awareness regarding these early signs grew from mild concern to distress. Four factors appear to have contributed to this process: the ongoing nature and duration of atypical behaviors, a lack of developmental progression, comparison with other peers (e.g. neighbor's children, preschool or childcare classmates), and the observations and comments of others outside of the family. Laura, the working mother of an eight year-old son, was already concerned about her son's lack of verbal development when the

childcare staff at her local preschool confirmed her observations. As the staff informed Laura,

He's not using any words. He drags us around and points at things. He won't play. He sits and just wants to roll trains back and forth all the time. He wants to mess with our CD players and that kind of stuff and he doesn't really want to play with any of the kids, but when he does, he's very inappropriate.

All interviewees reported expressing distress regarding their children's development to their children's pediatricians during routine and sick visits. However, mothers' initial concerns were nearly universally dismissed. A pattern emerged across interviews with regard to the frequent dismissal of mothers' concerns about their child's atypical developmental trajectory. Meredith, a speech pathologist and mother to a five-year son describes her ongoing effort to obtain appropriate referrals from her son's pediatrician.

At about nine or ten months, he wasn't pointing. He wouldn't say ball. He never startled. That was another thing, someone would slam the door and he would just sit there. [His older sister] had been so hypersensitive to everything that I think at the time that was probably the reason I even noticed . . . So I had all of the stuff building up and at his year appointment said, "he's not saying mama or dada or anything." [His sister] had been doing this for awhile and [they pediatricians] blew it off. At 15 months, we were there and I got really upset. I was like, "he's not doing anything. He's babbling a little but he's not even really babbling" . . . At 18 months, I threw this huge fit and cried and said "I'm not leaving until I get a recommendation for [state services]. Something is wrong. I know it and this is just not right." They just kept saying "wait and see," "he's a boy." I got the whole thing about being a boy.

While Meredith was granted a referral for state services, these services did not lead her directly to a diagnosis. Rather, Meredith like most mothers continued to experience dismissals of their maternal concerns as they navigated a labyrinth of professional and

therapies. After having obtained speech therapy, Meredith expressed her concern to the treating specialist.

I kept saying, “I just feel like there’s something else going on [in addition to speech delay].” And she was like, “No no, he’s fine, he’s fine.” I was like, “he has words and he’s talking to me but if I ask him a question, there is no reciprocal conversation. He can’t keep it going. He doesn’t understand the question, at all, like zilch. He doesn’t understand what I’m talking about.” And oh my God, she said, “I think you just have a behavior issue on your hands. I just think he is a problem.”

For Meredith, like most mothers, her snowballing concern engendered a persistence that led to a maze of assessments and therapies. Over the course of time, this labyrinth eventually led to a diagnostician. While some mothers’ routes to diagnosis were more direct, most mothers did not receive a referral for a diagnostic evaluation for at least 18 months after initially expressing their concern to their pediatricians.

The experience of recognizing and addressing these early signs demonstrates the multitude of ways in which ambiguity characterizes the context of raising a child with autism. “Early signs” represents a significant theme in that prior to having the word “autism” to describe one’s reality, mothers recognize that they experienced a different and unexpected maternal journey--one that is characterized by liminality and more accurately defined by the unknowns than by concrete realities. In light of this ambiguity and despite dismissals on the part of healthcare providers regarding mother’s concerns, subjects demonstrated incredible effort in pursuing a diagnosis and treatment options for their children. Together, these factors point to a context that is shaped by children’s atypical behaviors and nonnormative development, the impact of external individuals and institutions, ongoing uncertainty, and maternal perseverance.

The Experience of the Period of Diagnosis

Participants' experiences in obtaining a formal autism diagnosis for their children varied. Several mothers reported a fairly straightforward process whereby their children were referred for a diagnostic evaluation and a diagnosis was received. Other mothers navigated labyrinthine services and waitlists for months before finally obtaining the diagnosis. The logistics and nuances of seeking an appointment with a diagnostician and the experience of undergoing the evaluation(s) are certainly relevant to mothers' personal stories of autism entering their lives. However, interviews for this study more specifically focused on mothers' meaning-making during this period and their accompanying emotional and behavioral responses.

The diagnosis experience, for many mothers, was often related to the stereotypes and presumptions about autism. Generally, mother's perceptions of autism reflected extreme characteristics and behaviors. Dustin Hoffman's character in the movie *Rain Man* was often cited as a stereotyped example of a person with autism. Mothers who held these stereotypes believed that these extreme behaviors were a certain outcome of an autism diagnosis. Margo, for example, described the bargaining process she employed while navigating diagnostic services for her daughter.

The "A" word is a bombshell. You know, people just relate that to *Rain Man*. You don't understand that it is a spectrum and you just think the worst. Boy, it was a bombshell. It was the first time the [autism word] was used and I thought, "this can't be right." I was like, please just let her be deaf. I don't want her to be autistic.

After having sought professional opinion regarding their children's developmental trajectories on several occasions in conjunction with their own research efforts, most

participants were not surprised by the diagnosis. However, anticipation of an autism diagnosis does not necessarily offset the devastation experienced among mothers. For Kristi, a speech pathologist and mother to an eight year-old son, the diagnosis brought a sense of relief. Knowing that something is amiss with your child's development yet not having the terms to describe the challenges or direct research and treatment efforts can be demobilizing. Upon receiving the diagnosis, "I was relieved," stated Kristi.

Because I was just glad that it was something. Because if it's something, I can do something about something. I can't do anything about nothing, you know? Before the diagnosis, I didn't know what to do. I had no way to approach it.

While relief was a prevailing emotion for Kristi because it provided her with an orienting context and therefore a treatment direction, she also experienced the devastation that was commonly expressed among interview participants. "A diagnosis like this is like a head-on collision," she stated. "It's like everything stops and it's like, 'okay, now what?'"

Like Kristi, most of the mothers described the period of diagnosis as one that engendered both a profound sadness and a renewed focus. "It was a wake-up call," claimed Laura, "In September we got the diagnosis and I just refocused. I was like, 'wait a minute, my focus has been in the wrong place. I need to reprioritize.'" Each mother experienced and processed the balance of these complex emotions in a distinct way. For some mothers, sadness was the initial overriding emotion followed by a sense of refocused drive and for other mothers, these psychological processes were experienced simultaneously. For Michelle, it was the former process in that the diagnosis correlated with her lowest point. She recalls this period,

[The devastation] fades in time, thank God. But it was devastating. I mean, you look at a child and I'm like "Oh my gosh, is he going to be home with us? Are we

going to have to take care of him for the rest of our lives? My husband and I are never going to have a life together. Our son is never going to have a life for himself. What happens when we're dead and gone and our daughter has to take care of him?" We're like, "This is a prison sentence, a death sentence" . . . It was horrible.

Michelle continued by describing how the drive to improve her child's outcomes took hold. Interestingly, this drive is often closely intertwined with notions of a developmental window and the promise of early intervention. For some mothers, it is these constructs that facilitate a shift from a debilitating sadness to treatment seeking and management.

Michelle's statement illustrates this process,

I gave it a little time to feel sorry for myself but not much because I was like time is of the essence here. We're in a battle and we have to get him by the time that developmental window closes at five. We've got to jam him full of everything we possibly can to see what's going to help him and get him out of his little cell . . . I was like, I'm not going to let this take over our son. I'm not going to let this take over our family. I'm not going to let it happen.

Interestingly, the vast majority of mothers interviewed noted that their spouses and partners experienced a reaction dissimilar to theirs during the period of diagnosis. Despite having shared their concerns with their partner, mothers described their partners as being completely shocked by the autism diagnosis or "in denial" during this period. In discussing her husband's reaction, Jennifer shared the following,

I told Blake weeks before we went [to the diagnostic evaluation] that Davis was meeting [the autism criteria on] the list. [I said] he's this, he's this, he's this. . . . he's autistic. He told me I was nuts. And then when [the doctor] said it that day I was like phew. I didn't want him to be, of course, but I wasn't completely shocked . . . Blake was floored. Completely floored. He was a mess. He was a complete mess.

The diagnosis also came as a surprise to Laura's husband. "My husband, just . . . his denial was horrible so I had to just start kicking in and doing my homework."

Not having acted as the primary caregiver role, in addition to having not been as involved in early research and treatment efforts, mothers found that their partners experienced an extreme sadness and/or denial at receiving the autism diagnosis. While recognizing their partner's contributions, most mothers noted that they were the primary caregiver to their children and more closely involved in the daily nuances of the child's life. Moreover, mothers led early research and treatment efforts (e.g. hearing assessments, speech assessments, occupational therapy, physical therapy, etc.) even prior to receiving an autism diagnosis. In the week following her six year-old son's diagnosis, Christian who was unsurprised by the diagnosis, was taken aback by the depth of her husband's sorrow. "I remember," she said,

It was the middle of the night and I woke up because the bed was literally shaking and he was sobbing, just sobbing. It happened two different nights in one week. The first time, I said something to him and tried to comfort him. And the second time, I just didn't even say anything. I just rolled over and thought, "we all have our ways, and this is his."

As such, participants felt that their more direct engagement with their children's atypical behaviors and developmental idiosyncracies facilitated an early awareness and in some cases, set in motion early stages of coping that their spouses did not experience.

Mothers' Initial Reactions and Early Coping

For some participants, their partner's grief correlated with the onset of enacting a treatment "direction" or therapeutic "plan." In essence, after finally having a specific and concrete disorder to research and treat following years of ambiguity, in addition to witnessing their partners in mourning or denial, mothers began to "plug away" at "the business of autism." As Cindy, a single stay-at-home mother to an 11 year-old son stated,

[At times], I didn't know if I had a lot of feelings about it because I didn't have a lot of time to sit back and examine my feelings. I remember reading "Understanding Autism" and [there was] some incredible number . . . something like ten hours a day or eight hours a day is supposed to be therapeutic for your child or something like that. As a single parent, I couldn't make it happen. I couldn't afford to pay people to do it and I had to walk the dog, make dinner, clean the house, set up appointments. I didn't have enough hours in the day to do as much [therapy] as I wanted to do. So I remember just being stressed there for about a year and a half that "oh my God, this time is passing me by . . . this window of neural plasticity is closing down and I'm not getting to it."

All except one of the mothers retrospectively identified the period of diagnosis as their lowest point emotionally. Despite the devastation, most participants felt that allowing themselves to engage in an extended period of sorrow would have inhibited their ability to implement the necessary treatment approach. Jennifer described this perspective,

It's not that I'm falling off a cliff or anything but like, if I keep freaking crying everyday, all day, I can't do anything. I've got to get over this hump and start fixing this . . . not fixing it, but dealing with it and figuring out the next step. I can't do that if I'm sitting around feeling so sorry for the fact that this has happened to me, [saying] "poor me."

Megan, a young suburban mother to a five year-old echoed this view.

I remember I was a basket case. Since then it has been a struggle but I don't remember being a basket case. I read the book [on autism]. I had my notebook the whole time I was reading it. I had to read it after he went to bed and I would have to stay with him because he wakes up at night and can't get back to sleep. I would just lay next to him with my flashlight reading the book and making my notes. I had a game plan and I just worked at it.

Tennielle's experience varied slightly from the other interviewees. Unlike the other interviewees, Tennielle notes that the period following diagnosis "didn't initially have any emotional component," she stated. Yet, like the other interviewees, Tennielle's story reflects the impetus to put in place a treatment plan. She states,

Initially, it was like, this is what I have to do. So that's just what I did. I don't think it had an emotional component for me or my mom initially. This is what we do. This is what he requires. It didn't become overwhelming until the effects of the financial impact really set it.

While the period of diagnosis is often recounted as the most difficult period in mothers' lives, the lengthy process of coping with the diagnosis continued for years. As Laura described,

I really do feel like it took from age three to the beginning of his sixth year to where I could discuss anything without crying. I cried over it . . . I would just say the word [autism] . . . it's just very emotional.

Participants' ongoing emotional coping did not preclude their efforts at effectively carry out research and treatment efforts for their children. For many mothers, in fact, the process of coping was tied intimately with "doing everything [they] could do" to improve their child's outcomes, a theme that is further discussed in the following section.

“The Business of Autism”: Mothers as Researchers, Therapists, and Case Managers

While all participants had pursued one or more types of therapy (e.g. speech therapy, occupational therapy, physical therapy) prior to receiving the diagnosis of autism, the specific diagnosis engendered greater focus and intensity with regard to mothers' treatment seeking direction.

Assessment and Ambiguity

Mothers discussions of their treatment seeking behavior prior to diagnosis was often characterized by an overriding ambiguity with regard to the best way to approach unnamed challenges. That is, mothers' journeys during this time were often guided by assessment-seeking with the aim of clarifying the child's specific issues in order to define

a treatment direction. Here, Libby, a part-time working mother to five year-old twins, one of whom is on the spectrum, speaks to the frustration of navigating the evaluation labyrinth that is common to the pre-diagnosis period.

We did the hearing testing. We did the speech testing and initially they were like, okay, we have the speech delay but let's get his hearing tested because it could really be that. So we did that and he didn't have any hearing problems. And I remember the day that he did the hearing testing. At first they couldn't tell so they sent him for more testing . . . medically they had to look in his ear. And, that day, I just remember wanting to cry when they figured out that it wasn't his hearing. Because then I was like, well, now what? But they sent us to a neurologist. I need to back up . . . when we noticed he wasn't speaking to we decided maybe he needs to go to school because he was at home. So we put him in a school and they evaluated him. We finally went to a neurologist—a pediatric neurologist. She looked at him. She said she wanted to get some genetic testing done and I didn't want to . . . I just kept trying to figure it out. I was like, "What am I going to do? What am I going to do?"

Libby's experience was similar to most of the interviewees in that the pre-diagnosis timeframe was marked by ambiguity with regard to attempting to clarify children's challenges. Ambiguity also typified mothers' discussions of the post-diagnosis treatment period, yet manifested differentially. During this timeframe, mothers experienced ongoing uncertainty with regard to researching, selecting, securing and carrying out the most effective treatments for their children and families from among a range of competing perspectives. Jennifer explained this process as it related to searching for a school for her son, Davis,

I was trying to figure out what we were going to do for kindergarten. Should we stay at Peachtree with a facilitator or should I try to get him mainstreamed . . . but getting him into an actual school where he is going to stay. He has a psych ed evaluation and [the practitioner] said she felt like a good fit for him were schools for auditory processing and that type of fit. She suggested Swift and Howard. Howard interviewed him and said "no way." He wouldn't come out from underneath the table. He was freaking out. They didn't want to have anything to do with it. I just kept telling my husband, I just want somebody to say, "ok, this is

your plan, this is what you need to do, this is what type of school he needs to be in” . . . As far as the schools went, Howard and so many of them, you call them and by the second sentence out of my mouth I’d be choking up because I was so desperate for help . . . “this is what my kid has, this is what I’ve been told, we’re looking for a school” and immediately most of them would say either “We have no room” or “That’s not a fit” or “That’s not a fit for him.” It just seemed very cold and very, you know, I would oftentimes think . . . just a little bit of compassion goes a long way.

Treatment Seeking Experiences

Jennifer’s description about her search for schools speaks to several themes that emerged across mothers’ stories. First, as noted, ambiguity was commonly cited with regard to determining the direction in which one should proceed in seeking treatment methodologies and related services. Second, all participants experienced a significant lack of assistance with regard to others offering guidance in this process—particularly practitioners and experts. Third, all mothers spoke of the various barriers to entry they experienced in treatment and service seeking. These barriers most commonly included prohibitive costs, waiting lists and being declined for admission or services due to a child’s level of functioning. Moreover, Jennifer’s emotional experience parallels that of most interviewees in that each barrier in the treatment and service-seeking journey invoked despondency, isolation and desperation.

Here, Jennifer’s treatment-seeking story continues,

It was horrible because at that point [I was calling anybody], calling all the schools [even those] way up in Alpharetta. At the same time we had same time we had signed up for a parent training course in Floortime [therapy] just based on doing my own research, coming across it, hearing about it and I read about it and thought this sounds a lot better than ABA [therapy]. I could see us doing [Floortime] way more than I could see us doing ABA. It was all very expensive. I was staying home with the kids and [my husband] would come home from work and I would say, “There is this awesome program out there and it’s only \$2,000 a month” and he would completely freak out and we would get into this huge

argument. It finally got to the point where he said, “If we need to do that, we will do it but let’s make *really* sure that it’s what we really need to do.” So hence, we are searching for all of these answers and it just felt like we weren’t really getting any and I felt like any answer that I was getting was because I was figuring it out.

Without outside guidance, Jennifer, like all participants, felt the impetus was exclusively on her to direct her son’s treatment. This sense of sole responsibility was compounded by the feeling that answers were only successfully obtained based on the extent of her efforts— a concept that one participant referred to as her “getting a Google Ph.D.” In addition to the themes mentioned above, Jennifer’s statements also illustrate the common practice of having to choose between different, and sometimes conflicting, therapeutic approaches without significant guidance.

Shifts in Treatment Trajectories

Even after determining a direction in their service-seeking, many mothers were met with sudden shifts in their trajectory for a host of reasons. Alison, for example, shifted schools when the treatment methodology employed at the school began to lose its effectiveness. “We did [the] Walden [school] for about a year,” she recalled.

As a matter of fact, for one year exactly . . . because, what happened was initially, at Walden, he thrived. He started speaking. But about a year later, he was speaking but he sounded like a robot. I talked to [the staff] about it but, what happened, I believe . . . is that he kind of out-paced their program. They got him to a point within a year where he was probably where kids who come in, leave.

Kristi also experienced a sudden shift in treatment trajectory when, after finally finding a school for children with learning differences that she believed would be a good fit for her son, experienced discrimination from the administration. Kristi shared this story that began with attending a cocktail party for new parents prior to the school year commencing.

We went and happened to be standing in a group of other parents and another mom mentioned that her child was high functioning autistic and I was like “oh my gosh, so is mine.” They were the same and there was only one class for their age and we thought “Oh my God, they are totally going to be in the same class. This is great. We need to get together, go to the park . . . “ Then, a couple of weeks later, two weeks before school starts, we got a call from the director of the school asking me to come in and go over his file. My husband is at work and I go by myself and the woman in charge of admissions . . . she said, basically, “I understand that you were at a cocktail party and discussing with some other people about your child’s autism. We do not advertise that we take kids with autism. We do not want to be a school for autism. I’m not sure if you’re aware of this but it is still a very bad word in the community.” Oh yeah . . . she laid it out . . . and she said, “If you decide to send your child here...which he is absolutely welcome to attend,” she said, “you just need to know and be in agreement with us that the subject will not come up anymore unless it is behind closed doors between a staff member of the school who is aware of his file. Otherwise, we do not want you talking about this with anyone.” And I said to her, “it has taken me two and a half years to even become comfortable with it myself and I really don’t see the point in me hanging around here trying to talk you into being comfortable with it because clearly that is not your goal at all” . . . I said, “he won’t be coming [here].” We had already paid in full. They fought us on it. We got a lawyer . . . [and] got [the tuition] back . . . It was horrible.

Kristi’s experience with having to unexpectedly shift directions in regards to her son’s therapeutic and educational services is indicative of a pattern that many participants experienced. In all interviews, mothers spoke of their unceasing quests for services. While participants often found treatment services and schools that were effective and/or suited their needs for a specific timeframe, these services frequently did not provide longterm solutions.

The Experience of Simultaneous Stressors

The lack of continuity and ongoing uncertainty invoked stress and exhaustion in mothers—emotions that were compounded by additional stressors such as financial hardship and long commutes to services and schools. For example, after enrolling her son

in a new school, Alison found it necessary to move her family closer to this new program to address some of the hardships they faced previously.

We moved to Decatur [to change schools]. We bought a house in Decatur that we couldn't afford. We still had our house in Fairburn. We rented it out. But [my son] was falling asleep on the way to school and on the way home and it was just so destructive . . . it was just so exhausting.

Laura spoke to both her long daily commute and the exorbitant cost of her son's special needs pre-k program.

We live [outside of Atlanta] and [the daily drive] is kind of a triangle . . . I take [my daughter] and then drive an hour to the city and then head back and then do it all over again. Last year, [with a different program] we did the same thing. We could have stayed until kindergarten there but it was from 9:00 am to 12:00 pm and it was 30 something thousand dollars. And I was so stuck down there. I had to move my life down there . . . the dry cleaner, my gym . . . I switched my grocery store there.

The financial challenges that Laura and her husband experienced as a result of the cost of her son's treatments echoed that of all participants. Here, Laura further describes that hardship.

All of his expenses ended up being equivalent to three or four kids, which . . . we didn't opt to have three or four kids for financial reasons. If finances weren't in the way, I would be the one for sure driving around with four [kids]. I love that idea but we made that mature decision not to [have three or four children] for that reason. And then you get this. So it's a huge hit . . . I don't see any retirement in my future.

Margo, likewise, identified financial factors as her most significant source of stress in her efforts to treat her child.

[Finances] are the biggest stressor for me. If I had unlimited resources this would be so much easier because I could do everything that I wanted for [my daughter]. Somebody, especially a single mom . . . it's hard to see all these things that you think are going to be great for your child and you know would help them and then have to pick and choose which ones to do. This is an endless source of stress for me . . . trying to afford what she needs and choose one over another.

The financial burden for all mothers interviewed was significant and ongoing. Yet the pressure of the belief that early intervention holds the greatest promise for positive developmental outcomes influenced mothers to make difficult decisions like refinancing one's home, moving, borrowing money, and selling belongings in order to pay for therapeutic services.

The Developmental Window

As noted previously, the construct of the “developmental window” coupled with the widely accepted early intervention perspective functioned to influence mothers’ post-diagnosis treatment seeking behavior. As Margo stated,

[The diagnosis] definitely refocused me to say “wait a minute, you get one chance at this and the window of neural plasticity and all that—strike while the iron is hot. I don’t have the time to spend another year freaking out about it. We’ve got a game plan.” We just started working.

Michelle’s statement illustrates a similar mindset,

We’re in a battle and we have to get him by the time that developmental window closes at five. We’ve got to jam him full of everything we possibly can to see what’s going to help him and get him out of his little cell.

For several mothers, like Meredith, the desire to promote speech and language development incited the greatest urgency. “There’s a whole statistic,” Meredith noted,

He did not talk his first words until he was about two and three-quarters . . . he started talking and I was stressed before that because they say that if they don’t talk before five, they’ll probably never talk and I’m like “oh God, we have to get this child talking”.

Extended Mothering

These theories coupled with the commonly cited recommendation that children with autism receive 40 hours per week of direct therapy fueled the undertaking of “the

business of autism,” a term used by one of the subjects. The “business of autism” refers to the multifaceted roles well beyond that of typical maternal practice that these participants took on in their efforts to provide their children with the most efficacious therapy possible. For all mothers involved in this study, these roles included that of researcher and case manager. For the majority of participants, these roles also included that of direct therapist to their children. As mother, researcher, case manager, and therapist, participants found their daily lives revolved nearly exclusively around researching, selecting and securing treatments, treatment approaches and schools. This process frequently included navigating waiting lists, administrators, evaluations and assessments, securing proficient practitioners, managing the provision of these treatments on a daily basis, and oftentimes personally providing supplemental therapy to one’s child. Reflecting retrospectively on her early efforts to carry out the business of autism, Margo, a single-parent, shared the following,

I didn’t have enough hours in the day to do as much [play therapy] as I wanted to do. I remember just being stressed there for about a year and a half . . . I was trying to do all the reading after Megan would go to sleep. I was trying to read and research and there’s too much information. There is so much and it’s all varying and conflicting information that it stressed me out . . . I just had to step back a little bit. I was making myself crazy for about a year trying to do it all . . . I felt like I had to get it all done right now. I had to fix it. I had to turn the ship around.

Alison also referred to the business of autism and specifically to how the responsibilities that she undertakes in caring for her are those that one expects to find on a resume rather than in one’s role as a mother. Here she discusses how the two-year gap in her resume does not accurately reflect the work that she has been doing in her field of social work by way of caring for her son.

I mean, I'm a social worker, I put case managing my son on my resume. It was my first entry . . . I'm a perfectionist and when I started revamping my resume . . . I was like, I did stuff, I have been doing stuff for two years that I am going to have to do on [a potential job]. I have been advocating with insurance companies. I have been treatment planning.

Gina, a stay-at-home mother to an eight-year-old son, described her daily life carrying out the business of autism,

We started eating, living, and breathing therapy and that was a hard thing for us in some ways because it was easy to lose track of us and just be noting but therapy, therapy, therapy. And, we have a daughter . . . and it was very hard for her . . . you could just tell that her self-esteem took a knock because we were so busy with [my son, Max]. Everything was Max, Max, Max. Our family took a big hit at that time . . . We spent pretty much our retirement. We spent a lot of money.

Relational Stress

Gina continued, describing the impact of such intense therapeutic efforts and the toll that it took on the whole family.

We had read that one of the highest divorce rates is autistic families and I could totally see why because of my focus [on my son]. My husband would say, "Gina, you're so focused on our son. Hello, I'm here." I delved in so hard. I ate, lived and breathed therapy and our house was eat, live and breathe therapy. We had picture boards everywhere. We got our homework when the therapists left [for the day] and that didn't mean that the work was over. Now it's our turn to pick it up because we would sit and listen to what [the therapist] would do and we would watch and make sure what each of the therapists were doing so that we could make sure we were mirroring whatever they were doing. My husband took a year off of work to stay home the entire time and watch everything that happened in our house during the day and to be able to mirror the therapy. It was exhausting. It was a tough road . . . a really tough road.

For all participants, the responsibilities of carrying out the business of autism greatly impacted the family dynamic and placed considerable stress on participants' relationships with their partners. While Gina's relationship with her husband suffered as a result of her intense and singular focus on her son, other participants described

relationship stress arising from divergent opinions regarding the appropriate treatment, ongoing financial hardship, an uneven burden of responsibility between partners in carrying out the business of autism, and the daily stressors of raising a child with special needs.

Folami, a working mother to a seven year-old with autism, speaks to the cumulative toll that these stressors took on her relationship with her husband over the course of several years.

When it all first happened, so many of the doctors that we met with [for our son], one of their first questions was always, “Are you guys in therapy?” And we would always say “no.” It got to the point where we were kind of priding ourselves and patting ourselves on the back saying “We’re doing fine. We’re on the same page. We both agree with his schooling. We both agree with me staying home.” And it has only been recently, now that he’s seven that I’ve been looking back and the little things that we fight about or argue about and I think to myself, all of this really comes down to [our son] Kofi and what got us here in the first place. And so really, all those people were right. We probably should have been in therapy the whole time. I think it has kind of slowly crept up. It was there all along but I wasn’t really admitting it, I guess.

In her continued description of the swelling stress in her relationship with her husband, Folami speaks to a theme that emerged across many interviews: that is, the burden of carrying the bulk of the business of autism in relation to one’s partner. Folami’s statement captures this common yet complex sentiment,

I think a lot of [the arguing] is my own inner animosity towards him . . . I’m changing everything about me and you’re not [changing anything]. It’s all up to me. On the one hand I can say that this isn’t really fair. It’s up to me to research everything . . . where he is going to school . . . and I know everything about everything there is to know about his diagnosis. You are not doing any of that. And then of course, on another day, I will think . . . well, he can’t do it. His job is to make the money to pay for all of this. So I’m fine with that. This is my job and that is your job. It has taken us a long time to get to the point where he looks at what I’m doing and has complete respect for what I’m doing. That is all I have

ever asked for. Now I have more days where I wake up and I think, this is a really great job that I'm doing . . . as opposed to feeling like I got jipped.

A Sense of Sole Responsibility

The unequal distribution of direct caretaking responsibilities between participants and their partners was a theme that arose in all interviews. While some participants, like Folami, describe a sense of acceptance with regard to the current state of caretaking division of labor, many mothers described an ongoing sense of discontent. Furthermore, mothers linked the differential caretaking responsibilities to an intrapersonal burden of responsibility. That is, mothers felt that the unequal distribution of caretaking in carrying out the business of autism fostered a significant emotional burden of feeling solely responsibility for their child's potential outcomes. In the following statement, Alison speaks to some of the many interrelated facets of this complex process whereby mothers carry the bulk of the labor in managing and carrying out the treatment of their children and, in conjunction, experience a near-exclusive sense of responsibility for their children's well-being.

[My husband is] an ER doc. [His perspective is] you see a problem, you fix it, you move on. [Autism] doesn't lend itself to that. You may have to try 97 things before you find one [thing that works] and it might only work for a week and then you have to find something else. That is just the way it is.

We talked about this [in therapy] but I carry the optimism in their relationship and he carries the pessimism and it's exhausting. We are in couples counseling. [I say things to him like] "I think I see an improvement here [in our son], what about here?" And, "You don't really know what the future is going to be like." He says things like "This was the worst weekend ever." [My husband] is one of those pessimists who considers himself a realist. And it's very hard, I mean, we just sort of started exploring this aspect. I don't feel like I can be sad and depressed because there is no one to pick up the pieces. . . . it's not like we talked about who was going to take on these roles. We just did. My mother used to have a cartoon on her fridge. I think it was the *For Better or Worse* cartoon and where the punchline was, it said

“What does it mean when you talk to your parents and your children in exactly the same voice?” And the answer was, “It means don't die because everyone is counting on you.” I kind of feel like that, including [my son] of course.

I'm very different from the person that I thought I was going to be. The greatest lie that our generation got was that you could actually have it all . . . that something will not actually give in the process. Nobody told our husbands that. That, to me, is the biggest problem . . . We did not sign up for this particular division of labor, responsibility, all that kind of crap and that is frustrating in its own way. I don't blame [my husband] for it but it happened. What was the life that I envisioned for myself? . . . I don't do well with uncertainty. Much like my son. I don't know. I don't know who I am going to be tomorrow. I don't know who he is going to be when he wakes up in the morning necessarily.

Alison's account makes evident the complexity of factors that affect one's sense of sole responsibility and the interconnections between these various processes including, but not limited to, differences in parents' caretaking meaning-making and approach, notions of division of labor that are exacerbated by the business of autism, the sense that one is solely responsible for fostering the best possible outcomes for her child, the omnipresent ambiguity that undergirds the experience of raising a child with autism, and meaning-making with regard to these intricate processes. Alison's passage points the linkages between the context of autism, as is the focus in this chapter, and the perceptual and behavioral processes that influence maternal subjectivity, as is the focus of the following two chapters.

Isolation

For many mothers, the sense of near-exclusive responsibility was closely linked to feelings of being unable to relate to others and a sense of aloneness. These feelings, in turn, contributed to experiences of isolation. These sentiments waxed and waned for

mothers at different points in their maternal journey and were often described by participants as others “just not getting it.” Here Laura describes this sentiment,

It’s an emotional roller coaster . . . dealing with people that you constantly feel like don’t get it. It’s not a sympathy thing. It’s not that I’m looking for a high five or a pat on the back or a hug. Most people don’t know how to react about it or they just don’t have a heart and they say the wrong thing. It’s never really right. Even your parents and your best friends who you know can get it because they are with him and they know you, they get it but not like [other mothers of children with autism].

Two interviewees used the term “character study” to describe the ways in which their experiences in raising a child with a disability became a lens for characterizing the nature of certain relationships in their lives.

It has been a very interesting journey, so to speak. Almost like a character study on so many levels. Just as far as you had no idea that people would react a certain way. You know, certain friends that you thought you knew so well, their immediate reaction or the things they say, or now even the things they will say in front of me. I think that sometimes they are not thinking before they speak. They say things that are hurtful or hurts your feelings and I have to remind myself that they are not even thinking about me and my situation . . . It’s just a lot of feelings. So many things come from it.

For participants, the sense of others “just not getting it” led to a loss of relationships including close friends and acquaintances. When asked to reflect on the nature of this process, several mothers directly referred to the “chicken or the egg” phenomena whereby they were uncertain of whether these friends and acquaintances facilitated the relational decline due to their discomfort or whether the participants themselves slowly let go of these relationships due to a swelling inability to relate to these individuals. Most mothers concluded that the process was likely bidirectional with the inability to relate to each others’ realities as the cornerstone of the process. Here,

Margo describes the process of trying to relate to the mothers of neurotypical children in her daughter's mainstream preschool:

There are a couple [of moms] who are really sweet and welcoming, like there always are in any group, right? But the long and the short of it is that a child on the spectrum is going to do some odd things from time to time. Some of these moms, when my daughter does something wild and has a tantrum or has some sort of behavioral outburst, they look at me like "Oh my God, can't you keep your child under control?" . . . like I've just grown an arm right out of my head and they take their children away. That's just something that I think is inherent when being with a group of people that don't understand what's going on. They don't understand.

In the following statement, Margo continues to describe the emotional impact of these experiences, she makes evident the progression by which the emotional symptoms of these experiences function to facilitate a self-imposed isolation.

[I feel] like an outcast, like a total outcast. It makes me feel uncomfortable to the extent that when they have afterschool programs--like sometime they'll meet on the playground or they have Skate Night at the gym . . . or when the church has church services, or Sunday school and egg hunts and all this other stuff--that a lot of the other kids participate but I don't really do it with Megan even though she could really use that extra social practice. I kind of feel uncomfortable because I feel like everybody is looking at me, like "That's the mom with the weird kid."

Here, Margo points to a tension that was expressed by three additional interviewees. That is, mothers expressed guilt in their recognition that their children could benefit from social situations that would likely undermine their intrapersonal well-being. As Kristi states,

I feel like [my son] has missed out on a lot of opportunities because of my discomfort but I feel good that he has opportunities right now where I'm comfortable and that's in the special needs community. I think that from a particularly maternal perspective, that being in an inclusive program is probably less comfortable than being with a group of like-minded people . . . In a way, I think that [inclusion] is the best setting for him, but it's not the best setting for me. I'm just not comfortable. I'm just not comfortable going to a big, crowded park

[or] playground, you know, with a bunch of neurotypical kids and having to educate [them] or having to slink away embarrassed.

Mothers who relayed this tension justified their decisions by describing how they organize or partake in other social situations with special needs families that benefit their children, noting that socialization with neurotypical children is not their primary foci at present, and overtly recognizing the centrality of their well-being in terms of upholding the business of autism—a wellness that can be easily undermined by “having to keep your armor up” in potentially hurtful social situations.

Most mothers noted specific instances in which they felt alienated or were treated in a hostile way due to their children’s behavior and/or an explanation of autism. For example, when at her daughter’s soccer game with her son, Gina informed another mother that her son was autistic in order to explain his odd behaviors and, in response to her explanation, “[this parent] grabbed [her child] by the hand and walked away, like, get him away from me, he’s contagious. That has only happened once.” Aside from these specific hurtful exchanges, most interviewees suggested that the general sense of isolation they experienced was self-imposed. That is, mothers found that their children’s atypical behaviors and unique needs presented ongoing challenges with regards to engaging in mainstream settings and activities. In order to prevent such challenges and to protect oneself and one’s child from potentially hurtful exchanges, mothers were likely to self-isolate. Tennielle relays this experience,

You feel so isolated. I felt like nobody in the world could understand me. The only people who ever kept him [so that I could go out] were my parents. Ever. We couldn’t hire a babysitter. You can’t just bring a teenager to come in. Even when we had a moment, we weren’t doing anything fun, we were sleeping. I needed to breathe. I think that people in general, in the world, are very judgmental. I think it

is the reaction that you get from people seeing your child while out, wherever you are, [your child is] just all over the place. People are looking at you like you're crazy. You're like, okay, I can't do that again.

In this passage, Tennielle discusses the process of self-imposed isolation conveyed in all interviews. As participants described, this sense of isolation was as much of a psychological state as it was a physical experience. For mothers, the critical gaze and actions of others serves as a constant reminder of their child's disability and differentness. This critical gaze is further compounded by the everyday challenges of negotiating mainstream settings with a special needs child. In their efforts to avoid these challenges and others' judgments, mother often engaged in self-isolating practices.

Self-isolation is a contextual manifestation of the complex experience of raising a child with autism. The interrelated themes presented in this chapter speak to the shared experiences that mothers of children with autism identify as significant in shaping their maternal reality. These shared experiences shape participants everyday lives from their most minute maternal practices to the complex ways in which they make-meaning of and experience their subjectivity. While certainly not exhaustive of mothers' experiences, the themes presented in this chapter emerged as those that commonly impact the daily realities of raising a child with autism. That is, these contextual experiences give rise to distinct maternal practices and perceptual process that, over time, impact maternal subjectivity. The following chapter will delineate findings with regards to how the context of raising a child with autism impacts specific discerning interpretations of participants' maternal experiences.

CHAPTER V: MATERNAL MEANING-MAKING AND SUBJECTIVITY

In this chapter, I present results that point to the perceptual processes that mothers employ in making meaning of their experience raising a child with autism and the ways in which the contextual factors, presented in the previous chapter, influence these processes. I then present findings that illustrate how through complex meaning-making processes, mothers reappraise their maternal subjectivity and reconceptualize motherhood as an ideology. Six themes and fourteen related subthemes are presented in this chapter. The following table delineates these results.

Table 5.1

Themes and Subthemes Related to Maternal Meaning-Making and Subjectivity

Themes	Subthemes
The “business of autism”	“Tough decisions, limited knowledge” Navigating a divided community
“The lens of autism”	Sacrificing the present for the hope of the future Maternal responsibility Relational meaning-making
Daily acts of resistance	Enacting silence “Showing up” Voice “The only parent on the playground”: extreme mothering
Linked lives	Mindfulness
Worldview shifts	Enabling development Self-knowledge Privilege
Maternal subjectivity	Transformative motherhood as ideology

The “Business of Autism”

The current context for the treatment of autism and specifically, the recommendation that children receive 40 hours of direct, one-on-one therapy per week in conjunction with the theory that early intervention provides the greatest opportunity for positive outcomes, appeared to facilitate action-oriented behavior on the part of participants. That is, mothers frequently undertook the “business of autism” with incredible drive and effort after learning of these recommendations. However, these efforts were undergirded by significant stress. This sense of anxiety among participants was multi-factorial in nature. Financial issues, such as the high-cost of therapies, and logistical concerns such as hiring qualified and capable therapists, arranging therapy schedules and organizing one’s own schedule to support such therapies were commonly cited as stressors that underpinned mothers’ treatment efforts.

“Tough Decisions, Limited Knowledge.”

Mothers’ statements demonstrated that the most significant source of anxiety regarding education avenues and/or treatment options were the experiences of having to make early, rapid decisions that could impact the rest of their children’s lives with limited and conflicting information. Tennielle summarizes this point,

A diagnosis like this is like a head-on collision. It’s like everything stops and it’s like, “okay, now what?” And you have to make really tough decisions with a limited amount of knowledge and a very short time frame. It has to involve emotion because it’s your child, it’s not like a business decision or something you can be detached from emotionally. Whatever the outcome is, you’re going to live with it for the rest of your life.

In undertaking treatment and educational avenues, mothers were forced to confront the possibility that their treatment decisions could be ineffective, or worse yet, harmful to

their children. Jennifer speaks to the weight of this decision-making process as she recalls having selected to send her son to a public school where he was in a mainstream kindergarten class.

I felt like the year that he was in kindergarten when he was at Simpson, I felt like I was just throwing him to the wolves. That I was setting him up for failure. That he would just walk in there with the class of 24—they were all perfectly typical—and even his teacher told me that he would be on the playground talking to the swing as if the swing were Thomas [the Train] and all the other kids would just walk away [saying] “what is this weirdo doing over here?” But then, there is this whole other group [in the autism community] that says that he needs to be with typical children, that he needs to be learning . . . I’m not saying that I am going to keep him under a rock forever but for now, when he can’t speak out and doesn’t understand his disability, I would rather him stay at [a therapeutic school for special needs children] with kids like him.

Navigating a Divided Community

Jennifer’s struggle points to several themes that emerged across participants’ experiences. As a result of the prevalent divisions in the autism community, mothers carry an emotional burden of knowing that whatever treatment and educational avenues they undertake, their decision will necessarily be at odds with a significant share of practitioners and parents. For example, Jennifer’s prior quote references the conflicting perspective in the community on whether children with autism would be better benefitted by participation in inclusive, mainstream environments or settings that are uniquely designed to serve special needs children. In deciding to pull her son out of the public school that he was attending and enroll him in a special needs program, Jennifer continually confronts and provides a rationale for her decision to align with the latter perspective. The emotional weight of buying-in to a specific educational and/or treatment direction with limited outcomes-based research is exacerbated by the continual

presentation of alternative perspectives. That is, through the media, in interactions with other parents, and through contact with practitioners, mothers must constantly negotiate beliefs and perspectives that differ from that in which they are engaged. Constant confrontation with these alternative perspectives is likely responsible, in part, for the fact that mothers' descriptions of their children's treatments were nearly always offered in conjunction with rationales for the selected treatment.

As both Tennielle and Jennifer suggested, mothers' decision-making processes were complicated by the presently inconclusive and conflicting research regarding treatment approaches. The lack of longitudinal data concerning treatment outcomes in the field of autism plays out among parents and practitioners by fueling divisions regarding approaches to treatment. While most participants in this study eventually employed elements from a range of different treatment approaches, mothers' early decision-making was initially impacted by the divisive nature of the community. In fact, the majority of participants suggested that, in offering advice to mothers who are just beginning this journey, they suggest a different approach to researching possible treatments. Margo summarizes this perspective,

I would say not to do a lot of, I mean to do your reading, but not to spend hours and hours searching the internet. You know, googling everything and stressing yourself out with all of this conflicting material . . . It stressed me out. If I could go back three years and talk to myself, [I would say], "just try to take a deep breath . . . don't try to do everything right at once."

Reflecting retrospectively on that stress they endured in their efforts "to make really tough decisions with a limited amount of knowledge and a very short time frame" and "to do everything right at once," most participants echoed Margo's recommendation that

mothers of newly diagnosed children slow down, and “take a deep breath.” The consistency of this recommendation among participants in relation to their own actions points to the significance of this time period for mothers. Having to make emotion-laden decisions quickly, and in the face of ambiguity, upended and challenged the processes that mothers had historically employed in addressing significant decisions in their lives. Shifts in mothers’ information-seeking behaviors, such as having found trusted sources of information, may account for the reduction of stress that they had experienced since their early efforts. However, mothers’ descriptions of their past and current treatment efforts show that their treatment schedules have not significantly waned in intensity. As such, the pursuit and maintenance of ongoing, intense treatment efforts and the continuation of the sense of “hav[ing] to make really tough decisions with a limited amount of knowledge and a very short time frame” raises questions about how and why their current treatment efforts feel different than their early efforts.

“The Lens of Autism”

One participant provided an explanation by describing the process of “seeing the world through the lens of autism.” For the mothers in this study, the lens of autism was a meaning-making process that shapes maternal thinking and practice. It is a framework for interpreting and acting upon experiences that arise on a daily basis. This framework differs significantly from the perceptual processes that mothers employed prior to their experiences of raising children with autism in that autism becomes a distinct orienting context by which small and large experiences are interpreted.

For Margo, the lens of autism shapes many of her daily decisions.

I don't go out. I don't have "me" time. You certainly know how expensive these therapies are . . . Our playgroup has talked about having a *mom's night* . . . and going to [a restaurant] and having dinner and I think how expensive of a night that would be. A) I have to get a babysitter and then I've got to pay my check at [the restaurant]. That is probably going to be sixty dollars if I'm really cheap, and I'm thinking to myself, that's half a therapy session. So, I'm not as important. That's what I think and I don't do it. I just don't do it. I used to get my hair done . . . I used to always. I didn't even know my hair was brown until about two years ago. I cut it myself now. It was a fifty-dollar haircut. Those are days of the past. That's half a therapy session. Everything I do have this little mental image of, like, a calculator and therapy sessions.

In Margo's experience, one of the manifestations of the lens of autism is to assess all purchases, services and engagements in relation to the quantity of therapy that could be provided to her daughter. In this particular instance, the lens functions, in part, to situate Margo's well-being as inversely related to her daughter's potential progress. In other words, the less that Margo partakes in experiences that she once enjoyed, the more therapeutic opportunities she is creating for her daughter. Margo recognizes and justifies her meaning-making in her following explanation.

I don't think it will always be this way. I think there will be a time to get more of my life back. I hope so . . . as my daughter makes progress . . . if all goes well, you know, if we continue along making the progress each year that we've made.

Sacrificing the Present for the Hope of the Future

Margo's story demonstrates how the "lens of autism" and her shift in maternal meaning-making is embedded in the current context of autism. That is, the developmental theory of early intervention and the prevailing notion that more therapy equates with better outcomes has shaped Margo's perceptual processes in regards to both her everyday thinking and the larger perceptual construct of sacrificing the "now" for the hope of "later." This construct of present-day sacrifice is widespread in the autism community

and reflects a dilemma with which many parents struggle. In fact, the mantra of “giving up one’s childhood to therapy in order to gain a higher quality future” is often repeated among parents in autism communities of practice. A question posed by a parent to developmental experts on an online ABC health forum demonstrates this struggle. The parent asks, “Is it necessary to sacrifice my child’s enjoyment of his/her early childhood in the interest of obtaining sufficiently intensive intervention for autism?” (“ABC News/Health,” n.d.). For Margo, this construct has become a distinct orienting context that shapes the way she makes meaning of everyday experiences. Likewise, the sacrifices that Margo presently makes and her rationale in doing so speaks, again, to the experience of living liminality.

Maternal Responsibility

Evident in the prevailing constructs that shape the current context of autism, that is, the expectations of early intervention, the provision of extensive therapy hours at the costs of other endeavors, and the notion of sacrificing the present for the future, is the expectation of maternal responsibility. Because mothers historically and presently carry the bulk of the responsibility in caring for children with special needs, these embedded expectations of maternal responsibility manifest in distinctive maternal thinking and practice. Thus, it is unsurprising that mothers’ stories, like Margo’s, demonstrates the significant and unspoken psychological impact of these expectations including the sacrifices they make.

Relational Meaning-Making

For many mothers, the lens of autism was a framework for assessing and characterizing the roles of various relationships in their lives. As was noted in the previous chapter, two participants employed the term “character study” to describe the ways in which the lens of autism facilitated their re-evaluation of past relationships. As Laura stated,

It has been a very interesting journey, so to speak. Almost like a character study on so many levels. Just as far as you had no idea that people would react a certain way. You know, certain friends that you thought you knew so well, their immediate reaction or the things they say, or now even the things they will say in front of me.

For Laura, the lens of autism functioned to as a mechanism for reexamining and reframing her expectations of existing relationships in her life, and subsequently, the level to which she maintained involvement with these relationships. Likewise, Libby noted how the lens of autism framed the ways in which she approached social endeavors.

When I go to a place with people who don't have kids with autism, I always show up with my armor on and if I meet someone who gets it, then I may, maybe, let it down a little, depending on how much they get it . . . but most people don't get it.

For Libby, her “armor” was a protective mechanism employed to shield her from the potentially hurtful comments of people who don't understand the disorder of autism or the experience of raising a child who is affected by the disorder. The frequency with which she, and other mothers, encounter such circumstances impacts the development of preemptive mechanisms that shape her maternal practice in potentially psychologically harmful encounters. In other words, Libby's lens of autism functions as a psychological

resource that allows her to maintain involvement in certain social arenas in which she participated prior to having a child with autism.

For Libby, the lens of autism allows her to “show up” and to counter her strong inclination to disappear and self-isolate from mainstream contexts—a struggle that all mothers described in their interviews. This psychological resource helped mothers navigate a neurotypical world in which they are constantly confronted with reminders of their child’s difference and their divergent maternal experiences. As Folami succinctly stated, “I am constantly faced with how different I am. Constantly.” Mothers spoke, time and again, of the discomfort and desolation they experienced as a result of many of these “everyday reminders” and the disruptive nature of the critical gaze.

[It makes me feel] like an outcast, like a total outcast . . . I feel uncomfortable because I feel like everybody’s looking at me, like “that’s the mom with the weird kid” (Margo).

I feel like I’m such a people pleaser that it makes me uncomfortable to be different (Laura).

I’m not comfortable going to a big crowded [park] or playground, you know, with a bunch of neurotypical kids and having to educate [parents] or having to slink away embarrassed (Meredith).

I think that people in general, in the world, are very judgmental . . . I think it is the reaction you get from people seeing your child while out, wherever you are, [the children] are just all over the place. People are looking at you like you’re crazy. You’re like, “okay, I can’t do that again” (Kristen).

Daily Acts of Resistance

It is important to note that, unlike other childhood disorders, children with autism often do not appear physically different than typically developing children. As such, it is frequently the behaviors of children with autism that facilitate the experiences in which

mothers sense judgment and feel like “a total outcast.” Several of the mothers interviewed noted the uniqueness of autism in this regard in that poor behavior on the part of children is often perceived by general population as a result of poor parenting. And although their children’s odd behaviors in public locales are neurological in nature, mothers are constantly confronted with appraisals of their mothering.

Enacting Silence

Mothers stories of navigating a neurotypical world and negotiating constant reminders of their differentness points to several emergent themes in maternal thinking and practices in the context of raising children with autism. First, the uniqueness of autism—that is, that autism becomes “public” or visible to others through children’s behavioral manifestations—fuels a continual sense of necessary explanation among mothers that is undergirded by the “bad mother myth.” For the mothers interviewed, becoming visible as an autism mom in a neurotypical world is, itself, an act of resistance. Showing up in the public world and enacting silence in response to the critical gaze of others—that is, refusing to explain that their child’s behavior is the cause of a disorder and not poor parenting—is an act of resistance to a culture that perpetuates the bad mother myth. The following statement from Laura, speaks to this experience,

I think the biggest thing [that I would teach mothers who are starting this journey] would be just not to be concerned about the reaction that people give your kids. Like when people look at my kid sideways, I just look back at them like, “What?” I don’t care as much anymore. I think that depending on the kind of day I’m having, like if [my son] has been extra trying and then to get that kind of feedback from a stranger is more difficult and makes me want to say, “What the hell are you looking at?” I have those moments. I just don’t [say it].

“Showing Up”

Laura’s statement points to the second theme related to mothers’ experiences of navigating mainstream contexts, that is, the construct “showing up” and engaging in mainstream settings for mothers of children with autism is an evolving psychological process. As such, the mothers in this study “show up” to different extents. Furthermore, mothers appeared to vacillate in their daily acts of resistance, rather than employ a singular strategy. In this particular example, Laura enacted silence as resistance to an interaction in which she perceived maternal blame regarding her son’s behavior. Yet, at other times, as Laura explained, she will “educate parents about autism.” Laura noted that she was more likely to educate others as opposed to enacting silence when she perceived “genuine interest” rather than judgment on the part of those present.

Voice

As such, the third theme that emerged in regard to mothers experiences of navigating neurotypical contexts are the ways in which the psychological process of “showing up” is interwoven with voice. Meredith describes the shift that she experienced with regard to this process,

For me, it was a matter of time until I became comfortable with it. Once I got to the point where I felt like I was accepting it more, everything got better. For me, when I got to the point where I could talk about it without crying, I felt more confident about what his issues were. I’m not one to be confrontational with other people but I also feel like I’m a little bit more ballsy to speak up where I was never that kind of person.

Here, Meredith’s story shows how her ability to adaptively navigate mainstream contexts and her use of voice are behavioral expressions of, and a window into, her meaning-making and acceptance processes.

Tennielle's story echoes Meredith's in that it demonstrates shifts from self-isolation toward outward engagement, and from a self-imposed silence toward a direct expression of voice.

I think the isolation is the most difficult part. I think to really tap into and find what you think is available [during the diagnosis period], just other people that are going through the same thing so that you have that support system . . . and not allow a diagnosis to just become your existence completely . . . My biggest advice would be to talk to people. I think that the thing I tell my husband and I realized is that I don't mind talking to folks. I just don't care. He's more guarded, but I have met some of the most amazing people just because I don't care anymore what people think about [my son] being autistic. I don't mind people asking me questions about it. I have learned how strong I am . . . I'm not afraid of anything. I realize now how much fear keeps people, I almost feel like it's some type of bondage. You know, you don't try things. You don't go places. You don't do things because you're afraid of how you'll be perceived. I don't give a shit right now. I like that. That's probably my favorite thing, that I just don't care. Like, whatever.

The theme of voice as a resistance strategy that mothers employed to counter isolation and likewise, voice as a reflection of coping arose in all interviews. However, mothers' appeared to employ voice differentially. For some mothers, like Tennielle, a shift from self-imposed silence to voice appears to parallel an overall shift in active meaning-making and adaptive coping. Other mothers, like Laura, vacillate between selective use of voice and silence as psychological resources that aid in their ability to navigate mainstream contexts. Discrepancies in participants' use of voice suggests that mothers could be at distinct points in a larger meaning-making and coping process and/or that voice is employed in various ways for each mother.

“The Only Parent on the Playground”: Extreme Mothering

An interesting element that characterized the themes of voice and silence, and self-isolation and “showing up,” is the extremity with which these constructs were

employed. That is, mothers' stories of engaging these processes point to a hyper-use of these psychological constructs. Gina, for example, shared the following insight,

A point that I haven't really talked about with anybody is that you're not just a parent to your own child but that you have to educate everyone else, even strangers. You're always the only parent on the playground. I feel like every [child] in the pool would drown if I wasn't there because [all the other mothers] are sitting over there reading their magazines. They've got their "People" magazine up over their faces. Half of them have a cooler on a random Tuesday. And I'm not saying, trust me, I've been there but seriously, just look up occasionally. And if you hear [your kids] screaming, it is going to be because I am yelling at them.

Here Gina speaks to the common experience of having to be hyper-engaged in mainstream contexts. The phrase, "the only parent on the playground" was the exact statement that several mothers used to describe the experience of extreme mothering that was required of them as they navigated mainstream contexts with a special needs child. Mothers discuss the rare experience of being able to engage only partially in typical settings, like visiting a pool and simultaneously reading a magazine. Rather, participants spoke of how ensuring their children's well-being in public settings necessitated the engagement of a ceaseless, extended motherhood. Most commonly, these extended maternal practices include educating other parents and children, parenting and disciplining other people's children, and playing with and engaging other children alongside their own child.

Linked Lives

The construct of voice again becomes significantly apparent in regards to mothers' practices of extreme engagement in public settings. In these instances, mothers go beyond facilitating shared play for their children, and engage the process of making

evident and enacting their child's voice. Mothers' experiences of acting as their children's voice in social contexts—of literally speaking for them and representing their children's perspectives, perceptions, and opinions—is unique to the context of autism in that the disorder affects three crucial areas of children's development: verbal and nonverbal communication, social interaction, and creative or imaginative play. These developmental challenges and the various ways they manifest in different children facilitate, for mothers, unique and individual pathways of voice. These processes are, in part, shaped by each mothers' unique experience with the maternal practice of extreme mothering. Together, these constructs point to one of the most distinctive features of mother's meaning-making processes: linked lives. The experience of raising a child with autism in the current sociohistorical context, has manifested in an integration of relationship between mothers and their children with autism and, as such, offers a distinct orienting context that mothers employ in making meaning of and navigating the world at large. Here, Margo describes to the extent and nature of her linkage with her daughter,

When I talk to moms, you know, friends of mine with [typical] kids and I hear what they talk about. It's sometimes really frustrating to me. You know, they're going on about karate class and all their competitive sports and I just can't identify with that. I think it's shallow and I think the development of this, just the blessing of this . . . that a lot of these typical families, they don't really [get it]. They transport their children to soccer and this and that, but they are not really involved in their lives. For me, going through this process with Megan, I know every inch of her mind inside and out. It's true, it really is. Her and I have the most incredible bond because of this process. And when I talk to my friends with the typical kids, I don't hear that bond. I hear that their priorities are getting to school, getting to the sports and all this and my priorities are in the relationships with my child.

Alison shares a similar experience,

I know my child extremely well for someone who couldn't communicate until he was three. People are amazed about how well I understand how this kid works. I understand this kid . . . I get it. I get his fear of crowds. I hate all those people too. There is just so much stuff that I get. That is surprising certainly as far as that there.

Laura, too, echoes this sentiment,

It really is an incredible journey and I don't really have an opportunity to talk about it . . . about some of the great blessings. There are some tremendous blessings that, you know, [on] day one when I heard the word autism in that first year, I never would have guessed [that there would be such blessings]. I wouldn't have told myself that there are a lot of wonderful things that are going to come out of this, you know? We are so close. I mean, I'll be in the kitchen doing something, thinking about something and he will be at the table and he'll say what I'm thinking. I'm like "whoa." And not just one random time, it happens a couple of times a week. . . . We're just so connected and I just don't think I would have been [had it not been for the autism]. I think I would have been one of those typical moms. It just brings out the best of you. I think in most cases, in my case and in the case of most of the [autism moms] that I have met, it has really brought out the absolute best.

Mindfulness

Margo and Laura's description of this "bond" are similar to other mothers' descriptions of their interconnectedness with their child with autism in several ways. First, mothers described how the relationship with their autistic child differs from the relationships that they observe in typical families and even how it differs from their relationship with their own neurotypical children. Furthermore, mothers described how the integration of the relationship extended to involve the integration of norms and systems. That is, the experience of linked lives extends beyond the nature of the relationship to shape mother's meaning-making processes and provide a distinct orienting context for negotiating the world. In mothers' stories of how their bond with their child

has shaped their worldview, the themes of mindfulness and presence continually emerged. Folami's story makes evident this mindfulness in her story of linked lives,

Now I just cherish the relationship, just the one-on-one engagement, just spending time together and talking about emotions and feelings and trying to communicate. It's not at all about how many piece puzzles he can put together because I have some need to go tell my friends on the playground that he can do a 100-piece puzzle when your kid can only do a 48-piece puzzle. It's more about the quality of our relationship and it's not so much about getting from point A to point B. We are not trying to get to these milestone steps. We are enjoying the moment.

Like Folami, mothers frequently described an overall shift in their perceptive orientation that re-centered their attention to the present experience. In other words, mothers' interdependence with their children with autism facilitated a disruptive new awareness, that is, a psychological quality that involves nonlaborative, present-centered awareness. This bond that is linked lives is iterative and bidirectional whereby the ongoing integration of the relationship continuously fuels mindfulness, and likewise, this mindfulness makes evident the blessings that, without a present-centered lens, mothers would not have been aware. Hence, the blessings that are made evident through the process of mindfulness, in turn, facilitates a deeper bond. This bidirectional process is shaped by the context of liminality that characterizes the current sociohistorical climate of raising a child with autism, and likewise, becomes a distinct orienting context for making meaning of and navigating one's intrapersonal and interpersonal experiences.

Worldview Shifts

Enabling Development

Evidence of this evolving process—a maternal metamorphosis whereby one finds that present-centered awareness provides stability in relation to a life in flux—is apparent

in regards to concept of enabling development. participants' stories of their maternal journey evidenced a process whereby mothers began to make meaning of their child's development through a lens of enabling development as opposed to a lens of engendering independence. That is, mothers recognized how they were once focused on the attainment of developmental milestones with the overarching objective of fostering independence in their children. Over time, mothers experienced a shift in maternal thinking and practice where they reframed their goals and expectations with regard to developmental outcomes and as such, began to operate within an enabling development orientation. By engaging an enabling development perspective, mothers were able to experience profound joy in their children's developmental gains in conjunction with the significant efforts that undergirded the attainment of these gains. In reconstructing their maternal thinking and practice regarding child development, mothers resisted a westernized framework of child development that situates their children as developmentally deficient in relation to neurotypical children. Folami's above statement captures the very essence of this perspective,

It's not at all about how many piece puzzles he can put together because I have some need to go tell my friends on the playground that he can do an 100-piece puzzle when your kid can only do a 48-piece puzzle.

Kristen's story, likewise, demonstrates the intersection of mindfulness and enabling development,

He can talk now, thank God. He talks non-stop, as a matter of fact, which is like "yay." I told my husband that we can never really get upset because he won't shut-up. We spent years and lots of money trying to get him to talk and now he's a chatterbox. I am just so grateful.

Folami and Kristen's statements show how mindfulness, as it interacts with an enabling development perspective, allows mothers to experience the hard-won blessings of their children's development as independent from normative developmental markers that continuously situate their children as lacking. Viewing development in this way further fuels a present-centered orientation in that the focus rests on finding enjoyment in the present achievements—in, as Laura states, “appreciating the little things.” As such, the interaction of mindfulness and an enabling development orientation are cyclical and self-propagating. These orienting contexts are both an outcome of the experience of living liminality as well as a psychological resource for negotiating the maternal journey of raising a child with special needs. The intersection of these distinct orienting contexts elucidates the connection, for participants in this study, between their personal worldview shifts and the abandonment of mainstream ideologies. In this case, employing an enabling development orientation challenges mainstream developmental ideologies that situate the engendering of independence as the ultimate objective.

Self-Knowledge

For the participants in this study, the theme of worldview shifts in relation to one's resistance of mainstream ideologies extended beyond the engagement of an enabling development lens. Mothers' interviews also demonstrated a perceptual shift with regard to an increased reliance on self-knowledge. That is, mothers spoke of an increased trust and confidence in their maternal intuition. Whereas early in their children's lives and during the period of diagnosis, mothers were apt to rely on the perspectives and opinions of perceived experts and authority figures including doctors, therapists and

educators, as their stories continued toward the present day, mothers spoke more and more frequently of employing an internal compass to guide treatment and educational decisions. Jennifer, for example, decided that despite receiving advice from practitioners that she seek an inclusion-based private school for her son, she would “rather [her son] stay at [the special needs] academy with kids just like him forever.”

For Laura, a greater reliance on her self-knowledge and maternal intuition was illustrated when she her son received an evaluation through a state agency for children with developmental delays and disabilities. As Laura described, the woman who conducted the evaluation said,

Well, we’ll take all this information and we’ll bring it to a panel and they will decide [how to proceed]. And I said, “No, no one else will decide what happens with him. I will decide that. So this ain’t gonna work for us. And then you want to be the people that actually decide his future? I don’t think so.”

Prior to this point in time, Laura had relied on the viewpoints of practitioners to guide her decision-making. However, as her statement illustrates, Laura began to make treatment decisions based on her knowledge of her child and her maternal intuition over time. In doing so, Laura resisted the mainstream ideology that situates medical and therapeutic professionals as the ultimate authorities and experts on delineating the most efficacious treatment. Laura’s story makes clear how the concepts of linked lives and mindfulness undergird a shift toward increased confidence in self-knowledge and maternal intuition. That is, Laura described in her interview how her relationship with her son was one that had developed in such a way that she garnered great pleasure in the small moments and that she had abandoned external expectations of her child’s development. As described previously, attending to the moment and engaging mindfulness appeared to facilitate

linked lives and vice versa. Thus, Laura's distinct linkage with her son shaped her knowledge of his needs and her confidence in guiding his care.

Meredith's story also demonstrated a worldview shift in which she began to trust and apply her own self-knowledge over time through her maternal thinking and practice.

For me, things started to improve over time when I got comfortable with it. Once I got to the point where I felt like I was accepting it more, everything got better. Just time. Truly time. For me, when I got to the point where I could talk about it without crying, things got better. I felt more confident about what his issues are and how I could help him. I'm not one to be confrontational with other people but I also feel like I'm a little more ballsy to speak up where I was never that kind of person and to advocate for him.

Margo's story elucidates how her perceptual shift was correlated with the concept of voice. Being able to express her maternal reality was a barometer of her acceptance of her son's health issues as well her increasing confidence in her knowledge regarding her son's needs and her ability to guide his care.

Privilege

Participants' stories make clear how their maternal realities were displaced by autism. In navigating the dislocation of their realities and adapting to a maternal journey that is embedded in liminality, mothers developed distinct orienting contexts that facilitated worldview shifts and a rejection of certain elements of the dominant cultural discourse. For three of the mothers in this study, this disruptive new awareness was extended to affect a direct confrontation with the roles of entitlement and privilege in their lives. Tennielle summarizes this awareness,

This experience has probably required more of me than I thought I had. I do know that. I don't think I knew how strong I was or how capable I was. I don't know. I never in a million years would have thought that I would be on the other side of something so difficult and devastating. I could say that it has been the hardest

thing I've ever been through but I don't know. I don't know what the future holds. Nothing is a given, nothing is guaranteed and now I see that.

For Tennielle, the experience of raising a child with autism provided her with a lens for examining and reframing her understanding of privilege. Through this process, Tennielle came to recognize that she had led a life of privilege and in doing so, reframed her understanding that she was not entitled to a typical maternal journey. Tennielle's perceptual shifts disrupted the invisibility of privilege in her life, facilitating a confrontation of many assumptions of reality. In negotiating these assumptions and abandoning the underlying dominant ideologies, Tennielle began to rewrite a subjectivity that is liberated from narrow and restrictive norms, standards and expectations. Tennielle continued,

I'm like a whole different person now. It's so crazy. I look in the mirror and I'm like, "okay." Completely different. This [experience] did it, it changed everything. It changed our whole life. It changed me. I'm like somebody else. It's so strange. Benjii has brought so much light. Just in the ways I needed to grow. I'm sure [my husband] feels the same way. It's been difficult but I wouldn't undo a thing. Not one piece of it. I love it. Even in financial struggles it taught us how much more we could do without as much as we had . . . I think had this not happened, I think earlier before we were married, I was on such a chase to achieve and become. Now, I don't give a shit. People are like, "Oh, you're a lawyer." I don't care. It's the last thing on my mind. It's different now.

Tennielle's story speaks to the widespread impact of the perceptual shifts in her life. Furthermore, in reframing her discerning interpretations of her maternal experience, she rewrites her subjectivity. Through a maternal metamorphosis that was framed by the light of her son, Tennielle experienced liberation from the confines of externally imposed ideologies. "I like how strong I am," she says.

I'm good with that. I'm not afraid of anything. I realize how much fear I had and I realize how much fear keeps people. I almost feel like it's some type of bondage.

You know, you don't try things. You don't go places. You don't do things because you're afraid how you will be perceived or whether you'll be successful. People tell me that when you get to [age] 50, you get to this point where you don't give a shit anymore. Well, I'm there. I don't give a shit right now. I like it. I like that. That's probably my favorite thing . . . the best part of this.

In reconceptualizing her subjectivity, she simultaneously rewrites the self-in-representation with her son that is linked lives. Tennielle describes her child as the giver of the blessings, the facilitator of the transformation, the "light." In elevating her son to the giver of profound, existential gifts, Tennielle resists the deficit-oriented discourse that situates children with special needs as defective and lacking.

Folami tells a similar story of privilege and transformation.

When you are born, you have parents and they get you to a certain point. They put certain dreams and drive into you and that what you go for. I just woke up one day and I was here, and this is where I was. I had done all these things and it's interesting too that you do all of those things. You do everything that you're supposed to do and it's still not enough to keep you from having to go through something like this. You know it's funny, I was riding down the street the other day and I saw a man. He was very handsome. You know, but he was driving the most beat-up car I've ever seen in my life. I was sitting there thinking, just from where I grew up, I wouldn't have ever looked twice at him. I don't know another way to put that. The car alone would have just made me keep looking the other way. Now, it occurred to me how difficult it is to actually move up in, I guess, in the class from where you're born . . . It dawned on me then, you just have certain things in your life from where you've come from, not because of the things you've done.

Maternal Subjectivity

Like Tennielle, Folami's journey of hardship, struggle and adjustment proffered a lens for examining the role of privilege in her life. As her story continued, Folami highlighted the connection between the awareness of privilege in her life, her worldview transformations, and the reconceptualization of herself as a mother.

I am a firm, firm, firm, firm believer that everything that happens to anybody happens for a reason and I think that, ultimately, all the things that have happened to us, I almost feel like we are blessed. I think that in having [my son] and going through all these things made me a better person and a better mother. It has made me more patient. It has made me not so quick to judge other people. It has made me more tolerant of people. It has made me more sensitive to the fact that everybody is different. It has just really made me a better person. I feel like I've benefitted so much from it. I really do. I notice it everyday. On my job, where I deal with some really difficult people and it requires the patience of Job, which I did not have before now. It has just been a real tremendous blessing.

Transformative Motherhood as Ideology

Folami's story elucidates how her intrapersonal transformation extended beyond a shift in perceptual processes to impact behavioral changes across many contexts. The mothers who spoke of how their journey in raising a child with autism facilitated a disruptive awareness of privilege in their lives echoed Folami's statement, noting that this awareness affected change in all realms. Through this process, mothers noted how they approached all relationships and interactions with greater patience, compassion, and acceptance. "The biggest changes for me," says Laura,

The biggest area is that I have compassion for other people and their shortcomings, or I don't look at everything as shortcomings. I just feel like, I look at, I treat people now how I want people to look at and treat my child. We are all different and that's cool. I want people to treat my son like that. Now I look at other people that way.

Here, Laura demonstrates how in reframing her discerning interpretations of her maternal experience, she reconceptualized motherhood as an ideology. Motherhood, for Laura, is not defined exclusively in relation to her maternal thinking and practice within the context of her relationship with her child. Rather, Laura extends a grace to others that she hopes the world will extend to her son. In doing so, Laura's extends her maternal thinking and practice to incorporate her relationship with the world at large.

Like Laura, Meredith extended her maternal transformation in a similar way. In her interview she asked, “How can you love someone who is imperfect because they are your child and not love other people who are also not perfect?” For Meredith, like many mothers interviewed, motherhood is not confined to the relationship with her child. Rather, motherhood as an ideology was reappraised to incorporate the extension of compassion and caring to all contexts.

While not all participants spoke directly of a confrontation with privilege in their lives, all mothers spoke of how the experience of perceptual transformations affected change with regard maternal subjectivity. The following passages illustrate how the experience of raising a child with autism can facilitate a reappraisal of one’s maternal subject position. This theme is best illustrated by the words of the participants themselves. Here Margo, Meredith, Jennifer, Libby and Folami elucidate how the labyrinth that is their maternal journey has opened up the possibility for a transformed subjectivity by offering an alternative lens for ascribing meaning to their experiences.

I am absolutely certain that I am a good mother. Are you hearing that? I am 100% certain. I think I’m a pretty darn good mom. I’m not sure that I have a lot of talents in other areas. I’m not artistic. There are lots of things that I don’t really have a natural aptitude for, but I think a large part, because of this journey we’ve gone through, I’ve developed into a pretty darn good mom. I am happy about where I am . . . In the grand scheme of things, I think I’m a much better mother and when I look back to that first year and a half before diagnosis, I think I was a rotten mother. It certainly is a pathway. I look back at myself prior to [this journey] and the diagnosis and all that and I can’t even identify with her. This journey has changed me entirely. I am an entirely different person with entirely new priorities in life (Margo).

I’ve come to the conclusion that I was probably made for this journey and that it was my destiny . . . I honestly feel like my kids and my life and my situation, all of this, has just been tailor-made for me. I don’t know that there’s any part of it

that's missing. I just feel like it was all what it was meant to be. I really do (Meredith).

Everything is different now, the way I look at things. My reaction is completely different now. Even the way that I size people up because when I meet someone, it's interesting, I see straight through them almost. It's like I see more depth than I used to . . . I see there's more there. It's so different. I don't know. It's just really that different. I really just feel like a whole different person (Jennifer).

I think I'm a terrific mom, I think I'm just a really good advocate for my child and I'm doing the absolute best job that could possibly do under these circumstances. It's just a very unselfish love and I think is the best. I'm the best me. [My child] brings out the best me that I could possibly be (Libby).

It really is an incredible journey . . . some of the greatest blessings. There are some tremendous blessings that, you know, day one when I heard the autism word in the first year, I would never have guesses. If I could go back and tell myself back then something that I know right now, I would tell myself that there are a lot of wonderful things that are going to come out of this. It just brings out the best of you. It just has to (Folami).

For the mothers in this study, the experience of raising a child with autism facilitated a disruptive awareness of their subject positions as they are embedded in dominant cultural discourses. Through the maternal journey that is “autism mom,” mothers spoke of how a transformed subjectivity was called forth from the storyline of linked lives with a child with autism.

This investigation demonstrates that the experience of raising a child with autism can facilitate a reconstructed subjectivity. This reconceptualization, in turn, appears to facilitate the rewriting of mothers' storylines. Through their journeys thus far, a dynamic, in-process subjectivity emerged. In that one's storyline is embedded in sociohistorical contexts, the rewriting of mothers' subjectivities was linked to a reappraisal of elements of the dominant cultural discourse that were inapplicable to their stories. Participants demonstrated how raising a child with autism made apparent the inapplicability of certain

cultural constructs. As mothers came to learn that the ambiguity of raising a child with autism was unceasing, and as the inconstancy was maintained as the only constant, liminality emerged as a defining feature of participants' maternal journeys. In taking up the position of liminality, participants adopted distinct orienting contexts. From this vantage point, mothers begin to identify, deconstruct and reconstruct inapplicable and unattainable social structures and practices. Mothers' stories illustrated how, as the focus shifted from functioning within the dominant discourse, they began to articulate a different maternal journey—a journey in which new meaning was ascribed to motherhood and the conceptual repertoire and location of subjectivity was rewritten. As these final passages illustrate, mothers came to recognize themselves as belonging, psychologically and emotionally, to that position by adopting a worldview that is commensurate with the transformed subjectivity.

CHAPTER VI: DISCUSSION

Summary

Research shows that mothers do the bulk of the parenting work in raising children with special needs, including autism. Despite the prevalence of the disorder, a dearth of literature considers, as central, the maternal experience in raising a child with special needs. This qualitative study focused on the disorder of autism with the objective of elucidating how the context of autism shapes maternal meaning-making and subjectivity. Additionally, this study examined how mothers of children with autism reconstructed their meanings of motherhood as a result of their maternal experiences.

This study addressed the following research questions:

1. How do mothers make meaning of their experiences of raising a child or children with autism?
2. How does mothering a child or children with autism impact maternal subjectivity?
3. How do mothers construct or reconstruct motherhood in the context of raising a child with autism?

Results showed that the experiences of raising a child in the current sociohistorical context of autism give rise to distinct maternal practices and perceptual processes that, over time, shape a dynamic, in-process maternal subjectivity. More specifically, the context of autism is shaped by the experience of liminality, that is, the experience of existing between conditions that is characterized by the dislocation of established contexts, structures and systems and ongoing uncertainty regarding the future.

For the subjects involved in this study, the experience of living liminality facilitated the development of distinct orienting contexts for making-meaning and navigating intrapersonal and interpersonal experiences that, in turn, manifested in a reappraisal and reconstruction of maternal subjectivity.

This study reaffirms life course theory as a critical framework for examining human development in that the findings point to the importance of considering the role of the physical body as it relates to psychosocial development. So often the experience of the body remains absent from studies that focus on the development of the mind. This study demonstrates the inseparable impact of the mind and body, both on the individual and on his or her relational systems. In this case, autism shapes the development of the diagnosed individual as well as the development and subjectivity of the primary caregiver. In this regard, the current study supports the notion of examining development within the context of linked lives by evidencing the ways that mind and body are linked intrapersonally and interpersonally, as in the case of mothers and children with autism.

This study also speaks to the relevance of feminist theory as a framework for making meaning of the ways that childhood disability impacts the development of caregivers. The findings of this study support the notion that the salience of autism, by way of its impact on mothers, is contextual and socially constructed. That is, the experience of mothering a child within the current sociocultural context of autism highlights how the dominant discourse of engendering independence, the expertise that is attributed to the medical and therapeutic community of professionals, and the invisibility of privilege shapes mothers meaning making, resistance and eventual reconceptualization

of such constructs in their journey of raising a child with autism. As such, this study reaffirms the necessity of critically examining the stereotyped beliefs, cultural proscriptions and the ways that these constructs shape how mothers act, think and feel. The resistance strategies that mothers in this study employed as they navigated mainstream settings supports the feminist notion that occupying a subordinate position in the system of ability does not necessarily mean that one lacks psychosocial resources. Rather, occupying such positions can facilitate psychosocial resources like mothers' use of voice and silence, showing up, and mindfulness to promote intrapersonal journeys toward well-being. Mothers' accounts, and particularly the strengths, resistance strategies and intrapersonal resources they exhibited in the face of ongoing ambiguity, challenges deficit-oriented perspectives that frame mothers of children with disabilities as weak human beings who are passively accepting and even deserving of their situation.

Limitations

A few limitations of this study should be taken into account when considering the utility of the findings presented. First, the sample consisted on only 15 subjects. The small sample size does not reflect a representative distribution of the population of mothers of children with autism and therefore, descriptive and inferential conclusions cannot be drawn with regard to a larger population. While the results cannot be transferred to the population of mothers of children with autism on a wider scale, the objective of this investigation was to develop a theory about mothers' making-meaning of their journey in raising a special needs child. As such, it is hoped that the theory that raising a child with autism can significantly impact a transformation of maternal

subjectivity can provide a starting point for future research on this increasingly widespread experience.

The small sample size and the snowball sampling techniques employed in this exploratory study also impacted the demographic homogeneity of the research sample. Although specific data on race/ethnicity and socioeconomic status was not collected, the majority of the participants were Caucasian and African American, heterosexual, highly educated, and of a middle-class background. Moreover, all participants resided in the metropolitan Atlanta area. With a more ethnically, culturally, socioeconomically and regionally diverse sample, results may have varied.

This study is also limited by a lack of explicit attention to the sociocultural location in which subjects' stories are embedded. A more explicit analysis of the context in which this study is situated would have further explicated the ways in which mothers' experiences and meaning-which these contextual elements shape mothers' experiences. For example, an exploration of the types of services and resources that are available in the metro-Atlanta area would have helped to further flesh out mothers' experiences and interpretive processes. Likewise, a more explicit examination of this context would have provided a foundational understanding of why, as future research is undertaken on this topic, mothers' experiences of raising children with autism in different places and times may vary.

Another limitation that must be noted is that data was collected at only one point in time in subjects' lives. The development of one's subjectivity in relation to maternal meaning-making is an ongoing process and great insight could be gained from

investigating the phenomena presented in this study over a longer course of time.

Therefore, this study was limited in that it examined longitudinal psychological processes through a single point of data collection.

The lack of prior research studies on the topic of maternal subjectivity in the context of raising children with special needs presents another limitation to this study. In that very little scholarship exists on this topic, the foundation for understanding the research problem investigated presents a limitation. However, this limitation also provides the rationale for employing an exploratory, rather than explanatory research design.

The nature of the self-report data also raises certain limitations. It must be noted that while mothers' reflections of their experiences were likely accurate, the self-reported data gathered in this study contains several potential sources of bias that must be noted as limitations. First, it is possible that mothers may have employed selective memory in their descriptions of their experiences. Remembering or not remembering experiences and events that occurred at some point in their maternal journey is probable in light of the extreme emotionality that various events, like diagnosis, may have elicited in mothers of children with autism. Also, the possibility of telescoping may be a limitation in this study in that mothers may not have accurately recalled the time that certain events and experiences occurred in the course of their motherhood. Because mothers were interviewed about events and related interpretive process that occurred over extended periods of time in their motherhood, the limitation of telescoping must be considered in relation to the findings presented.

My role as a participant observer in data collection process raised several specific issues that likely shaped the direction of this investigation. Overall, my experience as a mother to a child with autism appeared to make subjects more comfortable in sharing their stories and discussing the nuanced landscape of their journeys. Likewise, mothers did not have to spend significant time providing descriptions of various local agencies, programs and treatment methodologies in framing the background of their stories. Because of my familiarity with these resources, mothers were able to spend more of the interview time discussing their specific experiences. Conversely, due to the nature of the divided autism community and the criticism that mothers have often received in selecting treatment approaches, subjects occasionally appeared hesitant in discussing the specific treatments they utilized. When hesitancy was noted, I attempted to allay mothers concerns of reproach by sharing my belief that each child is an individual and, as such, different treatment approaches will be effective for different children. Also due to my role as a participant observer was the experience of being asked my opinions, perspectives and feelings regarding certain issues that arose in the course of the interviews. These situations were navigated by the explanation that I wanted to ensure that it was the subjects' perspectives that shaped the interview and not the researchers. I informed all participants that I would be happy to meet with them at a future time to engage in a dialogue about specific treatments protocols.

In terms of data, challenges arose in regards to the most effective use of support group data in the larger analysis. Data collected from the various support groups were incorporated into the larger analysis through an examination of the ways in which they

supported or challenged emerging themes. However, the format of the support groups and the data that emerged from these sessions were difficult to meld with mothers' interview accounts in that statements made during support groups were not situated in larger storylines. Because this investigation focused on mothers' processes, mothers' brief statements in support groups were not situated in the more comprehensive contextual framework of their maternal journey and likewise, the format of the groups did not lend itself to the researcher seeking clarification from the subjects. This study, therefore, is limited by the fact support group data could have been used to a fuller extent.

Implications

The results of this study have important implications for organizations, programs, practitioners and educators who serve families affected by autism as well as for mothers, families and children impacted by the disorder.

Mothers' interviews demonstrated that the time period surrounding their child's diagnosis was the lowest point of their emotional journey. Asked retrospectively how this difficult period could have been made easier, mothers consistently spoke to the need for greater social support. Specifically, mothers pointed to the critical need for mothers of newly diagnosed children to connect with other mothers who have already navigated the diagnosis period. Mothers' need for support and guidance from people who understand what they are experiencing points to a greater need for resources that puts parents at different points in similar situations in contact with one another. This finding has implications for programs and organizations that serve families impacted by autism in that services like parent-to-parent networks, parent-as-coach programs, websites that

delineate local resources and allow parents to rate these services, and parent-led informational seminars and support groups can offer critical help during this difficult time period.

Likewise, because subjects consistently spoke of self-isolation as a result of experiencing “everyday reminders” and the critical gaze of others, organizations and programs that serve families with autism could expand educational programs to reach out to community members in addition to the services they provide directly to families of children with autism.

The results of this study also have implications for treatment approaches and protocols presented to families by medical, therapeutic and educational professionals. Mothers’ stories made evident that the therapeutic and educational guidance they received rarely considered the impact of such treatments on their well-being. For example, the expectation that children with autism receive 40 hours of direct, one-on-one therapy per week in combination with the suggestion that mothers act as their children’s therapist, places an enormous burden of responsibility on mothers who commonly carry the bulk of the caretaking responsibilities in special needs families. In that mothers’ well-being directly impacts children’s well-being, treatment protocols can be improved by considering, as central, the family system. Likewise, family centered treatment has the potential to make evident and shift the unequal distribution of direct caretaking responsibilities between mothers of children with autism and their husbands and to positively impact the stress that arose from the uneven burden of responsibility by appointing essential roles for each family member.

The findings presented in this study suggest that the process of trusting and employing self-knowledge with regard to their children's treatment was closely aligned with adaptive coping and acceptance of their child's disability for mothers of children with autism. However, subject's interviews made evident that certain factors may impede reliance on this psychological resource. Mothers' accounts of early treatment seeking behavior supports research that shows that mothers' concerns regarding their children's atypical developmental trajectory early in life are often dismissed. Failure to acknowledge mothers' knowledge regarding their children's health may contribute to maternal self-doubt regarding their children's needs.

Also, the experience of having to navigate a divided community with regard to conflicting treatment approaches while acting as researchers, case managers and treatment providers for their children could further impede mothers' reliance on self-knowledge. These findings suggest that programs and practitioners that serve children on the spectrum attempt to solicit and incorporate mothers' knowledge of their children into treatment protocols. As is suggested by the results of this investigation, the solicitation and acknowledgement of mothers' voices and self-knowledge regarding their children's needs and care has the potential to positively impact maternal and child well-being.

Findings with regard to mothers acting as researchers, case managers and treatment providers and having to navigate a divided autism community points to another important implication of this study for therapists, educators and medical professionals who serve families of children with autism. Mothers' accounts suggest that the alignment and provision of transdisciplinary resources including assessments, occupational therapy,

speech therapy, occupational therapy, physical therapy, behavioral treatment options and medical services could greatly benefit mothers in terms of reducing the vast psychological resources that mothers employ in guiding their children's treatment. Likewise, the provision of transdisciplinary knowledge can bolster mothers' confidence in their self-knowledge—a construct that, again, appears to correlate with adaptive coping and maternal well-being.

Finally, the findings with regard to the meaning that mothers ascribe to their motherhood and the ways in which they rewrite the cultural repertoire and location of their subjectivity speaks to the many strengths that can be leveraged by treatment providers in the field of autism. Mothers' stories elucidate a disparity between mothers' discerning interpretations of their experience raising children with autism and the ways in which the current research, assessment tools, treatment methodologies and therapeutic protocols are framed. That is, while mothers appear to harness and employ a vast array of psychological strengths in their maternal journey, much of the context of autism is embedded in a deficit-oriented framework. These findings suggest that the use of strengths-based treatment perspectives and methodologies that recognize and situate, as central, the assets of mothers, children and families could be indicative of improved outcomes for everyone affected by autism.

Recommendations for Future Research

The findings presented in this study are an initial contribution to the field of psychology's knowledge-base regarding mothers' experiences raising children with autism. The findings presented in this study can serve as useful starting points for future

researchers to explore in greater detail the nuances of each of the interpretive processes employed by mothers make-meaning of their maternal experience. For example, the landscape of each of the perceptual shifts evidenced by mothers, including mindfulness, a confrontation with privilege and the employment of an enabling development orientation, could be explored in greater detail. Likewise, a research design that employed a larger sample and/or multiple data collection points would likely reveal a wider repertoire of perceptual shifts and how these processes transform over time. Similarly, the inclusion of a more diverse sample would reveal interesting patterns of maternal thinking and practice as they related to and are embedded in various culturally bound sociohistorical contexts. Other variations of this basic research design, such as longitudinal analyses, could help map the relationships between various sociohistorical contexts, mothers' experiences of living liminality as they relate to these contexts, mothers' discerning interpretations of their experiences, and the ways that these varied processes are intertwined with subjectivity, maternal practice and other behavioral outcomes.

As was discussed in the literature review, very little research exists that focuses explicitly on the experiences of mothers who raise special needs children. It is important to note the even less research exists on the experiences of fathers and other members of the family system. Explorations of meaning-making, coping and subjectivity among fathers, partners, grandparents and siblings would flesh out unique patterns and processes and the ways they contribute to special needs family systems.

Much of the research that has explored parent's experiences of raising special needs children has grouped together families of children with various disabilities. The

findings from this study demonstrate that unique meaning-making pathways and outcomes exist as they relate to the context of autism. As such, the field would benefit from research that explores intergroup differences in parents' perceptual and behavioral processes as they relate to different disabilities.

Finally, the findings of this study have yielded several important research questions related to maternal subjectivity that warrant further investigation. First, mothers' experience of acting as their child's voice may be one of the most unique features of raising a child in the context of autism. Additional research with regard to this psychological process and how it relates to the construct of linked lives may be a window into the mother-child relationship and provide important insight into maternal subjectivity in the context of autism.

Also of interest is the juxtaposition between mothers' experiences of living in the ongoing state of flux that characterizes their realities and yet, simultaneously carrying out concrete and well-defined research, case management and treatment endeavors. A deeper investigation of this juxtaposition as it is delineated in this study as well as transdisciplinary research on other experiences in which individuals' lives are framed by states of liminality or similar experiences, like double-consciousness, could illuminate patterns and processes that are distinct to the thinking and practice that is operationalized by individuals in this unique paradigm.

Third, mothers' accounts of their treatment seeking behaviors in conjunction with their roles as their children's case managers and therapists, and the sense of sole emotional responsibility for their children's developmental outcomes raises important

questions on the impact of these specific experiences on mothers' psychosocial well-being. More specifically, the question arises regarding the benefits and detriments of these maternal practices as they are accrued to children. The nuances of the balance between the psychological toll of these unattainable standards and expectations of care, their impact on maternal well-being, and the influence on children's well-being warrants further research and has significant implications for current autism treatment methodologies and protocols.

Conclusion

This investigation shows that mothers of children with autism identify an array of shared experiences as significant in shaping their maternal reality. These shared experiences, as shaped by the current sociohistorical context, influence mothers everyday lives from their most minute maternal practices to the complex ways in which they make-meaning of and experience their motherhood. Mothers' accounts demonstrated how these experiences give rise to distinct maternal practices and perceptual processes that, over time, impact mother's worldviews and subjectivity.

For the mothers in this study, the experience of raising a child with autism in the current cultural context facilitated a disruptive awareness of their subject positions and the ways that these positions are embedded in dominant cultural discourses. Through their maternal journeys, and specifically, the storylines of linked lives and liminality, a transformed, in-process subjectivity emerged. In that subject positions are embedded in sociohistorical contexts, the rewriting of mothers' subjectivities was linked to a

reappraisal of elements of the dominant cultural discourse that were inapplicable to their stories. In taking up new subject positions, mothers took up a new discourse. That is, mothers began to identify, deconstruct and reconstruct inapplicable and unattainable social structures and practices. As subjectivity shifted, mothers began to articulate a different maternal journey—a journey in which new meaning was ascribed to motherhood and worldviews commensurate with this new discourse were adopted.

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APPENDIX A: SEMI-STRUCTURED INTERVIEW GUIDE

Initial Open-ended Questions**Time period preceding diagnosis and the time of diagnosis.**

- Tell me about how you came to know your child had autism?
- When, if at all, did you first notice any symptoms?
- If so, what was this time period like for you? What did you think then?
- Did you take any actions during this time? What did you do? What was this like for you?
- Did anyone or anything influence your actions/decisions during this time? Tell me about how they influenced you.
- Can you describe the events that preceded the diagnosis? What was going on in your life then? How would you describe the person you were then?

Intermediate Questions**Views of autism.**

- How would you describe how you viewed autism before you gave birth to [child's name]? How did you view autism before you received the diagnosis? How have your thoughts and feelings about autism changed since having [child's name]?

Time period following diagnosis.

- Tell me about your thoughts and feelings when you came to know that [child's name] was autistic?
- What was the time period after your received [child's name] diagnosis like?
- How did you go about dealing with [child's name's] autism? What did you do? What were your thoughts and feelings during this time?
- Who, if anyone, was involved during this time period? How were they involved? What was that like for you?
- As you reflect on this time period, are there any other events that stand out in your mind? If so, please describe them. What were these events like for you?

Present day experiences and perspectives.

- How, if at all, have your thoughts and feelings changed since this period? How would you describe the current time period?
- Can you describe a typical day for you when [you are happy, feeling strong, things are going well]? Now tell me about a typical day for you when [you are unhappy, stressed out, things are going badly]?

- Tell me about how you learned to handle the reality of mothering a child with autism? How do you deal with it? What do you do?
- What helps you manage mothering a child with autism? What are the main problems, if any, that you encounter? What are the sources of these problems?
- Who has been the most helpful to you during this time? How so?
 - Have any organizations been helpful to you? How so?
- What positive changes, if any, have occurred in your life since having a child with autism?
 - Describe the best part about mothering a child with special needs?
- What negative changes, if any, have occurred in your life since having a child with autism?
 - Describe the most difficult part about mothering a child with autism?
- How would you describe how you viewed motherhood before autism came into your life? How, if at all, has your view of motherhood changed since autism has come into your life?
- How would you describe the person that you are now? What most has contributed to this?
- Can you describe the most important lessons that you have learned through mothering a child with autism?
- Where do you see yourself in two years [five years, ten years]? How do you feel about this?

Closing Questions

Present day views and perspectives (continued).

- What do you think are the most important ways to manage the experience of mothering a child with autism? How did you discover these? How, if at all, have your experiences before autism entered your life affected how you handle this experience?
- How have you grown as a person since this autism entered your life? Tell me about your strengths that you discovered or were developed throughout your maternal experience? What do you most value about yourself right now? What do others most value in you?
- What advice would you give to someone who has just begun the journey of mothering a child with autism?
- Is there anything that you might not have thought about before that occurred to you during this interview?
- Is there anything else you think that I should know in order to understand your experience better?
- Is there anything that you would like to ask me?