

A Look is Enough: Interviews with Mothers of Children with Autism

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ABSTRACT OF THE THESIS

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This thesis provides an exploratory look at caregiving, blame, and mothers of children with autism. The framework of this project comes from historical patterns of mother blaming, gendered division of labor, and dominant constructions of disability as otherness. Theoretical insights from Michel Foucault and Margrit Shildrick on power, gender, disability, and bodily control are also brought into conversation to consider how these maternal and disabled bodies structure and are structured by systems of power. The project culminates with a presentation and analysis of themes from four in-depth interviews conducted with mothers of children with autism.

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Chapter I: Introduction and Methodology

Introduction

I arrived at the topic for this thesis through my lived experience as the aunt of a loving seven-year-old boy who has been diagnosed with autism; the intimate relationships I have with my sister and nephew are the driving force behind this project. And it is also from this place, during my undergraduate career, that I began to focus my research efforts on the fraught history of mother blaming and mothers of children with autism. Since that project and during my graduate career, in addition to continuing my work on mothers and how motherhood is treated, constructed, and understood¹, I have become increasingly interested in the treatment of disability, especially cognitive disability. These two interests converge in this project.

What follows is divided into four sections or chapters; this section, the first section, introduces the work and summarizes the methodologies I used as well as the methodological concerns I had at all levels of research. The second section begins with a review of the history of mother blaming and mothers of children with autism. This section also provides a brief review of some of the relevant literature pertaining to mothers and caregiving, care work, and the gendered politics of parenting. The second section ends with a theoretical discussion aimed at the dynamics of power, subject formation, mothers and disability. Here I utilize Michel Foucault's work on power, subjectivity, and discipline over bodies to explore the relationships that disabled bodies form with themselves and the world, and the

¹ I would like to note that I am not a mother, nor do I plan to become one in the foreseeable future. Therefore, from the beginning of this project, I want to be clear that I do not have personal experience as a mother, nor do I portend to understand the difficulties of the mothers I interviewed.

world with them. I then shift to the work of Margrit Shildrick on the construction of disability, embodying “monstrosity,” and the power of maternal bodies. By synthesizing Foucault and Shildrick’s work, I hope to highlight how mothers of children with disabilities and the children themselves are constituted or constructed via social and power structures and how these insights are useful for thinking about issues that arise in the interviews I have conducted. Moving on from the first two foundational sections, the third chapter delves into the in-depth interviews with four mothers of children with autism that I conducted with Rutgers IRB approval². It is in this chapter that I analyze the content of the interviews for issues of care work, gender inequalities in child rearing, and mothers’ perceptions of their children and of mother blaming. I also attempt to move the theoretical insights from the end of chapter two into my analysis of the interviews. Finally, the fourth section is a discussion about potential policy or program initiatives (existing or otherwise) from which these mothers could benefit. Here, I include general concluding thoughts about this project and where further research ought to focus.

Before going forward with a discussion of the methods used and methodological challenges in this project, I will briefly discuss autism as a developmental disability. “Autism Spectrum Disorders” (ASD) describe a set of neurodevelopmental conditions characterized by varying degrees of impaired communication, difficulties in social interaction, repetitive behaviors, and potentially narrowed interests. Autism spectrum disorders can be considered a privileged set of disabilities in that they are receiving a high degree of attention

² See Appendix A for IRB approval notice, interview information sheet, and interview questions.

from both the public and research entities, and this may be because of the reportedly high incidence of ASD. The Centers for Disease Control and Prevention now estimates “that an average of 1 in 110 children in the U.S have an ASD.”³ As this set, or spectrum, of conditions continues to attract attention, research has also begun to focus on the parents and caregivers of the children with these diagnoses. This thesis, in addition to contributing to feminist scholarly work concerned with women and caring, is aimed at filling in the silences in literature about mothers and caring for a child who has been diagnosed with autism.

Methodology

Before I can begin to outline the methods I use for this project, it is first important for me to highlight what I conceptualize as part of the epistemological stance from which I conducted this work—primarily, feminist standpoint epistemology. This system of knowing operates from the understanding that “knowledge claims are always socially situated” and because dominant groups fail to critically and systematically interrogate their privileged social position, “the effect of such advantages on their beliefs leaves their social situation a scientifically and epistemologically disadvantaged one for generating knowledge.”⁴ Therefore, because ways of knowing are *always* socially situated, knowledge production methods where the “knower” identifies their subject position, such as feminist standpoint theory, are closer to a more realistic kind of objectivity.

³ Centers for Disease Control and Prevention, www.cdc.gov/ncbddd/autism.html, accessed: 12/11/11.

⁴ Sandra Harding, “Rethinking Standpoint Epistemology: What is ‘Strong Objectivity’?” in *Feminist Epistemologies*, eds. Linda Alcoff & Elizabeth Potter (New York, Routledge: 1993), 55-56.

Furthermore, the utility of taking up such an epistemological stance is found in the way that it enables one seeking to know how to get at the knowledges of marginalized groups, or groups whose voices have been historically silenced (due to a dominant ideology's power over knowledge and knowledge production). Sandra Harding, a prominent proponent of feminist standpoint theory describes the process of getting at subjugated knowledges succinctly:

[T]he activities of those at the bottom of such social hierarchies can provide starting points for thought—for *everyone's* research and scholarship from which humans' relations with each other and the natural world can become visible. This is because the experience and lives of marginalized peoples, as *they understand them*, provide particularly significant *problems to be explained* or research agendas. These experiences and lives have been devalued or ignored as a source of objectivity.⁵

When dominant groups ignore the insights of certain groups, they are, in effect, portraying these knowledges as without value. However, as Harding shows here, marginalized knowledges, those that are based on how marginalized people understand their "experiences and lives," provide windows into new ways of examining the world and its social problems critically —that is, ways of critically looking at the world that are an alternative to traditional, dominant, masculinist, or positivist ways of knowing.

Mary Hawkesworth discusses feminist standpoint theory not just as an epistemology, but as a tool and discusses the advantages of using such a tool:

As an analytical tool, feminist standpoint theory has a number of advantages. It suggests a way of gathering information for analysis that presupposes multiplicity and complexity. It recognizes that knowledge claims are produced and accredited within specific communities, and it provides a mechanism for comparatively assessing accounts that emerge within

⁵ IBID., 54-55. Emphasis added.

markedly different communities...[and more recently] feminist scholarship has shifted...to a recognition of multiple feminist standpoints.⁶

Here, Hawkesworth points out that utilizing feminist standpoint theory as a comparative tool can be instrumental for acknowledging variations in the ways that knowledge is produced, or, rather, how dominant knowledges pass as objective, and therefore valid, while knowledge produced by non-dominant communities is deemed less objective, and therefore less valid. This hierarchy of knowledge has oppressed other forms of knowledge (of some women, people of color, or people with disabilities, for example) through demonizing the place of subjectivity while promoting, what is in essence a fabricated notion of objectivity. Knowledge produced from this perspective, from this false standpoint of objective purity, cannot help but undermine and silence voices whose subjectivities are, in fact, knowledge. In this project, I understand the voices of mothers who care for children with disabilities as one group whose ways of knowing have been undervalued and need more thorough exploration, amplification, and representation. And in embarking upon qualitative research with mothers of children with autism, I have made a concerted effort to identify my subject position through all stages of the process.

Methods Used, Methodological Issues

When I began thinking about this project, I started with the question of how some aspects of the historical paradigm of maternal blame and, especially blame

⁶ Mary Hawkesworth. *Feminist Inquiry: From Political Conviction to Methodological Innovation* (New Brunswick: Rutgers University Press, 2006), 177.

placed on mothers of children with autism, might still resonate with mothers currently caring for children with autism. To unpack the connections and dynamics of such instances, I realized that I needed to have some understanding about how these mothers *talk* about their roles as caregivers. I also needed to find a way to gain insight into the ways they might construct themselves and their children, and the ways that might demonstrate how they internalize and adopt external prescriptions about child rearing, child care, and disability. In addition to the importance of inspecting the class, race, location (etc.) differences among mothers, it became apparent that there would also be a different set of prescriptions for mothering promulgated to mothers of autistic children versus mothers of neurotypical children. These issues were central after analyzing the interview data, and I will comment on this in the third portion of this thesis. After considering what methods might be best suited for this group, I decided to conduct in-depth interviews with mothers.

Sharlene Hesse-Biber discusses the reasons for embarking upon qualitative research, specifically in-depth interviews in *Feminist Research Practice* and argues that interviews get “at the subjugated knowledge of the diversity of women’s realities that often lie hidden and unarticulated.”⁷ In the interviews, I asked women questions aimed at their particular experiences, and these questions reveal important insights for what it is like to care for a child with autism, how to cope with having a child with a disability, and how mothers think of themselves and their children. Without the experience of our interview, it is likely that most of these

⁷ Sharlene Hesse-Biber and Patricia Leavy. *Feminist Research Practice* (Thousand Oaks, California: Sage Publications Inc., 2007), 113.

women may not have had a chance to articulate their struggles and stories to anyone other than their closest confidants—as a rule, they are too busy to “dwell” on their difficulties and must instead put their energies toward their children. I chose to conduct in-depth interviews because of the potential to get at individual experience and not to make generalizations about mothers of children with autism. As Hesse-Biber points out, qualitative research is concerned with getting at a deeper understanding of participants and that the “goal is to look at the ‘process’ or the ‘meanings’ individuals attribute to their given social situation, not necessarily to make generalizations.”⁸ Because part the purpose of in-depth interviews is to reach for a deeper quality of the interviews, rather than securing a large breadth of information, I limited the number of interviews to four sessions, the lengths of which ranged from one to two hours.

As for “recruiting” willing participants, I generated a recruitment information sheet, on which I included a description of the project and information about myself, along with contact information.⁹ This recruitment tool was useful because I was able to give it to people in my social network: for example, family and friends who knew a mom of a child with autism, as well as to gatekeepers at schools who might be able to reach parents of children with autism. Though I did not hear from any of the parents at either of the schools I distributed the information sheet to, the sheet was helpful for providing potential interviewees with information so that they could have an idea about the project before they consented to participate. In the beginning stages of recruitment, I wasn’t sure how difficult (or easy) it would be to find willing

⁸ IBID., 119.

⁹ For the recruitment sheet and consent form see Appendix A.

moms. The information sheet became a reliable backup plan. In the end, I reached all of the women who participated via social connections and word of mouth.

All of the moms were constrained in terms of the time and location of the interview. Three of the four interviews were conducted in the homes of the women, with two of those occurring when their children were also at home. I drove to meet these women in their homes. The remaining, fourth interview took place in a local coffee shop in the hometown of the mom, with two of her three children present. I let the mothers choose the times and places for our meetings with explicit regard for their scheduling and time needs. As for the geographic location of this sample, I limited my reach to the south and central New Jersey areas. The location of my sample had to be limited in this way due to time and resource restrictions, as well as for the scope of the project. There was only once exception to this initial locating range, with one mom residing in eastern Pennsylvania. At the end of the interviews, all of the mothers offered their contact information in the event that I needed to ask any follow up questions and for me to let them know how my work was progressing.

Going into the interviews, I brought a set of pre-generated interview questions.¹⁰ These questions are divided into seven categories and covered the following: general-demographics; family composition; paid work; care work and child care; disability/child specific; stress, emotional well-being, and coping; and access to information and services used. I only ask a few “demographic” questions and did so in order to avoid making assumptions about how the women identify themselves in terms of racial or ethnic identity, their general age, and employment

¹⁰ For the interview schedule see Appendix B.

status or income level. I have included the other categories in order to get at various issues that might affect these mothers' care work situations, as well as questions that attempt to access potential feelings of guilt or blame. The latter group of questions were indeed the most difficult to generate due to the sensitive nature of discussing feelings of blame or guilt in one's role as a mother and caregiver. But as Hesse-Biber discuss, the "interview and conversations with the researched will assume an agenda independent of that of the researcher, and researchers should be ready to work with these changes."¹¹ This was the case with the four women I interviewed, and most of them spoke freely about their opinions and ideas about mother blaming. I will return to this discussion in the interview section.

By agreeing to participate in the in-depth interview process, these moms were graciously agreeing to open and share a vulnerable part of themselves. Understanding this dynamic, I took great care to be sensitive to these women's reactions to questions and generally let them set the tone for most of the discussion, intervening with questions or probes as needed. During the interviews, the tone was usually casual, because from the beginning of this project, a comfortable, conversational tone was part of my goal for the in-depth interviews. Conducting the interviews more like a discussion or a *conversation*, rather than a rigid, formal, and structured question-and-answer survey allowed for greater ease in conversation and opened up the space for mothers to talk freely about their experiences. Once I introduced myself and related my experiences with my nephew, it became apparent through comments, such as "I'm sure you know about [this] with your sister," that

¹¹ Hesse-Biber, 133.

there was some degree of trust about my knowledge of the trials of caring for a child with autism. The benefit of, so-called, “insider” knowledge probably gave me an advantage in gaining the trust and confidence of the mothers. I also remained, however, aware of my positionality in terms of race, economic class, age, social position, and non-parent status. I am a single, childless, college educated, white woman from a working class background who supports herself while pursuing an advanced degree. Sandra Harding contends that maintaining an awareness of positionality during research has the potential to “maximize” objectivity in that project.¹² Maintaining self-reflexivity can also result in a more clear and honest account of the responses from subjects who are interviewed. Operating with awareness of my standpoint, my positionality through the interviews helped me to remain conscious of the questions I was asking and to assess where I may have been inserting my own values into the conversation.¹³ In the way of the demographics, the four mothers interviewed were all married, Caucasian women and their ages ranged from late twenties to early forties. Three of the women could be considered upper-middle class, and the remaining fourth maintains a working class lifestyle.

Some of my initial, general methodological concerns for embarking upon the in-depth interviewing process were: How much would I rely on questions? How much would I “lead” the interviews? How much would I let the mothers guide the discussion? Would I disclose how I came to this research? How might mothers react to my status as a non-mother and what effect would this have on our interview?

¹² Harding, 69-72.

¹³ In one interview this was particularly difficult on the issue of the etiology and treatment of autism. The interviewee and I held quite different perspectives about the causes of autism. This will be discussed further in Chapter 3.

Would I identify myself as feminist to the women I interview? And, if so, how would they respond?

I have already addressed a few of these preliminary concerns in the sections above. The issue of my feminist identity, however, is important here. From the proposal stages of this project, I struggled with wanting to disclose my feminist identity, but wondered if it would be relevant to the interviewee. In two of the interviews, I did openly disclose my feminist identity. This occurred for a few reasons: either I felt comfortable enough to do so or the interviewee hinted at the topic. I had decided, early on, that I would “feel out” each interview to see if my self-identifying as a feminist was even relevant or important to each woman. And when it seemed to be relevant or important for the discussion, I did confirm that aspect of my identity. The women I disclosed my feminist identity to responded in generally positive ways. They nodded approvingly or asked about my program of study. But in spite of their seemingly positive reception, at certain moments in the interviews I wondered if their assumptions about my feminist standpoint might have influenced how they responded to questions. I was particularly curious to know if the women were compelled to speak more optimistically about their husbands’ contributions to domestic labor and caring responsibilities, but in the end, these questions were left to speculation.

The largest methodological concerns that arose after the interviews were underway concerned *who* I included in my small sample. Although, as I discussed above, the aim of a small sample of in-depth interviews is not to include a large sampling of people with resultant generalizable data, I found two salient problems.

The first, which I think can be more easily addressed, is that I invited my sister to be one of the interviewees. It is crucial that I discuss the implications of including someone with whom I have an intimate relationship in my work. When seeking to uncover the histories and experiences of an interviewee, I was clearly positioned to have a great deal of knowledge concerning my sister's situation. Going in to the interview with her, for whom I have chosen the name Leanne, we discussed the possible effects our relationship could have on the work that I was doing and on the process of the interview itself. Leanne understood that it would be helpful if neither of us assumed that we had already discussed or known answers to the questions and issues brought up during the interview. Certainly, however, neither Leanne nor myself can detach ourselves from all of the knowledge we have shared, including the emotional content that comes along with that knowledge. Therefore, Leanne's and my interview is quite clearly non-objective from the start. In our conversation, I posed the same interview questions that were asked of the three other women with the exception of demographic questions and questions about family composition. There were some advantages to having my sister as an interviewee. I did not, for example, have to perform as much research into the area where she lived or probe as deeply about the details of her background. However, the seemingly most advantageous component of this interview—that I could anticipate certain reactions from Leanne—became, in the end, what set our interview back. Admittedly, I did not probe Leanne on questions quite as much as I did the other moms, demonstrating the bias based on our intimate relationship and my existing knowledge of Leanne's

trials with her son and family. In chapter three, I will return to the dynamics of the interview with Leanne.

The second and less easily tackled methodological challenge is that my sample included two women who are sisters with particularly similar backgrounds. Michelle and Julie are women who enjoy the privileges of upper middle class status, identify as Jewish, are Caucasian, and who have children diagnosed on the Autistic Spectrum of Disorders. During our interview, Michelle provided me with Julie's contact information, and I later reached out to and met with Julie. Although, from a demographic point of view, Julie and Michelle are quite similar, they both came to and coped with their respective children's diagnoses in unique ways. A key and interesting difference here is that Michelle's son was diagnosed with autism (which is far more common), but it was Julie's daughter who received the diagnosis. This is remarkable, in part, because of the far fewer incidences of female diagnoses of autism. Current research estimates that "[m]ales outnumber females with autism spectrum disorders (ASD) an average of 4.3 to 1."¹⁴ For now what is important about the interviews with Julie and Michelle is that they provided me with the challenge of considering the uniqueness of their lived experiences, as well as pushing me to consider how mothering a child with autism might look different for specific class groups. In *Feminist Research in Theory and Practice*, Gayle Letherby acknowledges the need for flexibility when entering into a project that involves interviews. She notes that in her work she originally "thought that [her] data would

¹⁴ Tessa Taylor Rivet and Johnny L. Matson, "Gender Differences in Core Symptomatology in Autism Spectrum Disorders across the Lifespan." *Journal of Developmental and Physical Disabilities* 23 (October 2011): 400.

be all collected via in-depth interviews but more of [her] respondents...ended up writing, rather than talking, to [her]" because of issues of location and privacy. I have been reassured by Letherby's account of her research and the necessity of flexibility, not only in approaching these mothers' experiences, but also in the need for altering methods during ongoing research.

There were some outcomes that were predictable before I embarked on the interview process. I thought, for example, that these interviews would reveal some common concerns and problems of mothers caring for autistic children, and this turned out to be true. Although the potential for generalizability in such a small sample of interviews is quite low, I was prepared to hear from the outset—as I did—that these mothers seem to be investing significantly more time into their care work routine than mothers or caregivers of children without a developmental disability, as some of my literature review will show. Additionally, all of the mothers described themselves as the primary caregivers for all of their children. Despite these foreseeable responses, each interview yielded new and different insights about what it is like to live with, care for, and raise a child with autism. Each woman's situation was unique, and the in-depth interview process revealed the nuances of their feelings, thoughts, and experiences.

In the following chapter I will review some literature relevant for this project and I will consider some pertinent theoretical ideas. This next chapter will serve as a backdrop for the third chapter on interviews.

Chapter II: Literature Review and Theoretical Concerns

A. Literature Review

What can feminist scholarly research gain from studying children with disabilities and their caretakers? In recent years feminist scholars have made a call for integrating the concerns of disability studies and feminist scholarly work, which confirms that feminist scholars are indeed moving this direction. Rosemarie Garland-Thomson pushes for this integration, in part, because “[f]eminist theory is still resisted for exactly the same reasons that scholars might resist disability studies: the assumption that it is narrow, particular, and has little to do with the mainstream of academic practice and knowledge.”¹⁵ I agree with Garland-Thomson when she argues that “[w]e need to study disability in a feminist context to direct our highly honed critical skills toward the dual task of unmasking and reimagining disability, not only for people with disabilities, but for everyone.”¹⁶ Feminist lenses and projects would be incomplete without a critical analysis of disability.

The project of introducing analyses of disabilities into feminist work has been underway and this integration seems logical after a brief review of the historical lineage of feminist intellectual work. Identity formation and maintenance exists at the center of feminist theories and politics, and since the initial stirrings of feminist consciousness, identity and identity politics have been central to debates and discourse about gender struggles. Since those initial “waves” of feminism, theories about how identity and social positionality inform the way one thinks

¹⁵ Rosemarie Garland-Thomson, “Integrating Disability, Transforming Feminist Theory,” in *Gendering Disability* eds. Bonnie G. Smith and Beth Hutchison, (New Brunswick: Rutgers University Press, 2004), 74.

¹⁶ *IBID.*, 76

about and operates in the world have come to address issues central to contemporary thought. Feminist standpoint theory, for example, as I discussed in the first chapter, recognizes the socially situated nature of how one comes to know the world. The tactics and techniques of a critical disability studies approach to feminist academic work is entirely fitting with feminist epistemological approaches, and employing its critical methods will prove greatly beneficial to feminist theoretical scholarship.

How we know the world and the identities we take up are inevitably informed by those identities that we do not take up. Disability and the myriad identities that exist within this foggy category mediate *all* bodily identities; disability informs every identity, even those that identify as able bodied (i.e. not disabled). Again, Garland-Thomson states this point excellently and posits that “disability is perhaps the essential characteristic of being human. The body is dynamic, constantly interactive with history and environment. We evolve into disability. Our bodies need care; we all need assistance to live.”¹⁷ Disability, in its many forms, has the power to affect every body. It is from this stance, a position that believes that disability is crucial to a fuller feminist critical lens, that part of my project on mothers of children with autism are born. Now that I have attempted briefly to position this work within the larger network of feminist scholarly work, I will begin this literature review by revisiting the history of maternal blame and children with autism.

¹⁷ IBID., 92.

I. Brief History of Blaming Mothers

In past academic work, I conducted research that looked at the history of mother blaming and mothers of autistic children with the purpose of tracing the shift in thinking about the cause of autism between the 1940's and the 1970's. My methods consisted of reviewing all the articles published on autism in three formative psychiatric journals during this time period.¹⁸ While reviewing these materials, I discovered how the thinking about etiology changed during this time, finding that the progression from blaming "psychogenic" mothers to favoring biological explanations occurred gradually between 1960 and 1978. There were many causes for this shift, including a greater reliance on scientific data and technology, as well as growing suspicions that bad parenting did not produce autistic children (a suspicion that was informed by the women's movement).

In all three journals, articles during this time period included extensive details about the infant-mother relationship. During this era, the "psychogenic" point of view, in which it was believed that the transference of the mother's dysfunctional personality traits onto the child caused autism, was paramount. Mental health professionals frequently saw the mother in therapy sessions separate from her child, the underlying belief being that mothers caused autistic withdrawal, so without first rehabilitating the mother, there was no hope of eventually rehabilitating the child. Many of these case studies were comprised of family histories, medical histories, and details of the statuses at birth and during infancy. Some mothers only participated in these studies (or therapies) for a few months,

¹⁸ The journals reviewed were the *American Journal of Orthopsychiatry*, the *American Journal of Psychiatry*, and the *Journal of the American Academy of Child Psychiatry*.

while others continued with psychoanalytic therapy for years to resolve their presumed inner conflicts. But, of course, therapists also believed therapy for the autistic child was necessary. As Stewart and Sardo wrote in 1965:

In [autism], a core problem is the absence of a safe, growing-enabled relationship, yet its establishment is essential for the effectiveness of the treatment. If the child establishes a relationship with the therapist, this ability to relate can be generalized to the significant others in the patient's life.¹⁹

The central principle of this treatment agenda was that mothers were not giving their children the essential emotional and physical care that they needed to grow to be “healthy” members of society, but that a therapeutic relationship with a medical health professional could substitute for this presumed deficit in mothering.

Throughout these decades a slow shift in thinking about the cause of autism began to occur, and by the mid 1960’s, it was evident that some researchers were turning their focus toward a more founded, scientific etiology for autism, moving slowly away from the old ways of blaming the mother. Given that many answers simply weren’t available, the authors of many of these studies shied away from addressing the etiological roots of the illness, focusing instead on treatment. Also during this time, doctors conducted EEG, neurological tests, and blood tests.²⁰ The gradual accumulation of these studies led professionals to draw new conclusions about the etiology of autism, and this statement from 1963 by Dr. Jerome Schulman can demonstrate the change: “We believe that there is an innate biological

¹⁹ Russ Sardo and Ralph H. Stewart, “The Psychotherapy of a Blind Schizophrenic Child.” *The American Journal of the Academy of Child Psychiatry* 4, no.2 (1965): 123-132.

²⁰ Marian DeMyer, William DeMyer, and Philip T. White, “EEG Abnormalities in Early Childhood Schizophrenia: A Double-Blind Study of Psychiatrically Disturbed and Normal Children During Promazine Sedation.” *American Journal of Psychiatry* 120,no.4 (1964): 950-958.

disturbance of brain function in the autistic child.”⁵ During the late 1960’s, it was clear that a neurologically and biologically based explanation for autism was on its way to becoming dominant in the mental health profession, and outright blame placed on the mother, in addition to being unjust, was unprofessional.

In 1978, 100,000 women marched in Washington, D.C. demanding equal rights. The critical mass gathering around women’s rights and gender equality is likely to have had a strong influence on the ways in which researchers were approaching their studies. And this influence came through in some of the works I read from this time period. In one article, for example, two female psychiatrists, Jeanne Spurlock and Karen Rembold, directly confronted the mother-blaming paradigm. The authors pointed out that fathers, if and when present, needed to be held equally accountable for both the rearing of children and the dysfunctions that might have arisen in children from that rearing or lack thereof.²¹ With the heightened awareness of the status of all women in society during this time, the medical and psychiatric field became a likely place as any to locate and call attention to inequalities and imbalances.

In 1978, the same year that women were marching in Washington, D.C., the Diagnostic and Statistical Manual (DSM) III would include a definition of autism that stated that there were no known family factors for causing autism and that there was no correlation between autism and “parental psychopathology.” The classification of autism as a syndrome in the DSM came as a victory for the

²¹ Jeanne Spurlock and Karen Rembold. “Child Psychiatry Perspectives, Women at Fault: Societal Stereotypes and Clinical Conclusions.” *Journal of the American Academy of Child Psychiatry* 17, no.2 (1978).

opponents of the psychogenic mother point of view, and the forthcoming definition in the official text used by mental health professionals for diagnoses permanently affixed a change in perspective, on an institutional level, about the causes of autism. In this project I will utilize this history of blame to help inform my qualitative study and analysis of how mothers might still feel blame or guilt associated with caring for children diagnosed with autism. It is also important for me to note here that this brief section is in no way a complete or exhaustive history of the mother blaming paradigm—it should rather function as a backdrop from which to situate a contemporary discussion of how blame or guilt might still complicate the carework situations of these mothers.

II. Review of Relevant Literature: Mothers and Caring

Scholars concerned with gender and labor have produced a great deal of work about women and caring labor. Central to the discourse of caring and mothers is the performance of “care work” or work that is concerned with the daily monitoring and maintenance of the well-being, emotional and physical, of another. Nancy Folbre deems this type of work as important precisely because “it has a direct effect on our emotional well-being.”²² Folbre and Paula England point out that the strong emotional dimension of care work makes it a “highly gendered concept, one that tends to be located more within the feminine than the masculine realm.”²³ Sociologist Arlie Hochschild has written about care work and discusses the ways in

²² Nancy Folbre, *The Invisible Heart: Economics and Family Values* (New York: The New Press 2001), xii.

²³ Paula England and Nancy Folbre, “Contracting for Care,” in *Feminist Economics Today: Beyond Economic Man* Eds. Marianne Ferber and Julie A. Nelson (Chicago: University of Chicago Press 2003): 63.

which contemporary constructions of care implicate women in both commodified and uncommodified care labor, but the study of women and care work has extended across other disciplines and has received substantial attention in the fields of psychology, labor studies, public policy, economics, and, of course, academic feminism.²⁴

Fundamental to literature on women and care work is the gendered division of labor within a household; feminist academics have explored, exploded, and offered alternatives to the traditional, gendered frameworks of the division of labor.²⁵ The gendered delegation of duties within the family places the burden of care work onto women, and with the burden of care comes criticism. Whether a woman is the mother of a neurotypical child or a child on the autistic spectrum, all mothers incur some form of criticism about their parenting practices. What Sharon Hays describes as “intensive mothering” is rampant within discussions and prescriptions of how women should raise their children. The intensive mothering ideology pushes the belief that all women with children should provide the best quality of care and concern for their children. She writes:

It is my argument that the contemporary cultural model of socially appropriate mothering takes the form of an ideology of *intensive mothering*. The ideology of intensive mothering is a gendered model that advises mothers to expend a tremendous amount of time, energy, and money in raising their children.²⁶

²⁴ For example: *The Managed Heart* (2003,1983) and *Global Woman: Nannies, Maids and Sex Workers in the New Economy* (2002).

²⁵ T. Calasanti and C. Bailey, “Gender Inequality and the Division of Household Labor in the United States and Sweden: A Socialist-Feminist Approach.” *Social Problems* 38 (1991): 34-53.

²⁶ Sharon Hays, *The Cultural Contradictions of Motherhood* (New Haven: Yale University Press, 1996), x.

As a social code of conduct, it is utterly pervasive and reaches all mothers across class and race, but the pressure of intensive mothering ideology may affect women with autistic children more severely. Caring for children with disabilities, especially a developmental disability like autism, demands that the caregiver face additional challenges and, in some ways, a heavier care workload.²⁷

In recent years, autism as an illness has garnered a good deal of attention within popular audiences, and academically, and many disciplines have produced research on the multiple care needs of autistic children. Along with this greater focus on autism and the needs of children on the autistic spectrum of disorders, researchers have also focused their attention onto the parents, often specifically on mothers, of children diagnosed with autism²⁸; numerous studies across academic disciplines have investigated the “costs” of caring for a child with disabilities and the psychological well-being of parents, especially mothers, of autistic children. This relatively new wealth of research signifies a change in focus from mother blaming to concern for mothers’ well-being.²⁹ Some of the costs of caring for a child diagnosed with autism include family adjustment difficulties, especially for families with more than one child, time consuming search for services, responding to “stigmatization,”

²⁷ See: J.Bromley and K. Davidson, “Mothers Supporting Children with Autistic Spectrum Disorders.” *Autism: The International Journal of Research and Practice* 8, no.4 (2004): 409-423.; or Koydemir-Ozden, Selda. “A Qualitative Approach to Understanding Turkish Mothers of Children with Autism: Implications for Counseling.” *Australian Journal of Guidance & Counseling* 20, no.1 (2010): 55-68.

²⁸ Geffken, G., Morgan, S., and Rodrigue S. “Families of Autistic Children: Psychological Functioning of Mothers.” *Journal of Clinical Psychology* 19, no.4 (1991): 371-379.

²⁹ For one example: Mary Jane Weiss, “Hardiness and Social Support as Predictors of Stress in Mothers of Typical Children, Children with Autism, and Children with Mental Retardation.” *Autism* 6, no.1 (2002): 115-130.

financial issues, and child-specific challenges.³⁰ And indeed, as some of this work shows, mothers are typically the primary caregivers of children with disabilities.³¹

B. Theoretical Concerns

I. Foucault: Mothers, Disabled Bodies, and Power

In order to understand how mothers caring for children with autism are positioned in the world, looking at theoretical works that address gender, power, and subjectivity is critical. In order to do this, I turn toward the work of Michel Foucault and Margrit Shildrick. I begin with Foucault, whose work can be read as a challenge “to a conception of history as a linear and continuous process” and can show us how “multiple institutions, practices, and discourses constituted”³² both motherhood and autism. Foucault’s *Discipline and Punish* and *The Birth of the Clinic*, here, are useful for showing how power and the institutions through which power operates inform how we have come to view the disabled other as well as the mothering figure. Margrit Shildrick’s work is informed by feminist, critical disability, and psychoanalytic theories. In *Embodying the Monster* and *Dangerous Discourses of Disability, Subjectivity and Sexuality*, she argues that otherness exists within all bodies despite the construction of the other as outside of the self, and seeks to show how the boundaries between self and other are blurred. I will begin with Foucault’s ideas about power and bodies.

³⁰ Thomas L. Whitman, *The Development of Autism: A Self-Regulatory Perspective* (London: Jessica Kingsley Publishers, 2004), 245-256.

³¹ Shirley Porterfield, “Work Choices of Mothers in Families with Children with Disabilities.” *Journal of Marriage and Family* 64 (November, 2002): 972-981.

³² Licia Carlson, “Docile Bodies, Docile Minds: Foucauldian Reflections on Mental Retardation.” in *Foucault and the Government of Disability*, Ed. Shelly Tremain (Ann Arbor: The University of Michigan Press, 2005), 135.

Michel Foucault's work lends insight into the relationships that bodies form with themselves and the world, as well as the world with them, and how these relationships are informed (he says, always) by power. Both mothers and individuals with disabilities hold distinctive positions within the operation of institutional and social power; these are bodies that can challenge, through unique ways of living in their bodies in the world, disciplinary structures. Foucault would argue, however, that even with these othered positions in the world, mothers and differently-abled bodies are still subjected to and constituted through power structures. Below I will explore the specifics of such embodied experiences, of the mother and of the child with a disability.

The transformation of power over bodies is the subject of Foucault's *Discipline and Punish*. When Foucault writes about docile bodies, he describes them as ones "that may be subjected, used, transformed and improved."³³ He goes on to say that during and after the seventeenth century, the ways in which bodies became docile changed. Control of bodies began to occur at a different level, as Foucault points out, one where the new practice was to exercise "upon [the body] subtle coercion, of obtaining holds upon it at the level of the mechanism itself – movements, gestures, attitudes, rapidity: an infinitesimal power over the active body."³⁴ The ways in which control is exercised over bodies, these "methods," are what Foucault calls "the disciplines." Control over bodies, discipline, occurs at the level of the body, its movements and its processes. The shift in disciplinary power, according to Foucault, also required that bodies possess the ability to be efficient. He

³³ Michel Foucault, *Discipline and Punish: The Birth of the Prison* (New York: Vintage Books, 1979), 136.

³⁴ *IBID.*, 137.

writes: "Discipline is no longer simply an art of distributing bodies, of extracting time from them and accumulating it, but of composing forces in order to obtain an efficient machine."³⁵ Efficiency in bodily movement is, Foucault argues, required to obtain an ever increasing efficiency in use of time.

This point in Foucault's work prompts the following question: where do bodies with disabilities and maternal bodies with the capacity to reproduce unpredictably reside in Foucault's discussion of the micro-physics of power? That is, there will always be bodies upon whom greater discipline is required in order to obtain control and efficiency, and because of this, the mechanisms of control will have to adapt, and be adapted, in order to exercise control. Bodies which are not docile, such as that of a severely autistic child, challenge disciplinary mechanisms and require a greater degree of effort toward regulating movements, behaviors, and processes. I would argue that bodies that do not conform, or are not able to conform, to the standard systems required for efficiency, knowingly or not, resist control. The very existence of such bodies potentially opens space for a disruption of the power structure and for resistance. Autistic children, for example, possess varying degrees of verbal skill, with more severe cases completely lacking verbal communication abilities. Some children and adults with autism possess varying degrees of cognitive impairment. Children with severe autism are also quite prone to "running off" and, even at the hands of their most trusted caretaker, can require physical restraint and constant supervision. How is a mute, delayed, and physically and mentally resistant body "trained" or disciplined, in a Foucauldian sense? Their movements and their

³⁵ IBID., 164.

behaviors cannot be easily maintained, disciplined, or controlled. In a way, these children defy the disciplinary regimes set out by Foucault.

But, as Foucault shows in *The Birth of the Clinic*, shifts to institutional power during the eighteenth century gave way to the clinic, and with it, new methods, disciplines, were created in order to manage difficult bodies. Bodies, such as an autistic one, will be subjected to observation, testing, and classification. Medications and “treatments” will be prescribed. And, in the end, the body will have been subsumed under the power of the medical institution. In addition to the physical forces exerted on the body, he also argues that it is from the articulation of medical language and the naming of illnesses as such that an important change in the way we conceive of particular behaviors, bodies, and symptoms.³⁶ Which is to say that medical language has acquired the power to fuse the body (object) with the terminology spoken (the articulation). Foucault shows us that the illness or disease, through being named by medical professionals, confines the ways we can know a person with *that* illness, or here, disability. The biomedical institution and its proprietors, through naming and classifying illness, create the effect of a definitive Truth about those designated with that label. Foucault writes: “The nominalist reduction of existence frees a constant truth.”³⁷ What is freed in the naming of illness is a perceived sense of clarity from the ambiguity and amorphousness of unnamed illness, disorder. Naming illness, disease creates parameters and boundaries whereby one can position themselves. This rigidity in ways of knowing

³⁶ “[T]he articulation of medical language and its object will appear as a single form.” Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception* (New York: Vintage Books, 1994), xi.

³⁷ *IBID.*, 119.

illness has produced disastrous consequences, for both the subject-patient and family, as is evident with the psychiatric history of blaming mothers of children with autism. Autism, in its early history, was complete with a set of descriptors that drew a definite diagnostic shape, and attached to this diagnostic category was a supposed environmental etiology—cold mothers. Diagnosing autism during the 1940's through the 1960's also meant that the mother was named as the perpetrator of the disorder.

The new power regime—it is omnipresent, invisible, and demands that the subject under its control remain visible. Foucault explains:

Disciplinary power...is exercised through its invisibility; at the same time it imposes on those whom it subjects a principle of compulsory visibility. In discipline, it is the subjects who have to be seen. Their visibility assures the hold of the power that is exercised over them. It is the fact of being constantly seen, of being able always to be seen, that maintains the disciplined individual in his [sic] subjection.³⁸

This is especially true in institutions such as the hospital or the psychiatric ward where patients' behavior is carefully observed and classified. However, the imperative to be available for observation, as Foucault points out, is internalized and exists outside of these institutions. And through the invisible process of disciplining bodies, this kind of power also endows bodies with habits, rituals that operate toward the end of reinforcing and perpetuating the effects of power. Foucault argues that the outcome is bodies that are both *the effect and the object* of that power.³⁹ Disciplined bodies, as such, enact the reproduction of the effects of power while continuing to be the object of that power. This cyclical and invisible

³⁸ Foucault, *Discipline and Punish*, 187.

³⁹ *IBID.*, 192.

micro-physics of power makes the body one that “may be placed, moved, articulated on others.”⁴⁰ It is in this way that we, often in invisible or unrecognized ways, discipline *each other*. Here, it is not just the doctor, security guard, or nurse that use the gaze to discipline bodies—it is also the neighbor, the relative, or the anonymous stranger who function as instruments of power over other bodies. Turning back to historical paradigms of mother blaming, it is clear that mothers are watched as they mother, from the maternity ward to the neighborhood, and that this is not a passive watching, but a critical one. So, we see the general population act as the judges and the regulators of behavior.

I will return to these ideas in the next chapter as I examine how and when the women I interviewed may have felt judgment or blame. But first, I will engage with Margrit Shildrick’s work on anomalous embodiment and mothers in order to reveal how maternal bodies and disabled bodies have the power to elicit fear. Her work on “monstrosity” and anomalous embodiment intersects with Foucault at the point where power operates to normalize and standardize behavior.

II. Shildrick: Anomalous Bodies and Vulnerability of Self

Margrit Shildrick’s work on anomalous or monstrous embodiment is insightful for considering the normalization of bodies in society and how non-normative bodies (here, non-male or differently able) are treated. In *Embodying the Monster: Encounters with the Vulnerable Self*, Margrit Shildrick explores how the psychic boundaries between self and other are permeable and blurry, arguing that

⁴⁰ IBID., 164.

this is especially true when confronted with otherness, difference. Shildrick focuses on “monstrous” bodies and disabled bodies and argues that they have historically been “cast as others whose anomalous bodies served to fix the normalcy of the standard (European) model.”⁴¹ ⁴² In this section, I argue that disabled bodies and maternal bodies are othered and even considered abject; the impulse to blame or enforce discipline upon differently-abled or maternal bodies is, at its core, derived from fear of these abject or different bodies.

Margrit Shildrick’s ideas about disabled and maternal bodies are useful for my project on mothers of children with autism precisely because she is concerned with difference and reactions to difference. Shildrick’s analysis of bodies deemed disabled is useful for a wider discussion of how difference affects the treatment of bodies, but it is also instrumental for discussing the complicated interplay between mother-caregiver, autistic child, and outside observer. When we consider disabled bodies as an other from which normalcy is gauged, the historical trend toward blaming mothers for causing their child’s illness can be understood in a different light. I contend that the impulse to blame mothers comes from viewing (conscious or not) the disabled child as unsightly, an unacceptable product that could only have come from an unacceptable source. And, going along with Shildrick, I argue that anomalous bodies elicit fear because they represent our own vulnerabilities to embodied otherness—they show that the boundaries between self and other are

⁴¹ Margrit Shildrick, *Embodying the Monster: Encounters with the Vulnerable Self*, (London: Sage, 2002), 28.

⁴² Monstrous is a category in which Shildrick includes bodies deemed to be disabled. In my reading of Shildrick, I implicitly considered children with autism, or all people with a developmental disability, as included in the category of monstrous.

penetrable. First, I will use Shildrick to consider how the disabled or maternal body becomes abject.

Shildrick summarizes her argument about vulnerability, monstrosity, and the self below. She posits that

*we are always and everywhere vulnerable precisely because the monstrous is not only an exteriority. In both cases [with the monstrous and with vulnerability] what is at issue is the permeability of the boundaries that guarantee the normatively embodied self...neither vulnerability nor the monstrous is fully containable within the binary structure of western logos, but signal a transformation of the relation between self and other such that the encounter with the strange is not a discrete event but the constant condition of becoming.*⁴³

I will consider two parts of what Shildrick proposes above: the “binary structure” and the threat of vulnerability. First, I will explore how we construct and understand disability through binary understandings of the self and other.

Through Shildrick’s use of “monstrous,” she shows us how abject otherness is used to reinforce and define normalcy. She describes the monster as “something beyond the normative, that stands against the values associated with what we choose to call normality and that is a focus of normative anxiety.”⁴⁴ In order to cope with the “normative anxiety” produced by the abject other, we establish boundaries between normal and anomalous, boundaries which then construct the illusion that monstrosity, abnormality, and disability exist apart from normalcy. In this line of thinking, the normal cannot be touched by the external, abject other. Through myriad of Foucauldian interventions, from naming and classifying to institutionalizing and punishing, the other is kept away from the assumed “normal”

⁴³ IBID., 1. Emphasis added.

⁴⁴ IBID., 29

self and exists on the other side of a delineated space. This process, in turn, creates a binary between the disabled other and the presumed normal self. Shildrick explains that “human monsters,” according to this logic, “both fulfil (sic) the necessary function of the binary opposite that confirms the normality and centrality of the accultured self, and at the same time threatens to disrupt that binary by being all too human.”⁴⁵ Within this kind of psychic structure, one identity could not exist without the other, they are mutually reinforcing.

It is clear, therefore, that the bodies of children with disabilities are constructed to be the opposite of what is normal and safe: they are disabled. They are diagnosed, labeled, and treated accordingly in the worlds in which they live. The construction and reinforcement of this binary—the disabled child as other—can and is (re)produced by all people. And, as I found in some of my interviews, these children’s otherness is constructed through their families, their mothers. Of course, we are all implicated in creating and recreating the category of abject otherness because, as Foucault’s work shows us, we are all implicated in the same systems of power that govern our actions, including speech. When we speak of the other in terms that seek to highlight difference, we reiterate and reinforce that difference. This is not to say, however, that mothers are to blame for (re)creating their children’s disabilities; rather, I mean to show that these binary constructions are pervasive and are deeply entrenched in our understandings of the world and of ourselves, and from these notions, mothers, just as every one else, perpetuate abject otherness.

⁴⁵ IBID., 55.

Inspecting the construction of this binary—disabled child and self—gives way to this question about mothers: What happens when a body regarded as normal creates an anomalous other? Disabled bodies are treated as abject precisely because they represent and threaten to reveal that *all* bodies are unstable. But, the disabled child is not the only threatening force; mothers, too, represent the threat of the permeability of self—their bodies have the potential to create new and unpredictable bodies and situations. The threat of physical reproduction of abjection is what is most fearful or what, in Shildrick's terms, can elicit the most normative anxiety. Shildrick turns toward historical accounts of fear produced by the power of the maternal body. She points to pregnancy as a distinct time where the boundaries between self and other are especially unclear, writing that women's bodies

exemplify an indifference to limits evidenced by such everyday occurrences as menstruation, pregnancy, lactation and such supposedly characteristic disorders as hysteria, and more commonly today anorexia and bulimia. In particular, the pregnant body is...actively and visibly deformed from within. Women are out of control, uncontained, unpredictable, leaky: they are, in short, monstrous.⁴⁶

Shildrick contends, that mothers are themselves monstrous in pregnancy and through the continual leakiness that is inherent in female embodiment. I would add to this argument that the power mothers have to recreate a state of abjection is a threat and that this threat is what, in part, leads to mother blaming. For abjection to exist in the normative world, something must contain it and *explain* it. In looking for a reasons as to why, where, and how disability as abjection occurs, mothers—with

⁴⁶ IBID., 31.

their unpredictable and anxiety provoking female bodies—are ideal culprits. The woman’s bodily “unpredictability,” the psychic logic goes, produces an unpredictable child. This view conforms with what Shildrick calls the western “ideological burden” which “associates women with danger, particularly in the spheres of sexuality and maternity.”⁴⁷ Here, a woman’s potential for fertility and childbirth is especially dangerous when it also involves the potential for producing abjection.

Shildrick’s use of abjection lends salient insights for my project because she shows us the psychic workings of abjection and discusses how the boundaries between self and other, the disabled other, are permeable. What are the consequences of this permeability or slipperiness of the boundaries between self and other? For Shildrick, the answer is vulnerability. Vulnerability, in terms of the psyche, signals a state where one’s sense of self is threatened. The blurring of boundaries between self and other exposes the façade of safety from otherness and the self becomes vulnerable, or aware that it is vulnerable; the internalized other, the abject, or disabled self is brought to light. That is, the normative self is constituted, as discussed above, through an opposing other who is, in this case, disabled—but we are all in a tentative state of “ableness,” or to use Shildrick’s terms, non-monstrous. Separation of self and other comes from the fear of and vulnerability to becoming the other. Shildrick makes this point succinctly: “It is precisely the threat of engulfment with its breaching of boundaries and loss of self-

⁴⁷ IBID., 30.

containment that makes clear the psychic function of abjection.”⁴⁸ When the normative self is confronted with its potential to become non-normative, or other, it is vulnerable.

And, Shildrick contends, it is not only selfhood that can be vulnerable. Power structures, such as biomedical institutions, for example, are also caught up in this cycle of creating binaries which then give way to vulnerability. Shildrick explains the slipperiness of boundaries and vulnerability in the biomedical model:

If...biomedicine itself is structured by a culturally and historically unstable series of metaphors imbricating with a wide range of other discourses, then it can make no claims to purity. It is from the start inherently contaminated by its discursive others, and always vulnerable, therefore, to alternative readings that contest received truth.⁴⁹

Biomedical practices, she argues, do not exist in a vacuum. Rather, participants and discourses mediate these practices. Shildrick, in a way, picks up where Foucault left off—she creates a space for contestation, resistance to institutional power by showing its fallibility. She highlights the unstable state (vulnerability) of biomedical knowledge and practice. It is informed, interpreted and, through its reiteration, further destabilized from the core of its meaning. These insights are useful for thinking about the formation and institutionalization of diagnoses such as autism. Both psychiatric and biomedical diagnoses and “illnesses” are constructed through and by this inherently flawed system of knowledge production. These diagnoses are subjected to and caught up in the same pattern of binary creation that reveals vulnerability. For my work here, for example, the meaning of “autism” changes and

⁴⁸ IBID., 82

⁴⁹ IBID., 83.

has changed, through its (re)iteration outside of and within psychiatry and biomedicine. And movements that seek to raise awareness or advocate for the rights of people with disabilities, here autism, also in turn have the power to strengthen the logos, understanding, of “autism” or to recreate and change its meaning. Shildrick’s use of vulnerability and identity, as the biomedical or activist examples above show, is helpful for thinking and rethinking how disability is constructed and informed, how these notions cannot be stable.

Shildrick discusses this potential for change and rethinking disability via the coexistence of seemingly disparate identities and binaries:

The responsibility for enquiry and analysis falls, then, not on disabled people alone but on all those who participate in the relevant structures. Just as scholarship of recent years has identified racism as a problem of whiteness, so too ableism must be addressed by those who are identified with normative standards and those who are excessive to them.⁵⁰

We are all implicated in the production of images and understandings of disability, and in the sociocultural imagination that affects everyday life, then, we are all responsible for rethinking and reimagining the discourses around disability. If we are able to see the blurry edges of our own bodies and abilities, perhaps, we can avoid repetition in history— such as mother blaming paradigms.

After considering Foucault’s work on the operation of power over bodies and the dynamic of a vulnerable self, as described by Shildrick, I turn now to interviews with mothers of children with autism with these additional questions: How do

⁵⁰ Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity and Sex*, (New York: Palgrave Macmillan, 2009), 15.

mothers create meaning around autism? How might the “monstrosity” of the child extend over to the mother’s identity? And in what ways does this come through?

Chapter III: Interviews with Mothers⁵¹

A. Categories and Coding

Keeping the theoretical and historical concerns of the last section as background, in this section I focus on the conversations I had with four mothers. Because my data set for this project consists of only four interviews, I engaged in a kind of loose coding to organize themes I found in the interviews. I use “loose” coding to describe five rough categories of issues that were common during my discussion with all of the women. These five categories are: (1) access and resources; (2) care load; (3) self-time and emotional well-being; (4) autism; and (5) blame and/or pressure and mothering.

In the “access and resources” category, I have included details about each woman’s financial situation, location, supports, and social networks that make them more or less able to access helpful supports, services, and resources. The second code, “care load,” consists of the specifics about the time they spent caring for their children, including how this care situation has changed over time, particular difficulties, and who, if anyone, helped them provide care. The third category, “self-time and emotional well-being,” includes information about how the women find time for themselves, as well as issues pertaining to their emotional health and how they cope with having a child with autism. The fourth code, “autism,” includes information about how the mothers talked about their child’s autism. The fifth and final category is “blame and/or pressure and mothering,” and it is in this section that

⁵¹ In order to protect their privacy, I have given code names to the interviewees and their families.

I detail the mothers' responses about feeling pressure from outside sources about how they care for their children.

As is to be expected in a discussion about child care, there are places where multiple issues from these categories are bound together. With Michelle, for example, when she spoke about support groups, she also brought up the pressures put on mothers caring for a child with autism. Michelle describes how other parents in the support group she attended disagreed with her choice of treatments for her son Justin, which, in part, led her to stop attending the group. As some of the pieces of our conversations will show, the categories I impose on my data are not to be taken as distinct and isolated issues; they are, rather, problems that are often blended, occurring at once. The coding process acts as a way to tease out particular issues so that I can focus on and discuss each concern in greater detail. In this chapter, I will begin by introducing each mother and providing details of her particular situation. Then I will move to each of the six common categories of concern.

Before moving forward, however, I would like to briefly engage in a discussion of the difficulty of autism as a diagnosis and some controversial points about treatment. While it is beyond the scope of this paper to delve too deeply into a discussion of etiology and treatment of autism, a few points are relevant for the interviews I conducted. First, the issue of etiology and autism has been, to date, a contested and debatable topic, and most recently, the tension has mounted around vaccinations as a potential cause of autism.

B. Etiological Disputes and Alternative Treatments

A discussion of vaccinations as a cause for autism is relevant here because at least two of the mothers interviewed believed that early childhood vaccinations were in part to blame for their children's conditions. The debate about vaccinations and potential heavy metal poisoning, such as mercury poisoning, causing autism has been on-going since the 1990's.⁵² In recent years, this theory has been both shot down and exalted by parents and researchers in the field. The dispute revolves around a lack of biological evidence linking metal compounds, like the mercury found in early childhood vaccinations, to autism. The proponents of the mercury theory argue that the list of mercury poisoning symptoms are strikingly close to the list of symptoms used to diagnose autism. The substance in question in the vaccination debate is the organic mercury compound called thimerosal that was used as a preservative in some drugs and, until the early 2000's, was widely found in early childhood vaccinations.⁵³ The authors of a more recent study, published in 2010, review literature on mercury exposure and children with autism and conclude that:

...there has been a great deal of information from different studies that seems to indicate that repetitive mercury exposure during pregnancy, through thimerosal, dental amalgam, and fish consumption, and afterbirth, through thimerosal-containing vaccinations and pollution, in genetically susceptible individuals is one potential factor in autism. Certainly this question continues to stir debate among professionals across the medical and behavioral sciences. It serves as a grey area for many families as they seek to quell their anxieties invoked by this debate by discovering the facts.⁵⁴

⁵² Jeffrey P. Baker, "Mercury, Vaccines, and Autism: One Controversy, Three Histories," *American Journal of Public Health* 98, no. 2 (February 2008): 246.

⁵³ For information about the use and decline of use of thimerosal in vaccinations, see: <http://www.fda.gov/BiologicsBloodVaccines/SafetyAvailability/VaccineSafety/UCM096228>

⁵⁴ Jie Zang and John J. Wheeler, "Mercury and Autism: A Review," *Education and Training in Autism and Developmental Disabilities* 45, no. 1 (2010):113-114.

Despite indicators of a possible connection between thimerosal and autism, dominant medical and epidemiological communities consistently reject the mercury hypothesis. The debate about vaccinations, heavy metals, and autism is, however, much more complicated than “for or against,” as Jeffrey Baker shows in his historical analysis of mercury, vaccinations, and autism. Baker details the history of how each of these components of the debate convened through time to form a tricky and complicated picture. But, above all, what is interesting for my project is that Baker names organized parents as the catalysts for spreading the idea that autism is epidemic and that vaccinations are to blame.

Parents within the “alternative” wing of the autism community were the primary agents in popularizing the concepts that autism had become epidemic and that vaccines were its cause...There is genuine anger in the autism community that has fueled the polarization of the thimerosal debate, but this anger is best understood in terms of frustration with the medical and educational systems, not the cynical manipulation of lawyers.⁵⁵

In spite of parents’ and some medical professionals’ passion for alternative treatments, the negative consequences of certain therapies aimed at ridding the body of heavy metals have been documented. In a report from 2006, two toxicology specialists argue against the use of one such alternative treatment, chelation therapy, whereby substances are introduced to the autistic child that remove heavy metals, such as mercury, from the body. They argue that research has indicated that chelation can cause fatalities and has not been clinically proven to treat autism successfully. This report cites the 2005 death of a five-year-old British boy who was

⁵⁵ Baker, 251.

receiving chelation therapy in the U.S. as one example for why this treatment path should be abandoned by both parents and clinicians.⁵⁶ And they also conclude, interestingly, that “desperate and vulnerable” parents are the primary agents pushing for continued availability of chelation and other alternative therapies:

Despite the lack of scientific evidence to support the effectiveness of chelation as a treatment for autism, desperate and vulnerable parents continue to seek medical professionals who will provide the therapy.⁵⁷

I will refrain from inserting my own argument for or against alternative therapies, such as chelation, because what I am most concerned about here is the power of impassioned and organized parents to influence how autism is understood and treated. And consequently, these parents may receive potentially negative attention for their influential presence in medical and autism communities. Two of the mothers I interviewed, sisters Michelle and Julie, subscribed to alternative or “fringe” treatment pathways, with one of their children receiving chelation therapy.⁵⁸ Both of these mothers were passionate about sharing their knowledge and their stories, but directed this passion toward different ends. I will elaborate on their individual experiences below as I summarize each mother’s situation.

C. The Mothers

I. Michelle⁵⁹

⁵⁶ Arla J. Baxter and Edward P. Krenzelok, “Pediatric fatality secondary to EDTA chelation,” *Clinical Toxicology* 46 (2008): 1083.

⁵⁷ Arla J. Baxter and Edward P. Krenzelok, 1084.

⁵⁸ It is important to note that “alternative” treatments, also known as “biomedical” treatments, include other, less invasive measures such as the administration of vitamins and supplements and hyperbaric oxygen treatment (HBOT).

⁵⁹ Some of these mothers, such as Michelle and Leanne, are from a less populated, largely working class region of New Jersey. I was admittedly raised in this area and therefore have more knowledge

Michelle lives in southern New Jersey with her Husband, Chris, and two children, Justin, who is thirteen and diagnosed with autism, and daughter Anna who is sixteen. Justin was diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), which is one of three forms of Autistic Spectrum of Disorders, just before he turned four. Since that time, Justin has made large improvements in his skills and symptoms of autism, progress that Michelle believes came from biomedical and alternative interventions. Michelle and her family live in the less populated working class area of southern New Jersey. Despite the larger economic disadvantages of such an isolated area, Michelle enjoyed some of the privileges of living in and being a part of a community on one of New Jersey's popular coastal islands where the median family income is significantly higher than the national average.⁶⁰ In contrast to the surrounding mainland area, the quality of life on the island is higher due to the well-funded local government, school system, and the wealth of the residents on the island. Even though Michelle described herself as somewhat distanced from the privileged members of this area, she and her husband own and run a successful local restaurant which afforded them enough capital to own a large house on property near the bay. The family's monetary resources made it possible for Michelle to pursue alternative interventions for

about everyday life, the school systems, and social networks that mothers referenced during our interviews. This also means that I have preexisting ideas about the way of life of people from this region. Therefore I attempted to remain aware of when I might be bringing this knowledge into my conversation with the mothers from this area both in ways that may be helpful in the interview or inhibit the discussion.

⁶⁰ From Table 697 "Money Income of Families--Median Income by Race and Hispanic Origin, in Current and Constant (2009) Dollars," http://www.census.gov/compendia/statab/cats/income_expenditures_poverty_wealth.html. Access on March 2nd, 2012.

treating their son, Justin. The family paid for these treatments out of pocket because most insurance plans do not cover biomedical or alternative treatments. Despite having monetary resources, Michelle and her family were still lacking options in terms of support resources and groups for families and individuals with autism, probably due to their location.

Michelle has a master's degree and works as a teacher at a local elementary school during the school year and helps out at the family restaurant in the summer. Her husband, Chris, works year round at the restaurant and, during the summer, often works very long shifts. She identifies herself as the primary caregiver for both of her children, but says that her husband explicitly relinquished control over how to treat Justin and left all of those decisions to Michelle. In our interview Michelle was passionate about her son and his progress, as well as about the biomedical treatment program she pursued for Justin.

II. Julie

After my interview with Michelle, she informed me that her younger sister, Julie, also had a child who was diagnosed with autism. Thanks to Michelle, I soon contacted and was able to schedule an interview with Julie. She is in her late thirties, and she and her family reside in a central New Jersey town. This area has a higher median income than the area in the southern part of the state, where Michelle is located, and is more populated. Because of these differences in location, Julie has more resources and supports in her area. Julie's husband, George, is employed as an attorney for a major pharmaceutical company in the area. She, like her sister, is also

college educated and now works from home heading an organization founded by her and her husband that promotes the formation of Jewish alternative schools.

The couple has three young daughters, Leah who is eight, Hannah who is diagnosed on the ASD and is five and a half, and Rina who is three. In our interview, she explicitly described herself as the primary caregiver for the girls, noting that George works a lot and that it makes sense with their schedules that she would care for the children. In spite of their current arrangements, Julie was not always a stay-at-home and work-from-home mother. When their family was younger, she worked for a number of years in the “corporate world.” She says: “I look like a stay-at-home mom, but that’s not really who I am. In my heart, I’m a suit.” The family seems to enjoy the comforts of upper-middle class status, and Julie is active in her community and with their organization. Working from home has allowed Julie to have the flexible schedule that she needs to provide care for their three daughters. However, as I will elaborate in later sections, Julie does lament that working from home means that it is harder for her to get away from childcare and domestic responsibilities. Julie also utilizes some of the alternative treatments that her sister does, and they both see the same alternative doctor in the state. Despite these broad similarities in approach to treatment for their children, Julie has quite a different perspective from Michelle about these treatments, though she does believe that the alternative therapies can be used to treat autism effectively. I will elaborate more on the nuances of these treatment viewpoints in a later section of this chapter. Julie and George’s daughter, Hanna, was diagnosed as autistic earlier, thanks to the

experiences she had witnessed with Michelle's son, and Julie now describes her status as "so close to neurotypical that people dispute her diagnosis all the time."

III. Leanne

Leanne is in her late twenties and resides with her family in the southern area of New Jersey, not far from the island where Michelle is located. Their family consists of Leanne's three sons, Dominick who is ten, Charlie who is diagnosed with an ASD and is eight, and Adam who is six. The household also includes Leanne's husband, Nathan, and his daughter from a previous relationship, Marie, who is also six and who lives in the household half of the time. Leanne has not received her high school diploma but completed the training necessary to become a home health aide and is currently employed full-time as an aide for patients in the hospice stage of life. Nathan works as a technician for a company that installs wiring for home theater systems, security systems, and internet services. The family recently stopped receiving state welfare assistance based on their income, they live in a rented house, and their family is now entering into a more secure working class status. In comparison to the other mothers I interviewed, Leanne had the least amount of resources with which to access support, information, and treatment options. Additionally, as I discussed above with Michelle, Leanne's family is located in a more rural and isolated area of the state. These two components of their situation are mutually reinforcing; their lack of resources produces barriers to accessing information, and the lack of information contributes to the lack of resources.

Leanne's son, Charlie, was diagnosed with autism around three years of age and is the only child of the mothers I interviewed to have "low level functioning" autism. This means that Charlie is much more cognitively and socially impaired than the other children of moms interviewed. The only treatments Charlie receives are various therapies through the local school system and medication prescribed by the family physician. Leanne has been the primary caregiver for Charlie throughout his life; his biological father was unreliable and currently does not have contact with Leanne or Charlie. After marrying Nathan, she says that her care load has lessened some as Nathan will cook and watch the children when she is assigned weekend shifts. In addition to caring for three, sometimes, four children, Leanne has the double care burden from her employment as a care provider to hospice patients. I will discuss the dynamics of such a care situation in a later section.

IV. Kelly

Kelly, who lives in eastern Pennsylvania, is the only mother I interviewed who resides outside of New Jersey. Her family home is located in a pleasant suburban town within commuting distance to Philadelphia. Kelly is in her late thirties, is college educated, and works part-time from home telecommuting as an administrative assistant for a telecommunications company. Her husband, Matt, is also college educated and works as a banker in Philadelphia. The couple has three boys: Mathew who is six, Sammy who is four, and David who is two. What is most remarkable about Kelly's situation is that she has two children who have been diagnosed with autism—her oldest and her youngest sons, Mathew and David.

Mathew was diagnosed soon before his third birthday and David was diagnosed only a few months before the interview. While David is still quite young and the degree of his autistic symptoms is still being assessed, Mathew has received a phenomenal amount of services and therapies. Mathew is now in kindergarten and in an autistic support program through a local school and is 90% integrated into a mainstream classroom, which might be attributable to the high-level of treatment and therapies he receives.

Kelly's care load differs in an interesting way from the other moms in that she expressed having a much more egalitarian arrangement with her husband, Matt. He enjoys cooking and gives Kelly "space" and time for herself. She said in our interview that she thinks "he's rare as far as dads go." However, despite the understanding that she and Matt have, Kelly spends most of her day caring for the children and the household. And much like Julie, she notes that working from home, while allowing flexibility, also means that she has to balance working and caring for children all in the same moments.

Now that I have briefly introduced the mothers, I will discuss the common and important themes that arose during our interview sessions.

D. The Issues

I. Access and Resources:

"[I]t was a revolving door of people in and out of my house all the time." - Kelly
In this discussion of access and resources, I include details about each

mothers' monetary and social capital and how the amount of resources available to moms hinders or helps their access to services, support, and information. The social

and economic class statuses of these women and their families greatly affect their abilities to advocate on the behalf of and obtain quality treatments for their children with autism. Three out of the four mothers, Michelle, Julie, and Kelly, have relatively high monetary and social capital, while Leanne, on the other hand, does not. The disparity between Leanne's access to services, information, and treatments and the other mothers' is quite striking. This does not mean, however, that there is not variation among the three mothers with higher access to resources. In fact, the location and, interestingly, the treatment paradigm they've each chosen has created a surprising stratification of access between Michelle, Julie, and Kelly.

I consider high paying and/or flexible jobs part of the resources and access category, as they provide families with the ability to both purchase and access services which are unavailable to those with lower incomes or more rigid workplaces. In this regard, Michelle, Julie, and Kelly all have access to relatively flexible employment situations that allow them to be home more often, to take children to appointments, and to deal with any possible crises that may arise. Kelly's work situation, for example, is self-made and allows for a high degree of flexibility. She successfully petitioned the company she had been working for in-office and full time with a business plan for a new position that she could fill via telecommunication. This position allows her to work from home, schedule phone meetings around her the needs of her sons, and still continue to earn an income. While such an arrangement is certainly a privilege, Kelly notes that she took a pay cut and lost benefits, after nine years at the company, and stepped down from a

management position in order to meet the needs of her family. She explains what this decision was like:

It's funny, you know, you work so hard to climb the corporate ladder, and then when you have children, everything changes, your priorities. And I said, 'You know what, I don't want to be a manager anymore,' and I kinda climbed back down the ladder, and now I'm like the bottom rung [laughs]. But it's perfect.

Kelly's thoughts about her situation reveal much more than the perks of leaving the workplace in order to manage her care load better; she is also speaking to the pressure put on mothers to adjust their careers and plans to serve their children, a topic I will discuss later in this chapter. For now, what I would like to focus on with Kelly is that she was innovative in securing a situation that would allow her sons the best possible care. In addition to her unique work situation, Kelly and her family benefit from Matt's employment as a banker in Philadelphia. She notes that Matt had been employed as a social worker for some years before deciding to try something new, and an opportunity at a bank, with its financial perks, was something that was exciting for him. The couples' monetary stability has allowed them to pay out of pocket for an advanced screening, by a renowned doctor, for their youngest son's diagnoses. She describes the phenomenal services the local school provided saying, "It was a revolving door of people in and out of my house all the time." The community that Kelly and Matt reside in is also an enormous resource for support. Kelly says that she doesn't feel she needs autism support groups because her family lives in a very supportive, close-knit community. "People [in our community] have been very accepting. We've surrounded ourselves with, you know, a community of

people that are here to help.” Kelly’s support network and level of access to services are higher than any of the other mothers.

Michelle, as a teacher, has summers off and mentions that her employer allows her come in late and rearrange her class schedule to accommodate Justin’s appointments and needs. In spite of these perks, she still has to report to a job outside of the home most of the year. Michelle does, however, benefit from working at the family restaurant during the summer, which allows her to be home if and when she needs to be. And because she is the sole manager of Justin’s complicated alternative treatment plan, with numerous supplements and therapies, Michelle needs this kind of flexibility in her workplace(s). In the end, despite her family’s monetary stability, Michelle’s location and treatment choices for her son’s condition keep her relatively isolated from the kind of supportive community that Kelly has at her disposal. Michelle also has a difficult time finding other parents who she can lean on for support. In fact, she shares with me that she left one of the only support groups in the area for parents of children with autism after feeling that she was isolated because she was the only parent pursuing non-traditional treatments. Michelle’s experience makes it clear that despite having economic resources and even some social capital, mothers can still feel isolated and limited in terms of accessing a community.

Julie’s degree of access to resources lie somewhere between Kelly and Michelle’s; She has the advantage of working from home, with occasional travel for her and her husband’s organization, and she has the added benefit of her husband’s income as an attorney for a major pharmaceutical company. She has both flexibility

and economic capital. This allows her to pay for some of Hanna's alternative treatments out of pocket, as well as to cover the fees for the alternative doctor that she and Michelle see. Julie, however, doesn't say much about a supportive community or social network. Rather, she states that she was usually the one giving support: "I also sort of feel like I'm more giving support than needing support...because we've been so blessed." Perhaps Julie's needs are met in terms of support, so she doesn't feel that she needs to be highly involved and connected to a community for support with her daughter with autism. She does mention, however, that she subscribes to a LISTSERV from the alternative doctor that contains insights from other parents about particular issues for caring for autistic children. She describes how she utilized the forum: "You can send a message out to the LISTSERV asking, 'I cannot feed my child gluten free macaroni one more time. Help me out here, what else can I cook?' and you'll get three or four recipes back...It's really an extraordinary resource." Here, Julie shows that the kind of support she seeks is based around particular biomedical treatments, such as how other parents manage their children's special diets or behavior. Although Julie has high economic capital and a flexible work-family arrangement, she seems to lack the kind of community that Kelly benefits from. Despite this possible lack, Julie takes an advocacy approach to coping with Hanna's story and says she encourages moms to "get knowledgeable and get vocal."

But not all of the mothers share the same high-level access to a supportive community or resources with which to buy an early diagnosis or high profile doctors. In contrast to the other three mothers, Leanne has both low social and

economic capital and resources. She has never attended any parental support groups, as some of the other mothers have, and even if she found the time while working a demanding schedule with four children, there are few options for support groups in her area. She explains: "I've thought about [going to a support group], but by the time I get home from work and I'm done here [home], I'm just too tired to go anywhere." She occasionally talks to other mothers from Charlie's class about the difficulties of raising a child diagnosed with autism, but this is the extent of her access to a supportive community. In the end, Leanne is skeptical about advice from other parents, saying, "I don't want to hear advice from other parents...If you're not living [the situation], you have not a clue what it's like." Leanne is also limited in terms of resources and mobility for accessing higher caliber doctors, something none of the other mothers had trouble with. Leanne's resources for caring and treating Charlie are limited to the few specialists that her insurance and Medicaid allow. Additionally, Charlie is the only child of the mothers interviewed who is diagnosed as severely autistic and cognitively impaired. Severe impairment in autistic children means that the child is often very limited in verbal ability and has, often times, dangerous behavior issues such as "running off," both of which are characteristic of Charlie's condition. Despite these disadvantages, Leanne says she was satisfied with the treatments Charlie receives and felt that she has a good "parent teacher relationship."

II. Care Load:

"I always feel like, you know, I have all these balls that I'm juggling in the air, and there's no way to keep them all in the air..." -Kelly

Mothers, generally, are doing a disproportionate share of caring for children, and this is even more the case when those mothers have children with special needs.⁶¹ The information from the interviews further supports these claims. All of the mothers perform a large majority of the care labor demanded by their children, especially their children diagnosed with autism. When I ask about the amount of time they typically spend caring for their children, they almost unanimously, three out of four, respond by saying that most of their time is spent caring. Most of the moms also say that caring for their child with autism led to one to three additional hours of care work per day.

Julie's three young girls keep her busy all day long. Hanna requires a gluten free diet, which means that Julie spends extra hours every week preparing special meals for her. She mentions that bedtime is particularly difficult for Hanna. In addition to Hanna's special needs, Julie has two other daughters who also need her attention. She tells me that she was able to find a mature woman, who she trusts and who "can handle it," to watch the girls occasionally. When I ask if anyone else helps her with caring for the children she says that her husband is "working a lot," but that the girls are "very attached to him" and jokingly adds, "Has he given a bath since Leah [their oldest daughter] was an infant? No. Maybe once or twice when I was really pregnant." She makes it very clear that their household is more traditional in terms of "division of labor."

⁶¹ Ellen K. Scott, "'I feel as if I am the one who is disabled': The Emotional Impact of Changed Employment trajectories of Mothers Caring for Children with Disabilities," *Gender & Society* 24, no.5 (October 2010): 673.

Leanne describes her heavy care load with Charlie, saying that a lot her time is dedicated to him. She has to help him get dressed, bathe him, brush his teeth, and serve and clean up his food because “he doesn’t do any of that on his own.” Like Julie, she also has to pay particular attention to his diet—she describes, for example, how red food dye is “kinda like a drug...[it] makes him more hyper and defiant.” As I mentioned earlier, Leanne’s profession can be considered one where care work is commodified. This means that in addition to her familial and domestic care load, she has the added burden of caring for hospice patients during the day. As a hospice home health aide, her work includes supporting, bathing, feeding, and acting as a general companion for people who have reached the last phase of life. Leanne tells me that it is not an uncommon experience to have her patients pass away during her workday and that she will then go home to continue with her domestic and familial responsibilities. Her approach to such demanding days is this: “You do what you have to do...You’re always mommy. And you’re always caretaking, whether physically [or] emotionally.”

Having two young sons diagnosed with autism means that Kelly also has quite a heavy care load. She describes what it is like to balance working from home, caring for two boys with autism, and maintaining a marriage: “I always feel like, you know, I have all these balls that I’m juggling in the air, and there’s no way to keep them all in the air, [that] something is always going to fall, splat!” And when I ask her about the amount of time she spends caring for the children, she laughs and says “100% really...but physical, doing I’d say 80%.” She says that it would be easier if she was in an office. “A lot of times, I’m trying to do work, and they’re running in and

out of the kitchen [where she works]...screaming and yelling, crying, laughing, and I'm on the phone. I'm wearing two hats." She jokes lightly about this balancing act: "I put it on mute, wipe a nose, give a cookie. I mute the phone [laughs]." Although she exhibits a great sense of humor about the difficulty of working from home while caring for children, she also emphasizes how stressful it can be to juggle these "two hats."

Michelle's son Justin is older, now 13, and has made tremendous progress in terms of self reliance and maintenance, which she credits to her explicit goal of pushing him to learn to be autonomous "My goal is to make them independent...[Justin] is perfectly capable of making his own peanut butter and jelly or chicken nuggets," and she is currently teaching him how to do laundry. Michelle tells me that as her two children grow, her care load has gotten a bit lighter. "[M]y kids are now able to be self sufficient, you know. When I was younger, it was all about them. Kids, husband, house, and then me...[I was] fourth because the house came before me." When her children were younger her care load was very heavy. She took on the responsibility of driving Justin to his doctor (an hour and half away), administering his medications, tailoring special meals for him, and keeping up with the house. Despite Justin's great progress in skills and autistic symptoms as he grows, and while her husband cooks (he is a chef) and will drive their children to events, Michelle is still carrying a heavy care burden. She continues to be the primary planner and executer of his care and treatment routine, as well as the sole caretaker of household responsibilities.

Overall, in spite of differences between each mothers' care arrangement, they all have or have had very heavy care loads. All three mothers have balanced some form of paid employment with caring for multiple children, and they all describe themselves as the ones doing most of the caregiving. While it is certainly true that having a reliable "babysitter" or a spouse who is able and willing to look after children, these occasional supports do not outweigh the heaviness and emotional toll that comes with being the sole care provider.

III. Self-time and Emotional Well-being:

"It probably took nine months for me to say, 'My son is autistic,' without sobbing my eyes out." -Michelle

The massive amount of care work performed by these mothers can take a toll on both their emotional well-being and the amount of time they have for themselves. Research has shown that "mothers of children with ASD experience significantly higher levels of stress and lower levels of psychological well-being than mothers of children without ASD."⁶² From the beginning of their journey with a child who is diagnosed with autism, mothers described emotional struggle and depression. Two mothers succinctly describe how they reacted to their children's initial diagnosis. Michelle relates her feelings of hopelessness after first finding out about Justin's diagnosis: "When he was first diagnosed...if I mentioned it, I burst into tears. It probably took nine months for me to say, 'My son is autistic,' without sobbing my eyes out." Similarly, Kelly said that it took her six months to say the word "autism" without crying after hearing about her oldest son's diagnosis. The

⁶² Leann Smith and others, "Daily Experiences Among Mothers of Adolescence and Adults with Autism Spectrum Disorder," *Journal of Autism and Developmental Disorders* 40 (2010): 175.

initial shock of diagnosis brings out the mothers' worst fears for their children—that they might not get to live the life the mothers imagined. Kelly describes this feeling:

It's hard to think, 'Oh, the hearts and flowers in the sky when you get married and love and the chapel, and the wedding, and then we'll have babies and live happily ever after,' when *wham* one of your kids has special needs. It's not the life that I thought I'd be living.

Coping with the adjustments, both emotionally and structurally, that come with having a child with “special needs” can result in an increased level of stress and emotional difficulty for these moms.

Julie discloses to me that she has a history of 15 years of “dealing with” depression and anxiety. Her demanding care situation, no doubt, has made this history of depression and anxiety all the worse. She speaks about how losing sleep, because of stress and Hanna's sleeping troubles, has affected her emotionally and sapped her energy. Leanne describes how stress and depression factor into her situation:

[Stress] takes a toll on everything, it takes a toll on the other children, it takes a toll on any relationship, married or not...It gets depressing, cause even though I know it's not my fault...every parent wants the best for their child. And as stressed out as and depressing as it might get me, my depression comes a lot of thinking how hard it must be for him.

How are these moms dealing with stress? Michelle told me that she has begun to take morning walks and bike rides with friends as a way to get away from the house and to relieve stress. The interviews reveal that taking time to oneself is an effective way to thwart stress and depression. Kelly describes her active social life and how her husband regularly offers to watch the kids in the evening so that she can go out

with friends. The couple also goes out for group dinners with friends in their community a few times a month, which they can do because, as Julie tells me, they have a very reliable, adult babysitter who gives them more frequent time out of the house, solo or as a couple. Leanne, in contrast to the other mothers, has a harder time finding time for herself, which she attributes to the lack of reliable childcare for Charlie. She says that even though she didn't get much time for herself on a daily or weekly basis, she is able to do so once or twice a month.

IV. Autism:

"I was ready to do fringe." -Michelle

One aspect of these interviews that I had not anticipated was the degree to which moms would voluntarily provide me with extensive details about their children's journeys with autism. Of course, it makes perfect sense that moms would want to talk about their children at length; they invest a majority of their energy toward caring for these children. So perhaps my surprise at this aspect of the interviews reveals my naiveté about what it is like to be a mother, in general. Nonetheless, the amount of time that all of the mothers spent discussing each of their autistic child's (or, in Kelly's case, *children's*) journeys speaks not only to the degree to which they make their children a priority, but also how much of their worlds, their lives are comprised of caring for, thinking about, and planning for these children. In this section, I want to look at how moms talked about their children's autism or autistic symptoms in order to return to some of the theoretical concerns from the last chapter—that is, how these mothers might create meaning around autism through the way they talk about the condition itself.

My interview with Michelle is most striking with respect to this topic. She is enthusiastic and passionate in her discussion of Justin's diagnosis and treatment. She explains to me, in great detail, the various alternative treatments for autism and the rationale behind them. After reading about mercury poisoning and its hypothesized relationship to autism, Michelle was convinced that this was what Justin needed. She tells me: "I believe that my son's autism was caused by his vaccinations." Soon after learning about alternative therapies, she was "ready to do fringe." She whole-heartedly believes that biomedical therapies, such as chelation and a strict supplement regimen, are responsible for the vast improvements in Justin's autistic symptoms. Michelle speaks about Justin's condition as though she believes that he is "recovering" from autism. Some families who subscribe to alternative therapies, such as Michelle, believe that their children can eventually "live a normal life." Michelle, through her doctor, learned about children that had presumably "recovered" or has been "cured" of their autistic symptoms, so she was on board for the alternative treatment agenda that supposedly led to recovery. While explaining to me how she felt before she heard about the potential for Justin to recover, she says:

[A]t the time, your hopes and your dreams for your child are gone. And as far as you know, this is the way they're going to be for the rest of their life. Back then, there was no such thing as a recovered child, and I hate to say it, but there was no hope...but now look what I did. He's gonna have a life, he's gonna have a future, he's gonna be able to get married, and when he was non-verbal, you're thinking institutions as an adult. But that's not going to happen because I didn't allow it to happen, because I'm the mom, and I did what had to be done.

This aspect of Michelle's view of autism, as well as others who believe in the recovery paradigm, is controversial precisely because the goal is to "return" the child *normal*, which can signify that having a diagnosis of autism is not normal and, therefore, not acceptable. She also explains to me that her family does not "label" Justin and that he is not fully aware of his diagnosis. While I respect Michelle's decisions as a parent and do not wish to contribute to the pressure put on mothers, I would also like to complicate the decision to reject labels. Rosmarie Garland-Thomson writes about the choice to reject disability as part of one's identity: "People with disabilities routinely announce that they do not consider themselves as disabled...Our culture offers profound disincentives and few rewards to identifying as disabled...the refusal to claim disability identity is in part due to a lack of ways to understand or talk about disability that are not oppressive."⁶³ Garland-Thomson is indicting the pervasive culture that privileges the normative and rejects the subjectivities of those living beyond the purview of the normal. The autism recovery paradigm has the potential to turn the autistic individual into the other and to reinforce the construction of the abjection of disability. This paradigm also aligns with the Foucauldian concept of disciplining bodies to conform to a normative and efficient standard. Michelle and other parents who believe in this recovery paradigm, however pure their intentions, run the risk of creating a culture that views the autistic body as unacceptable and in need of discipline.

⁶³ Rosmarie Garland-Thomson, "Integrating Disability, Transforming Feminist Theory," in *Gendering Disability* eds. Bonnie G. Smith and Beth Hutchison, (New Brunswick: Rutgers University Press, 2004), 93.

Julie heard about the potential of alternative treatments from her sister and decided to take Hanna to the specialist Michelle recommended. In contrast to Michelle, Julie tells me that she is not certain if autism is curable, but the alternative therapies, she says, are a way to treat the symptoms of autism. “I don’t know about cured, but [autism can be] treated effectively.” Julie is very interested in the research conducted in the alternative treatment community. She speaks a great deal about the problem with research on autism in the U.S., especially as compared to the U.K. The problem, as she describes it, is that researchers concerned with the cause of autism in the U.S. are asking the “wrong research questions.” I was fairly convinced by her argument about the common practice of administering vitamin B12 shots to autistic children—it isn’t that autistic children do not have enough B-12, it is that they are supposedly unable to digest the vitamin because they lack the enzymes to convert B-12 into a usable form. This makes sense to me, especially when the drive for pharmaceutical companies to profit from patentable medications and treatments is taken into consideration. Julie says the real problem is that B-12 cannot be patented as a drug; it already exists as a vitamin.

My husband works for a major pharmaceutical company. I know what it takes to get a drug through the FDA. The bottom line is that nobody is going to pay millions of dollars for it, because nobody’s going to make millions of dollars on it because you can’t patent B-12.

B-12 cannot be marketed, packaged, or sold the same way that mood drugs, such as, the antipsychotic medications that many “low-level” functioning children, like Leanne’s Charlie, are prescribed. Although Julie utilizes the same doctor and some of the same treatments as her sister, it is clear in her interview that she holds a

different perspective on the problems with the treatment of autism and research into its etiology.

Leanne and Kelly hold much more mainstream perspectives about how to treat autism. Leanne's doctor did recommend a B-12 supplement, which medical professionals think increases cognitive functioning, and melatonin, so that Charlie can sleep through the night, among other medications, but Charlie's treatment plan is much more "mainstream" and typical of a child with his degree of autism. Leanne says she had heard about the alternative treatments, and is interested in the vaccination theory, but is satisfied with the treatments Charlie receives.

While Kelly's approach to treating her two sons is also quite mainstream, she voices a strong negative opinion about the proponents of the recovery paradigm. She believes that pushing for recovery is more about the parent's interest than the child's:

The parents, to me, are not thinking about their child—they're thinking about themselves. It's very painful to say I have a child with autism...[but] it's not about you and what you want for them, not to be labeled or whatever, because like it or not, your kid is going to get labeled anyway.

Kelly makes an interesting case for those that oppose the recovery paradigm.

Hoping for a cure or deciding not to label a child stem from parents' desires to make autism go away, not necessarily from wanting to help the child.

Regardless of the position these parents take up on the issue of treating and curing autism, I want to make it clear that every one of these mothers describes that they did what they felt was best for their child in terms of treatment and care.

Additionally, the tension between parents "for" or "against" alternative treatments and recovery theories has the potential to create further pressure on and judgment

of mothers' choices about how they treat their children with autism. It creates new hierarchy of pressure, one which is from within a community of women that are already faced with additional pressure. This brings me to the topic of the final set of issues from the interviews, mothers and their feelings of blame or pressure.

*V. Blame and/or Pressure on Mothers:
"[A] look is enough." -Leanne*

In this final set of issues, I want to return to one of the initial concerns of this project: how blame, guilt, and pressure may still complicate the care work situation of mothers of children with autism. During our interviews, none of the mothers say that they have been blamed directly for causing their children's conditions. But while they have not been blamed directly, the ways in which they speak about their experiences caring for their children suggests that they have indeed felt pressure and judgment from outside sources. It was not surprising to hear Kelly, for example, say: "I have never felt blamed that Mathew's condition's my fault." But in our discussion about caring for Mathew, she did indeed express feeling pressure. She talked about the pressure to be a "great mom" and how motherhood is something women are pressured and trained into; she says, "You know, as a young girl growing up, what do you play? House, Barbies, like all that." Kelly invokes the gendered ideals that are pressed upon many women and in turn reveals the extent of the effects of gendered socialization and traditional familial ideology.

Additionally, Kelly talks about putting pressure on herself, "I feel like I put that [pressure] on myself, I put pressure on him to conform to what he should be doing

in that moment, what a typical child would be doing.” Self blame and self-imposed pressure are a common theme throughout the interviews. Michelle echoes this kind of self-imposed pressure when she told me that she feels she contributed to Justin’s supposed mercury poisoning through breastfeeding. She also says that she puts a lot of pressure on herself to stick strictly to his treatment regimen, “Back then, I felt like if I miss [a dose] he’s gonna relapse, he’s going to get worse, you can’t do that, *you have to be the perfect mother.*”

The pressure on mothers to produce healthy, “functional,” and productive children surfaces in other ways. Two of the four mothers had left careers in order to care for their children. Julie says she left her career because balancing the care load and a career got to be too much and she felt she had to focus on her daughters. She feels that: “The pressure to do whatever can be done [for children] is on women.” And the pressure put on moms, in Julie’s case, can operate in ways that make moms feel guilty for leaving work, creating a lose-lose situation where a mother feels like she has to leave work in order to provide better care for her children, yet people may look down on her for doing so. She tells me, for example, that her decision to leave her career was met with disparaging remarks from her male boss.

He made a lot of comments about me choosing the ‘mommy track,’ and I told him, ‘No, I have a kid who is extremely difficult.’ [And] he’s like, ‘Every kid is extremely difficult and you’re just choosing not to work...and you want to have a job for your self esteem so you’re still working in your head’...He was really, really horrible.

Kelly stepped down from her managerial position for similar reasons; the pressure of caring for multiple young boys, two of whom are diagnosed with autism, ultimately led her to leave her office and her hard earned managerial position in

exchange for working from home in a lower-paying position that did not include benefits.

In addition to self imposed pressure and the pressure to leave work in order to care for children, some of the mothers feel that the people around them are placing judgment in more subtle ways. One of the most interesting and compelling points that comes up is the looks or stares that moms and their children receive from strangers in public. One striking detail about Leanne's interview is that she felt like people have judged, and possibly blamed, her with their glances and stares at her and Charlie. She explains that in public places, like the grocery store, she has been subjected to staring eyes that often felt accusing: "I get a lot of looks...when [Charlie] is acting out. You know? Some people look at you like, 'Get your kid under control.'" When I ask her if she has felt blamed in any way for Charlie's conditions, she replies, "Sometimes it's the looks, it's just a look is enough, a look is enough." She said that she is able to "blow it off," but that she does notice when and how people stare at her and Charlie. And Leanne is not alone in perceiving the gaze of judging eyes. Michelle described a few similar scenarios. She, for example, cannot talk about Justin's pica episodes with parents of neurotypical children because "they look at you like, 'Oh my god, what a horrible mother are you.'" And she recalls that when Justin was having a tantrum in public and she did not know the cause, "It could have been the color of the carpet, it could have been the picture on the wall—you don't know. He's having a tantrum to end all tantrums, and I'm trying to pay this tax bill...and [a woman who worked in the office] comes out and gives me the dirtiest look." Michelle has many examples of the judgmental stares she and Justin receive in

public. Another instance included when Justin had a hard time swallowing medication and supplements; she used to mix them with juice and had to force him to drink the mixture. “The parents thought I was horrible: how could I make my child take all those pills, and what a horrible mother I was...I did what I thought was right. But people look at you funny.”

The issue of mothers noticing the stares and looks of outsiders brings this discussion back to the theoretical concerns of this project—disciplining bodies and monstrosity and motherhood. I will revisit these theoretical concerns in the final chapter, but before moving toward those theoretical discussions, I would like to address the gendered dynamics of carework and household division of labor as expressed in the interviews. As I discussed above, women are shouldering a disproportionate amount of the caring for all children and this is especially true with their children on the ASD. One father, Michelle’s husband Chris, was open with her about his inability to cope with the process of treating their son and told his wife that he couldn’t “deal with it.” Although the couple agreed that Michelle would be the one to take over Justin’s treatments and care, agreeing to divide the labor in a particular way does not change the fact that the situation is unequal. All of the women mentioned that their husbands would “help out” with the children occasionally, for example on weekends or evenings after work. And though there was some variation in the amount of “helping”—Kelly’s husband Matt, for example, seemed to be the most helpful with childcare as he would care for the children at least one evening a week—the general trend for all four couples was that fathers spent most of their time working outside of the home while mothers worked from

home and cared for the children. In addition, there was a unanimous consensus that the fathers had a “harder time” coping with having and caring for a child with an ASD. When Kelly touches on Matt’s difficulties in dealing with have sons on the ASD, she says that he “absolutely” has a harder time seeing the positive progress of their sons. She says:

He doesn’t see that daily triumphs with our kids because he comes home, ya know, at 6 o’clock at night, and that’s the *worst time of day!*...So, he sees the kids at their worst...[and] for a Dad to see his son not enjoying baseball...that’s painful. And I get it, but at the same time, sometimes I’m like, ‘Alright, enough. This is our life...get in the game.’ And he does.

Kelly shows that she understands her husband’s difficulty but also wants him to “get in the game” and understand that this is their reality. It seems, at moments like this, that these women, in addition to caring for their children, must also guide and support their spouses through the coping process.

During all of the interviews the women seemed to want to emphasize that their husbands *did help* and that they were involved in some way in the raising and caring for their children. In spite of the occasional meal, day or evening watching the children, and “helping out” around the house with chores, the husbands of the women interviewed appeared to be doing just that—helping or assisting the women with the childcare and domestic responsibilities. It seemed that the male partners of this group of women largely fell into traditional patterns of household division of labor. Of course, this is true for some families more than others, but the gender inequity in the distribution of caring duties none-the-less remains true for all of these families.

Although there is no panacea for the heavy care load of these women, it would seem that women could find some degree of relief if fathers and partners put effort toward helping carry the family care burden. In the next and final chapter, in addition to working through the theoretical questions mentioned earlier, I will elaborate on other, extra-familial supports from which women such as those interviewed can benefit.

Chapter IV: Concluding Thoughts, Programs and Supports

The interviews showed that these mothers are not being blamed explicitly for causing their child's autism, but, as we saw, mothers still feel pressure and sustain the burden of pressure in other ways: through looks and stares. I would like to revisit these questions: *Is staring a way of policing and disciplining mothers and their children? Is the pressure that is internalized by mothers a product of a Foucauldian kind of disciplinary mechanism? Does monstrosity, in Shildrick's terms, indeed extend from the child to the mother? And is the pressure put on mothers to provide the best care possible evidence of this extension of monstrosity?* Looks from others show how mothers have become an extension of their child's autism, their child's perceived monstrosity. The onlooker, who responds to something they may see as abnormal, stares at *both* the mother and the child, in effect equating the child's condition with the mother. And further returning to Shildrick's ideas, the threat of otherness and the vulnerability to otherness is also embodied in the mother who created and creates otherness. The onlooker, by staring at mother and child, collapses a complicated situation down into one spectacle, something that is to be stared at—the monstrous child *and* mother. The one who stares, presumably stares out of fear (of otherness), out of confusion, and, perhaps, out of curiosity for the otherness before them.

The gazes mothers receive also evince the exact kind of subtle and pervasive disciplining that is the subject of Foucault's work. To the onlooker, the mother is responsible for the child's condition; she is to be held accountable for what is perceived as abnormal (in need of discipline), and she is the one who should *fix*

(discipline) and control the child's condition. The gaze is an act that works to discipline the mother, who is in turn supposed to be the one responsible for disciplining and correcting the autistic child. Without knowing what the onlooker is thinking, it is, of course, impossible to be certain of the look's intention. Intention, however, is not my concern here. I am concerned rather with the effect of the look. Regardless of the onlooker's intention, I argue that these looks affect the mother and have real consequences—the mothers who are subjected to these looks feel subject judgment and blame.

Returning to the initial concerns of this project, I want to conclude with some thoughts about where mothers of children with autism are now positioned in terms of blame, pressure, and care work. It is clear that outright blaming of mothers for causing autism is no longer a common experience. From the interviews with these four mothers, we can see, however, that mothers still feel pressure and judgment from outside sources. And as the discussion at the end of the last chapter illustrates, the examples from the interviews of moms feeling judged and pressured confirms how they are, in some ways, held accountable for their children's condition and well being. Looks received in public demonstrate how people outside of the mother may be evaluating, inspecting, and even attempting to enforce discipline upon her behavior and parenting habits. What can be done to help ameliorate the pressure these mothers face? What interventions, support programs, or social changes could help their situations?

To begin, it is important to highlight that the socioeconomic differences and differential access to services among mothers could indicate that there is no

singular solution for their difficulties. Not all mothers have the time or resources to travel long distances to meet with support groups, and not all can afford to pay for an outside care provider to watch their children while they attend support meetings, and for these mothers, perhaps online resources and communities may be more helpful. Below, I highlight a few current, and some local, programs and support networks that could be vital resources. One possible local solution for these moms is the Brooklyn based group, My Time Inc, which is geared toward providing hands-on support for caregiving parents. On their website, they describe their goal as follows:

My Time Inc support[s] parents by providing support and friendship circles, education and training to gain the appropriate strategies and skills to work with their children at home and advocate on their behalf navigating governmental regulatory structures. My Time Inc is at place of refuge, free expression and relaxation.⁶⁴

One study on the effects of support groups on the mental health of mothers of children with autism found that these moms need time “for self-exploration and sharing ideas and experiences.”⁶⁵ A group, such as My Time Inc, could function as just such a space for self-exploration and thought sharing. The organization holds meetings four times a week for a “support circle” where parents can vent about their troubles, share stories, and give advice. The group also advocates for parents’ needs in their schools and their communities.

In terms of access to professional advice and support, St. Joseph’s University in Pennsylvania created a center for autism education and support, called the

⁶⁴ My Time Inc., “Welcome.” <http://www.mytimeinc.org/index.php>.

⁶⁵ B.C. Shu and F.W. Lung, “The effect of support groups on the mental health and quality of life for mothers with autistic children,” *Journal of Intellectual Disability Research* 49 (January 2005): 51.

Kinney Center. The Kinney Center provides parents with information and more practical supports, such as advice and support, about diagnosis information, school programs, and how to cope with aging children with autism. Their main objective in helping parents is, "To provide a resource center that builds networks linking parents and family members across systems and settings, throughout the life cycle."⁶⁶

For moms who have a difficult time getting away from the house and cannot afford any additional expenses, there is the recently created blog and forum, "Special Learning Expert Blog," which describes itself as "the comprehensive autism solutions company" and has a free and open forum of professionals and specialists on autism who answer questions and post blogs.⁶⁷ A resource such as this is valuable because even as the diagnosis rate of autism continues to increase, there continues to be a dearth of information on how to cope with Autism in everyday life. In addition to providing informed advice from professionals in the field, parents on the Special Learning blog can share their experiences in blog entries that can then be followed by friends or other parents looking for advice. Interestingly, when I asked moms about the services and supports they used, other than Michelle who utilized a LISTSERV, none of the mothers mentioned getting support through online communities.

The Arc is a national non-profit organization that has state and local chapters and is geared toward supporting both caregivers of and people with autism. Formed in 1950, this group claims to be the nation's largest "community-based organization

⁶⁶ The Kinney Center, "Objectives," <http://kinneyautism.sju.edu/about/objectives.html>.

⁶⁷ Special Learning Expert Blog, <http://www.special-learning.com/home>.

advocating for and serving people with intellectual and developmental disabilities and their families”; there are currently over “140,000 members who are affiliated through approximately 750 state and local chapters across the nation.”⁶⁸ The Arc’s local chapters provide a wide range of services, such as respite care, educational services, and supported employment, while still others focus on advocacy and changes in policy. In New Jersey, there are currently 20 local chapters of The Arc, which means that every county in the state but one has a location that is accessible to families with children with developmental or intellectual disabilities. Because of this organization’s local presence, I asked the mothers I interviewed if they had heard of or attended meetings with The Arc of their area, and two mothers knew about the organization and its efforts, but neither mother had used their services.

The options are unfortunately few for mothers of children with autism in the way of governmental support programs, with only two programs that have attempted to reach caregivers standing out. First, the U.S. Department of Health and Human Services’ Administration on Developmental Disabilities (which is part of the Administration for Children and Families) created the Family Support 360 Program. In this initiative, states receive grants in order to serve the families of children with developmental disabilities. The goal of this program is to create so-called “one-stop support” centers for families with children who have disabilities, where all members of the family, including caregivers, can potentially have some of their needs met. Some of the services available at these centers include assistance locating and navigating public human services agencies and connecting to private community

⁶⁸ The Arc, “History of The Arc: The Power of Parents,” <http://www.thearc.org/page.aspx?pid=2338>.

organizations; this includes help finding respite or childcare, education, financial education, and transportation.⁶⁹ The focus on caregiver support is lacking or inconsistent on the ground, e.g. in state specific centers and, in New Jersey for example, the only “FS 360” programs that are currently operating are geared toward specific portions of the developmentally disabled population—specifically, the two programs are designed for students transitioning from formal education into vocational training in one of the state’s urban areas, and one only provides support for military families.⁷⁰ These population specific programs concentrate their efforts toward transitional adjustments for particular groups of disabled young people and do not, as per their mission statements, largely focus on caregiver support.

The other additional governmental support program is the National Family Caregiver Support Program (NFCSP). The program was established in 2000 under the Older Americans Act (Title IIIIE) of 1965. It is the first piece of federal legislation that is aimed at helping or supporting family caregivers. This program “provides grants to states and territories based on their share of the population aged 70 and over, to fund a range of supports that assist family and informal caregivers.”⁷¹ Some of the services that NFCSP provides to caregivers include information about assistance services, counseling, training, and respite care services. And according to the Administration on Aging, studies “have shown that these services can reduce caregiver depression, anxiety, stress, and enable them to provide care longer,

⁶⁹ Administration for Children and Families, “Administration on Developmental Disabilities, Family Support 360,” www.acf.hhs.gov/programs/add.

⁷⁰ IBID., Administration for Children and Families.

⁷¹ Department of Health and Human Services: Administration on Aging, “National Family Caregiver Support Program (OAA Title IIIIE),” http://www.aoa.gov/AoA_programs/HCLTC/Caregiver/index.aspx.

thereby avoiding or delaying the need for costly institutional care” and that “89 percent of caregivers reported that services helped them to be a better caregiver.”⁷² In a state-level report in 2009 on New Jersey caregivers’ use of services, however, only 1,680 people were served respite care, while 15,288 persons used caregiver “access assistance.”⁷³ These numbers show that the supports offered to caregivers are less than optimum, with a very small amount of caregivers actually receiving valuable services like respite care, while a large group receives a referral service. This program has also been limited in its scope and does not reach out to families of children with disabilities or special needs and is instead aimed primarily at the aging population and issues of long-term care. The expansion of the NFCSP to include the caregivers of children with disabilities is one of the policy changes proposed by non-profit and advocacy organizations, demonstrating that while they’re doing the groundwork, governments are slow to respond.

The most disappointing efforts aimed at supporting this group of caregivers have been at the governmental level. Overall, governmental supports that target the primary caregivers of children with disabilities are severely limited in their scope and reach. As the Administration on Aging’s NFCSP shows, a great deal of government focus on supporting caregivers has been allocated to those who care for the aging population. And although the Family Support 360 program is geared toward the needs of families with persons with developmental disabilities, this program is also falling short in providing tangible supports for caregivers. Heller and associates argue that “family support policy has not emerged as a national

⁷² IBID., Administration on Aging.

⁷³ IBID., Administration on Aging.

priority in the United States [and only] 5% of developmental disabilities funding is allocated for family support.”⁷⁴ It seems this population is given ritual nods—on the governmental level that might take the form of initiatives, such as the Family Support 360 program—and they are left with menial supports, like referral services, instead of substantial, useful assistance. In *Market Friendly or Family Friendly? The State and Gender Inequality in Old Age*, Madonna Meyer and Patricia Herd argue that rather than the “market-friendly approach that maximizes individual choice, risk and responsibility...the state must support unpaid care by providing economic and social supports for those who do care work and providing alternative sources of care for those who do not.”⁷⁵ It is crucial, as Meyer and Herd contend, that policy makers begin to turn attention toward a policy path that is supportive of family caregivers, like mothers of children with autism, rather than leave the burden of care to be shouldered by female caregivers, who are addressed minimally and with limited programs.

The variety of existing support programs and policies for caregivers and parents described above shows that there is a growing culture of awareness about how difficult caring for another individual can be, especially when that individual has special needs. It is hard to say which of these options would best meet the needs of the mothers I interviewed, but from the information collected in the interviews, it was clear that all of these mothers felt that they benefited from being able to

⁷⁴ Tamar Heller, Joe Caldwell, and Alan Factor, “Aging Family Caregivers: Policies and Practices,” *Mental Retardation and Developmental Disabilities* no. 13 (2007): 139.

⁷⁵ Madonna Meyer and Pamela Herd, *Market Friendly or Family Friendly? The State and Gender Inequality in Old Age* (New York, NY: Russell Sage Foundation, 2007): 130.

connect with other mothers of children with autism, the people who most closely understand what they are going through and can give the most relevant advice. For this reason I think that groups such as My Time Inc, the Brooklyn based parent's support network, could be the most valuable resources for moms like Michelle, Julie, Leanne, and Kelly. An added issue with the supports available to this group of women is that all of the programs masquerade as programs for "caregivers" or "parents" in a way that is gender neutral; it is clear, however, that female caregivers are the intended audience and the most common patrons of these support resources, groups, and forums.

In light of the lack of governmental and institutional supports available, mothers caring for children with autism, like the ones I interviewed, are left at a loss for support outside of their immediate social network. So, if they are lucky enough to have access to a supportive community like Kelly has, they may be able to supplement the deficit of established supports for moms. The support networks, both online and in real life, discussed above can also work to supplement the deficit of institutional support, but only if moms are able to access those groups and services. Otherwise, these mothers are left to continue on the paths they are already on—to continue to use what supports they have to cope with the pressure and stress of caring for a child with autism. And, of course, there is a great deal of research that remains to be conducted that extends upon some topics of this paper. For one, I think that a study that looks at mothers, caring, and the differential levels of ability in autistic children would be invaluable. The disability specific symptoms and behaviors of children are likely to have a considerable impact on the care load

of mothers. A project designed to look more closely at class and racial differences in care work of mothers of children with autism is also needed. The implications of choosing an alternative treatment path on mothers of children with autism could also be a particularly interesting and important research endeavor.

Appendix A: IRB Approval, Recruitment Letter, Consent Form

RUTGERS UNIVERSITY
Office of Research and Sponsored Programs
ASB III, 3 Rutgers Plaza, Cook Campus
New Brunswick, NJ 08901

August 5, 2011

P.I. Name: Parker
Protocol #: 11-641M

Jennifer S. Parker
435 South Second Ave
Highland Park NJ 08904

Dear Jennifer Parker: ✓

(Initial / Amendment / Continuation / Continuation w/ Amendment)

Protocol Title: "Interviews with Mothers of Autistic Children: Mothers Thoughts on Caring"

This is to advise you that the above-referenced study has been presented to the Institutional Review Board for the Protection of Human Subjects in Research, and the following action was taken subject to the conditions and explanations provided below:

Approval Date:	8/4/2011	Expiration Date:	8/3/2012
Expedited Category(s):	6,7	Approved # of Subject(s):	7

This approval is based on the assumption that the materials you submitted to the Office of Research and Sponsored Programs (ORSP) contain a complete and accurate description of the ways in which human subjects are involved in your research. The following conditions apply:

- **This Approval**-The research will be conducted according to the most recent version of the protocol that was submitted. **This approval is valid ONLY for the dates listed above;**
- **Reporting**-ORSP must be immediately informed of any injuries to subjects that occur and/or problems that arise, in the course of your research;
- **Modifications**-Any proposed changes MUST be submitted to the IRB as an amendment for review and approval prior to implementation;
- **Consent Form(s)**-Each person who signs a consent document will be given a copy of that document, if you are using such documents in your research. The Principal Investigator must retain all signed documents for at least three years after the conclusion of the research;
- **Continuing Review**-You should receive a courtesy e-mail renewal notice for a Request for Continuing Review before the expiration of this project's approval. However, it is your responsibility to ensure that an application for continuing review has been submitted to the IRB for review and approval prior to the expiration date to extend the approval period;

Additional Notes: Expedited Approval per 45 CFR 46.110

Failure to comply with these conditions will result in withdrawal of this approval.

Please note that the IRB has the authority to observe, or have a third party observe, the consent process or the research itself. The Federal-wide Assurance (FWA) number for the Rutgers University IRB is FWA00003913; this number may be requested on funding applications or by collaborators.

Respectfully yours,



Acting for --
Sheryl Goldberg
Director of Office of Research and Sponsored Programs
gibel@grants.rutgers.edu

cc: Mary K. Trigg

Interviews with Mothers of Children with Autism: Mothers Thoughts on Caring for
Children with Autism

Jennifer Parker

Introduction

You have been invited to participate in an interview-based research study in which you will be asked questions about what it is like to care for a child with autism. The interview will last between two and three hours and, at your convenience, can be split into multiple sessions.

Background Information and Purpose of Study

This project is being conducted as part of my master's thesis in Women's and Gender Studies at Rutgers, The State University of New Jersey. The purpose of this research is to gather in-depth information from mothers who have autistic children and to collect information about the difficulties of caring for a child with autism. This will be done in interview format. The questions during this interview include details about caring for an autistic child, mothers' perceptions, and feelings about caring for children with autism, as well as information about balancing employment and caring for a child with autism and details about family structure. After completing this interview research, I will analyze and compile interview data into a Master's thesis.

Risks and Possible Benefits

The interview process that you will engage in during this study does not pose any physical risks to you. However, some of the questions you will be asked to answer may affect you emotionally. These questions include information about what it is like to care for a child who is diagnosed with autism and your feelings about caring for a child with autism. Therefore, you may experience some level of emotional distress.

There are no direct benefits for you in this study. However, your participation in the interview process can help open up further research about mothers of autistic children, as well as provide a broader understanding of the needs and problems this group faces when caring for their children.

Confidentiality

This research and information collected during the interview process is confidential. Confidential means that my research records will include some information about you, such as your name, job, family composition, and phone number. I will be assigning a "code" to your name and will use that code in my research notes. This code will link the identifiable information you give to me to you. However, the code list will be in a file, in a secure area with access limited to myself (i.e. a password protected computer file) and separate from my research notes. I will keep your information confidential by limiting individual's access to the research data and keeping it in a secure location. The Institutional Review Board at Rutgers University and myself will be the only parties that will be allowed to see the data, except as may be required by law. If a report of this interview is published or if the results are presented at a professional conference, only group results will be stated unless you have agreed otherwise.

APPROVED

Date: 8/1/11

Compensation

You will not receive any monetary compensation for your participation in this study. **EXPIRES**

Subject Initials _____

AUG 03 2012

Approved by the
Rutgers IRB

Audio Recording

During the interview process I will be running an audio recorder. This is done to be sure that I do not miss any of the important information you give me during the interview. If you prefer not to have the interview recorded, please let me know. If you agree to complete the interview with the audio recorder on, please sign and date below.

Subject Signature

Date

Contacts

If you have any questions about the study procedures, please ask me. I can be contacted at (512) 665-7256 or at jennifer.s.parker@gmail.com. If you have any questions about your rights as a research subject, you may contact the IRB Administrator at:

Rutgers University Institutional Review Board for the Protection of Human Subjects
Office of Research and Sponsored Programs
3 Rutgers Plaza
New Brunswick, NJ 08901-8559
Tel: 732-932-0150 x. 2104
Email: humansubjects@orsp.rutgers.edu

APPROVED
Date: 8/4/11

Graduate Faculty Advisor:
Mary K. Trigg
Women's and Gender Studies
162 Ryders Ln.
New Brunswick, NJ 08904
Tel.: 732-932-9331
E-mail: trigg@rci.rutgers.edu

EXPIRES

AUG 03 2012

Approved by the
Rutgers IRB

Participation

Your participation in this study is voluntary; you may decline to participate at any time without penalty to you. If you decide to participate, you may withdraw from the study at anytime without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be removed from the data set and destroyed.

Please sign below if you agree to participate in this study. You will be given a copy of this form to keep.

Signature of Subject

Date

Signature of Investigator

Date

Subject Initials _____

Attachment 3

Researcher Looking for Mothers of Children with Autism to Interview

Jennifer Parker, Rutgers University Women's and Gender Studies

What is this research about?

This project is being conducted as part of my master's thesis in Women's and Gender Studies at Rutgers, The State University of New Jersey. The purpose of this research is to gather in-depth information from mothers who have autistic children and to collect information about the difficulties of caring for a child with autism. This will be done in interview format. The questions during this interview include details about caring for an autistic child, mothers' perceptions and feelings about caring for children with autism, as well as information about balancing employment and caring for a child with autism and details about family structure. The larger purpose of this research is to get a better understanding of how mothers of children with autism think and feel about raising a child with autism and to look at areas where future research might need to focus (for example, what kinds of support programs does this group need). After completing this interview research, I will analyze and compile interview data into a master's thesis.

Who is the researcher?

I am a master's student in the Women's and Gender Studies graduate program at Rutgers, The State University of New Jersey. I am a New Jersey native and I received my Bachelors degree in Women's and Gender Studies from Rutgers University in Camden. I have conducted research in the past that looked at the history of the causes of autism and also at the history of mothers of children with autism. I am also the proud aunt to a young boy who has been diagnosed with autism.

What will the interviews be like?

The interviews will be between two and three hours in total, but these hours can be split into multiple sessions for your convenience. The location of the interviews can also be arranged to suit your needs, and if necessary, I will travel to meet you wherever is most convenient for you. There will be no cost to you for participating in this study. However, there will also not be any monetary compensation. If you agree to participate in this study, you will have the right to stop the process at any point.

If you agree to be interviewed, how will your interviews be used?

Information from your interviews will be used in the final report, which will be my master's thesis, and also may later be published in scholarly or feminist publications. Your responses will be considered confidential, unless you give me permission to use it otherwise.

If you think that you might be interested in participating in this research study, please contact me at:

Email: Jennifer.s.parker@gmail.com

Phone: (512) 66-7256

APPROVED

Date: 8/4/11

EXPIRES

AUG 03 2012

Approved by the
Rutgers IRB

Appendix B: Interview Schedule

Interview Questions for Mothers on Caring for Children with Autism

I. General and Demographic Questions:

1. What is your age?
2. How would you identify yourself racially or ethnically?
3. If you are employed, what is your current occupation? If you are not employed, what is your current source of income?

II. Family composition:

1. How many children do you have?
2. What are the ages of your children?
3. How many children have special needs?
4. How many of these children are diagnosed with Autism?
5. What is your marital status?
6. Do you currently live with a partner? Other family?
7. Who else lives in your household?

III. Work (If Employed Outside Home):

1. What is your paid work situation like? What kinds of work do you typically perform at your job? How many hours a week are you working?
2. Do you feel that your workplace is flexible to your needs as a person who has children to care for? Do they provide time off? Do you have paid time off for sick or vacation days?
3. Does your work place offer paid maternity leave? Or, does your employer allow you to take time off to attend events at your child's school or to tend to a sick child?
4. Do you feel that your need for time off for family related matters is met?
5. Have you had to leave your place of employment or take time off because of issues related to your children's health or needs? If so, how often has this occurred in the last 6 months? Year?

6. How often have you left work / taken time off specifically to care for the needs of your child with autism? Could you describe one of these situations?
7. Have you ever been fearful that you might lose your job because of taking time off for your children's needs?
8. Has your spouse/partner/other household member had to leave their place of employment in order to care for any of your children recently? Have they left work or taken time off in order to care for your child with autism? In the last 6 months? Year?
9. Has your spouse/partner/ other household member expressed fear of losing their job because of taking time off of work to care for your children?
10. Do other members of your extended family or friend network helped care for your children when you are unable to leave work? Who and how often?
11. Do you feel that you have been discriminated against because of your status as a mother? (Examples: paid less than a co-worker without children? Received a negative job evaluation because of your parenting responsibilities?)
12. Have you ever felt discrimination, like the examples just mentioned, in the work place because you are a parent with a child with a disability?

IV. Care Work and Child Care:

1. If you were to think about the amount of time you spend caring for all of your children (including bathing, playing, and helping with homework as well as cooking and cleaning), about how many hours a week would you currently say you typically spend caring for your children?
2. Specifically, about how much time do you spend cleaning and cooking?
3. How much time do you spend weekly playing with your children and helping them with their homework?
4. About how many hours a week would you say that your spouse or partner spends on cooking, cleaning, playing and generally caring for your children? What about other members of your household?
5. Do members of your family or friend network help you care for your children? How often does this occur? Who is helping?
6. Do the needs of your autistic child demand extra time from you? How much time do you spend on care needs specific to your child with Autism? What kinds of extra care do you time on?

V. Disability/Child Specific Questions:

1. How do medical professionals describe your child's level of ability? (e.g., where would your child be placed on the autistic spectrum?)
2. Can you tell me about your child's behavioral challenges? (For example, is your child prone to "run off" and do they require constant supervision?) Can you tell me about any specific physical needs your child might have?
4. How much of your attention does this child require of you on a daily basis?
5. Many parents of children with disabilities describe experiences where they felt other people treated them differently because of their child's disability. Have you ever felt that you were treated differently in public or social situations because your child has autism (or acted differently than neuro-typical children)?
5. In the past some mental health professionals used to say that mothers had a hand in "causing" their child to be autistic. Since then, however, we know that scientific research has proven those theories to be wrong. Have you ever felt like you were being blamed, in any way, for the condition of your child with autism (by doctors, therapists, specialists or others)?

VI. Stress, Emotional Well-being, and Coping:

1. Being a mother is already a stressful job, but often parents of children with autism and other disabilities feel even greater levels of stress. How "stressed" do you feel on a daily level? What would you attribute your feelings of stress to? (work, family, or other)
2. In the past have you had to reach out for help, such as therapy or other treatments, in order to help cope with stress?
3. Have you felt depressed or anxious in the last 6 months to a year? Have you sought treatment for depression or anxiety during this time?
4. If you were to think about some of the probable causes of why you felt stressed, depressed, or anxious, what would they be? To what degree do you think your role as a mother and caregiver has contributed to these issues? To what degree has your role as a caregiver to a child with autism contributed to these issues?

VII. Access to Information & Services Used:

1. Including your doctors office, where do you find information about autism? (Online, doctors office, specialists, schools, other parents, etc.) In general, do you feel that you have sufficient access to information about autism?
2. Do you visit, participate in, or support any autism awareness groups (ASPEN, Eden, the Autism Society, or The Arc) in your area? Have you ever used services, such as respite, through autism family support groups?
3. Do you feel that the services and information you access through these sources/groups are helpful for your situation? What other services do you think you would benefit from that aren't currently available in your area?

-Suggestions? Comments?

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