Jewish Mothers of Autistic Children: Ritual & Disability Through a Feminist Lens

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Abstract

This thesis explores the lives of Jewish mothers with autistic children to understand how their unique position informs the construction of identities as activists, advocates, and reformers of Judaism. It employs feminist theories on disability, activism, and religion to understand the ways in which these women must navigate societal expectations of neurotypicality as the parent of a non-neurotypical child.
Chapter 1 - Judaism and Disability

“I have a vision of inclusivity: we have to recognize everyone’s differences instead of only recognizing our similarities. The Jewish community has certain expectations of intellectuality, and we seem to value some ways of contribution more than others. We need to see that someone’s presence is valuable. The idea is not only to include people [with autism] in order to ensure that they feel welcomed, but also so that we can learn from them, because their presence is a necessary contribution to the community. As Jews, we have to recognize that everyone’s presence is needed for the well-being of our community.”

An Introduction and Overview of Disability and Judaism

This ideal vision of inclusivity within the Jewish community presented above comes from a woman interviewed for this study: a Jewish mother who has a child with autism. Reading between the lines, her longing for a community that not only welcomes but also appreciates the special contributions of autistic children reveals that achieving a sense of belonging has been a painful struggle. In a community where children are expected to be high intellectual achievers, this mother not only desires recognition of her child’s special contributions as “valuable” but some form of acknowledgement that the community can also learn from child, just as from any other individual. The invisibility of her autistic child’s personhood is juxtaposed with the glaring visibility of differences that pose a barrier to understanding and acceptance.

Autism Spectrum Disorder, also known as ASD or simply as autism, is defined by the DSM-5 as a disorder whose symptoms present in early childhood, often limiting and impairing everyday functioning in some way. ASD is often diagnosed when a child meets some of the major criterion, including “persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays”, and “restricted repetitive patterns of behavior, interests, or activities.” The

severity of symptoms in individuals diagnosed with autism varies widely, which is why the term “spectrum” is useful. Severity levels range from displaying decreased interest in social interactions to displaying deficits in verbal and nonverbal social communication skills, meaning that some individuals with autism end up requiring minimal support from caretakers, while some others need a high level of care at all times.2

Autism affects approximately 1 in 68 children in the United States,3 and disproportionately affects males; for every four boys diagnosed with autism, one girl is diagnosed.4 Many anecdotal and informal sources theorize that Asperger’s Syndrome – which falls under the category of ASD but is no longer separately defined in the DSM-5 – is more highly represented in the Ashkenazi Jews5 than in the general population. However, this claim is not backed by any scientific studies. In the New York Times, Sheryl Gay Stolberg describes the unwillingness of some Jews to participate in gene studies to measure the incidence of disorders like autism among the Jewish population. Genetic researchers often look for populations that have a low level of genetic variance because this makes it easier to pinpoint genetic differences and mutations that can be attributed to higher incidences of certain diseases. Due to a history of close-knit communal living and endogamous marriages Ashkenazi Jews fit this profile. However, due to a painful history of racial science that classified Jews as biologically inferior and

5 Jews of Eastern European descent.
genocide during the Holocaust, Stolberg explains that many Jews are often not willing to take part in genetic studies, fearing that some diseases will be demarcated as specifically Jewish.\(^6\)

As Jews make up about 2.2% of the population of the United States according to the Pew Research Center, we can estimate that there are approximately 80,000 American Jews who have autism.\(^7\) The challenges that come along with a diagnosis of Autism Spectrum Disorder are not unfamiliar to parents raising an autistic child. However, these challenges are especially unique and numerous for Jewish mothers of children with autism.

This study will examine the intersections of Judaism, autism, and motherhood within a framework of feminist and disability theories. It will argue that Jewish mothers of autistic children have to revise their concept of motherhood to include roles not only as parents but also as teachers, advocates, activists, and “keepers” of a Judaism that can accommodate the special needs of their children. They become experts in their knowledge of autism and learn to navigate the barriers that threaten to exclude their children -- and by extension the entire family -- from institutional, educational, and religious spheres of Jewish life. In some ways, Jewish mothers face similar challenges that confront other parents of children with autism; however, what makes their experiences unique is the urgent need to transform their Jewish spaces--with the attendant rituals, customs, and expectations--into ones that will be accepting of their children’s special needs. Their role is not only to raise an autistic child but a Jewish autistic child.

\(^7\) With the assumption that the 1 in 68 statistic also holds true for the American Jewish population.
Review of Literature

This study builds on a foundation of literature that addresses feminist theories on disabilities, scholarship on rabbinic law and disability, studies on autism in Jewish contexts, and feminist constructions of motherhood.

Rosemarie Garland-Thomson’s foundational study “Feminist Disability Studies” elucidates how feminist disability studies can explain the processes of societal exclusion and identity formation. She identifies two major “critical practices” utilized by feminist scholars of disability theory: first, feminist theorists argue that disability should be defined from a social perspective rather than a medicalized one. This means that rather than visualizing what might be “wrong” with a body using medical categories, one should focus instead on how that same body may be denied access to certain facets of society, and defined as decidedly less important:

Feminist disability studies…questions our assumptions that disability is a flaw, lack, or excess…it defines disability broadly from a social rather than a medical perspective. Disability, it argues, is a cultural interpretation of human variation rather than an inherent inferiority, a pathology to cure, or an undesirable trait to eliminate. In other words, it finds disability’s significance in interactions between bodies and their social and material environments.

Secondly, feminist theorists attempt to avoid categorizing a body as “disabled”, as the very category itself is created by an ableist system which prioritizes certain types of bodies as more valuable than others: “We say things like “bodies that violate the normative standards and expectations of bodily form and function” [rather than “disabled] not to obfuscate but rather to clarify by insisting that readers do not fall back

9 Ibid.
on essentialist definitions of disability as inferior embodiment.”\(^{10}\)

Susan Wendell expands on these premises in “Toward a Feminist Theory of Disability,” with the inclusion of an intersectional framework to understand disability:

“To build a feminist theory of disability that takes adequate account of our differences, we will need to know how experiences of disability and the social oppression of the disabled interact with sexism, racism and class oppression.”\(^{11}\) This is particularly relevant to this study because autistic individuals experience oppression when they fail to meet societally constructed norms of gender, masculinity, and religion. Wendell shows that we must recognize all intersections of oppression while studying disability:

Ultimately, we might eliminate the category of "the disabled" altogether, and simply talk about individual's' physical abilities in their social context. For the present, although "the disabled" is a category of "the other" to the able-bodied, for that very reason it is also a politically useful and socially meaningful category to those who are in it. Disabled people share forms of social oppression, and the most important measures to relieve that oppression have been initiated by disabled people themselves. Social oppression may be the only thing the disabled have in common; our struggles with our bodies are extremely diverse.\(^{12}\)

Alison Piepmaier, Amber Cantrell, and Ashley Maggio discuss the personal applications of disability theory in “Disability Is a Feminist Issue: Bringing Together Women’s and Gender Studies and Disability Studies.”\(^{13}\) This is particularly important to consider in cases that deal with abstract theories and ideas that ultimately are less compelling unless applied to real individuals:

Ultimately we all recognize the potential richness of bridging the personal and the

\(^{10}\)Ibid., 1558.
\(^{12}\) Ibid., 108.
\(^{13}\)Piepmeier, Alison, Amber Cantrell, and Ashley Maggio. "Disability Is a Feminist Issue: Bringing Together Women’s and Gender Studies and Disability Studies." *Disability Studies Quarterly* 34, no. 2 (2014).
academic. This bridging happens in both women's and gender studies and disability studies, and we've experienced it as necessary, allowing us to delve into components of our own lives and understand them better, differently, and/or as shaped by the cultural moment in which we're operating. It is vital to build upon these feminist perspectives on disability in this study. In addition to understanding autistic children through a new lens, these theories help to recognize the intersectional positionality of Jewish mothers who occupy differing levels of privilege or disadvantage when it comes to advocating for their children. By employing feminist disability studies to understand both autistic children and their mothers together, a more comprehensive portrait will emerge about their mutual experience of disability--whether it be through stigma, exclusion, or acceptance.

The Jewish context is also critical for this study. Historically, halakhah (Jewish law) has dictated the ritualized procedures for public worship, the proper observance of the commandments, and the resolution of legal issues ranging from ritual slaughter to divorce. Although Jewish halakhic literature does not mention autism directly, it does address various notions of “disability” quite extensively. To be sure, there is no single Hebrew word equivalent to the Western conceptualization of “disability.” However, Julia Watts Belser observes that one form of stigmatized difference in the Talmud was described as mumim: blemishes that were either visible or invisible to the eye. Physical perfection was embodied in the priest, setting the precedent that the most holy men were

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14 Ibid.
15 The body of laws that govern Jewish life.
to have no physical deformities or disabilities.\textsuperscript{18}

Notably, conditions like deafness, skin conditions known as \textit{tsara'at}, and intellectual difficulties were not classified as \textit{mumim} in rabbinic literature. Belser demonstrates that “disability” was inextricably intertwined with culture, which constructed “bodily perfection” and demarcated certain kinds of bodies, as “normative.”\textsuperscript{19}

For instance, in “Brides and Blemishes: Queering Women's Disability in Rabbinic Marriage Law,” Belser discusses the concept of bodily blemishes and characteristics of women -- ranging from moles, scars, and bad breath, to even “abnormally” shaped or spaced breasts -- being considered as disabilities. A perfect, unblemished female body was demarcated as normative, while one possessing any blemished was seen as inherently and spiritually flawed.\textsuperscript{20} These disabling characteristics could serve as conditions for invalidating a marriage if a husband married his wife on false pretences that she possessed no blemishes because a “disability” was considered to take away a woman’s beauty and eroticism – obviously, her greatest contribution to her husband:

“…The construction of women’s disability in Bavli Ketubot centers on a different sort of gendered performance: the wife’s capacity to generate and satisfy her husband’s erotic interest.”\textsuperscript{21} The author also states that in this case, the Talmud shows how disability was constructed through the rabbinical (and obviously, male) gaze and interpretation of the normal and acceptable confines that a body -- specifically, a female body -- was meant to fit within:

\textsuperscript{18} Lev. 21:16-23.
\textsuperscript{20} Ibid., 410.
\textsuperscript{21} Ibid.
“Rabbinic texts on female disability center attention upon conditions or qualities that are presumed to impair a woman's capacity to “perform” as a wife—a performance that is constructed almost entirely in terms of her ability to stimulate male desire. In other contexts, rabbinic texts enumerate a wide range of physical capacities and capabilities that constitute rabbinic wifehood (Peskowitz 1997; Cohen 2011).”

This analysis is similar to that of Garland-Thomson's for it recognizes disability as a category artificially constructed by society which constructed expectations of what a normative body was “supposed” to look like.

In *Judaism and Disability: Portrayals in Ancient texts from the Tanach through the Bavli*, Judith Z. Abrams observes that the ancients believed, “If one is born without disabilities and they later develop, then the disabilities are a judgment from God. Those born with disabilities, however, are simply among God's varied creatures.” Similarly, Belser notes that disabled bodies were often frequently equated with sin in the ancient world. At the same time, Belser notes that the Hebrew Bible nonetheless “articulates a profound obligation to treat disabled people fairly” in order to affirm their humanity.

The humanity of the disabled in ancient Judaism is reaffirmed in Bonnie L. Gracer’s “What the Rabbis Heard: Deafness in the Mishnah.” The author observes that while infanticide of disabled infants was acceptable and common in Ancient Greece, there are no recorded debates or decisions within the Mishnah (compendium of Jewish oral laws) regarding whether children with disabilities should live or die, only evidence that

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22 Ibid., 404.
25 Ibid., 6.
Mishnaic and Talmudic scholars highly cherished life. However, it bears noting that although disabled individuals were considered to be valuable in terms of possessing life and a soul, Gracer also argues that possessing the abilities to hear and speak were strongly associated with moral capacity and cognitive ability by the rabbis. Gracer also examines the implications of deafness—which is occasionally accompanied by muteness—in a religion that relies so heavily on spoken participation and heard prayer. She uses the example of the obligation to say the Shema, and analyzes rabbinic debates about whether reciting but not hearing the Shema, in the case of a deaf Jew, constitutes fulfillment of the mitzvah (commandment) or not. This is extremely useful analysis to apply when thinking about individuals with autism who may not be able to participate in certain Jewish rituals in the same ways that neurotypical people can. Even though Talmudic scholars did not have the same conceptualizations of disability that we maintain today, it is important to read their debates because Jewish law is an ever evolving system that leaves room for innovation. Within the parameters of Jewish law, what new Jewish rituals might be created for people who cannot derive personal spiritual meaning and fulfillment from participating in them in a traditional manner? This is precisely the question that Jewish mothers are forced to grapple with as they seek to make Judaism meaningful for their children.

While we may never know the answer to this question, it is important to acknowledge that Jewish traditions have, for the large part, emphasized compassion and

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27 A prayer usually largely considered to be the most important part of the morning and evening prayer service; Jews are required to recite it twice per day.
28 Ibid, 197.
altruism toward the disabled. Matthew Parry discusses this at great length in his dissertation, “From Monsters to Patients: A History of Disability,” citing biblical passages that condemn malicious acts against the disabled:

Leviticus, for example, presents the following well-known command to the faithful: “You shall not revile the deaf or put a stumbling block before the blind.” Deuteronomy further provides that anyone who misleading a blind person on the road shall be cursed. Job, moreover, defends his righteousness by explaining how he helped the poor, orphans, the blind, and the lame. These examples suggest that despite the existence of negative stereotypes about disability in Jewish culture, able-bodied people demonstrated considerable compassion for disabled people in need.

Tzvi C. Marx’s *Disability in Jewish Law* also analyzes rabbinic ruling to demonstrate Judaism’s history of compassion for individuals with disabilities. Marx explores a case from the sixteenth century concerning a Jewish man who was disabled, and as a result, suffered from urinary incontinence. The man was unsure of his ability to pray and enter the synagogue for fear that he was physically unclean and therefore de-sanctify sacred space. Rabbis ruled that the man was not only allowed to enter the synagogue, but also did not need to sit separately from others. The justification for this decision was based on the principle that human dignity was to be upheld above all else. Rabbi Moses Isserles contended that if the man were to be segregated within the prayer space, his dignity would suffer harm; Rabbi Isserles felt very strongly that the man was to be spared personal humiliation at all costs, and felt a duty to show compassion to him and other disabled individuals.

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30 Ibid.
31 A prominent Polish rabbi, Talmudist, and legal scholar, circa mid-16th century.
In contemporary rabbinic literature, the discussion often revolves around whether Jewish individuals with certain disabilities, such as blindness, deafness, or cognitive impairment, can successfully fulfill the required mitzvot. Numerous rabbinical responsa debate this topic, such as the responsum by Rabbi Daniel S. Nevins entitled “The Participation of Jews Who are Blind in the Torah Service” (2003). The rabbis came to the conclusion that even though it is required of Jews to see and read the words of the Torah to fulfill mitzvot, “Jews who are blind should participate in synagogue rituals together with sighted Jews, all of whom are obligated to keep the Torah. Indeed, it is in the interest of the Jewish community to include as many Jews as possible in the rituals of studying Torah and fulfilling mitzvot.”

In an article entitled “Silent Majority: How Jewish Tradition Marginalized the Deaf,” Eddy Portnoy discusses the shifts that occurred over many centuries in the status of deaf Jews, who used to be considered as not “fully” Jewish, exempted from certain rituals according to the Talmud. Portnoy states that in the eighteenth and nineteenth centuries, rulings from scholars like Rabbi Simcha Bunim Sofer determined that due to advances in deaf culture and communication, such as improved sign language, deaf Jews could be more fully integrated into the religious community.

Although attitudes and definitions of disability within the Jewish community have changed greatly over time, there is no doubt that disabled Jews have faced challenges that

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33 Commandments that Judaism requires one to fulfill.
34 In Judaism, refers to a class of rabbinic literature that asks and answers questions concerning complex legal and ethical dilemmas.
36 A central rabbi of Hungarian Jewry, circa 19th century.
prevented them from participating fully in religious life in the past, as well as today. Drawing on the principle of human dignity and compassion, mothers of autistic children have had to struggle to press for inclusion as we shall see below.

A small number of studies examine autism in a specifically Israeli or Jewish context. In “The Social Trajectory of Illness: Autism in the Ultraorthodox Community in Israel,” Michal Shaked interviewed Israeli ultra-orthodox mothers of children with autism, finding that their most serious concerns varied from their disappointment that their child would never fully learn how to study Torah and fulfill mitzvot, to their questioning whether their child was “really” Jewish:

Twenty mothers referred to the different ways in which the child with autism fails to meet the expected codes of behavior such as modesty and scholarship that are emphasized at home and in educational settings. For example, the mothers expressed their disappointment that their son with autism would never be able to devote himself to religious study: ‘Did I expect to have an autistic child? I, of course, expected to have a learned religious scholar’. 38

All of the mothers also referred to the pain of recognizing that their child will not be able to meet the Jewish ideal of religious abidance and study, as in the following excerpt: ‘I once asked my eldest daughter, I was a bit broken spiritually, and I asked her ‘If she [the child with autism] cannot fulfill our commandments, then why was she born Jewish at all? What for?’ . The child's inability to perform religious precepts thus raised this mother's doubts concerning her daughter's very identity as a member of the Jewish community. 39

Shaked also finds that many mothers cast their children as holy and “ascended” as a coping mechanism for the fact that they could not share with them the joys of Jewish worship and tradition. As some articulated it: “[They are] sublime souls. They came to the world to mend one small thing... intelligent men are expected to achieve a lot in this world [while] these higher souls did not receive many tools, because they do not need to

39 Ibid.
achieve as much.”"\(^{40}\) Focusing on Israel’s ultra-orthodox Michal Shaked and Yoram Bilu similarly observe that parents sometimes cope with their child’s “odd” behavior, such as narrow fields of interests and blank expressions by reckoning that their children are simply closer to God, or more holy than their typically-developing peers:

The mothers found various clues for ascertaining their children’s higher spiritual status. The untainted physical appearance typical of many autistic children was taken as a measure for the purity of their soul: ‘He is as clean as a baby in many ways; I can see it on his face too, he has that angelic and childish [expression] of one who has done no evil.’ Specific behaviors of the children were interpreted as reflecting their inner sanctity. These included an “innate” attraction to the Scripture and to holy artifacts: ‘He apparently has a holy soul... any one can see it; the thing he likes most is [to look at] holy books and play with his tsitsit’ (prayer shawl).\(^{41}\)

Iris Manor-Binyamini’s study *Parental Coping with Developmental Disorders in Adolescents within the Ultraorthodox Jewish Community in Israel* examines coping mechanisms in parents of children with many developmental disabilities, and not autism in particular. However, the surveyed population was Jewish, which gives valuable information about ultra-orthodox and secular perspectives concerning cognitive disabilities. Additionally, the author addresses an important shift in recent scientific literature concerning disability:

In recent years, there has been a shift in the research literature towards examining the coping strategies of parents of children with disabilities. Rather than taking the approach that assumes an inevitable situation of crisis, stress and pathology, the alternative perception recognizes multiple and diverse ways of coping, including processes of personal growth (Maul and Singer 2009).\(^{42}\)


\(^{41}\) Ibid., 15.

A dissertation by Frances Rebecca Victory, “Exploring the Role of Perceived Religiosity on Daily Life, Coping, and Parenting for Jewish Parents of children with Autism,” also explored coping mechanisms that are specific to Jewish parents. Unlike many of the previous studies, Victory did not limit her respondent pool to Orthodox or ultra-orthodox Jews, but included Jews of varying affiliations. Findings in this study included the fact that many Jewish parents of autistic children reported that they used their faith and religion to cope with the everyday stressors of caring for a disabled child, and that even though they were not always able to perform all the religious rituals that they may have wanted to -- such as going to religious services frequently or lighting Shabbat candles every week -- that they held fast to their faith as means of coping.\(^{43}\) The author also found that over half of parents surveyed felt their religious community was a good source with which to help them cope with stress.\(^{44}\)

There is also a small body of scholarship that explores the implications of being a mother of a child with autism that are not specific to the Jewish community, but still provides an alternative perspective on how mothers cope with and understand a diagnosis of autism. Wei Zhang et. al’s study “Post-traumatic Growth in Mothers of Children with Autism: A Phenomenological Study” explores the “post-traumatic growth” of mothers with autistic children. Post-traumatic growth, also known in the psychology field as PTG, is “…a theory that explains this kind of transformation following trauma.”

Developed by by psychologists Richard Tedeschi and Lawrence Calhoun in the mid-1990s, the theory holds that “people who endure psychological struggle following

\(^{43}\) Frances Rebecca Victory, “Exploring the role of perceived religiosity on daily life, coping, and parenting for Jewish parents of children with autism” (PhD dissertation, City University of New York, 2014), v.

\(^{44}\) Ibid., 22.
adversity can often see positive growth afterward.”°° For the purposes of their study, the mothers’ experience of trauma was considered their child’s autism diagnosis. The study found that the parenting experiences of these mothers affected their post-traumatic growth in five main areas: their life philosophy, appreciation of life, relations to others, conceptions of personal strength, and changes in spirituality. This suggests that the difficult and traumatic experience of coming to terms with their child’s disability helped these women grow and change as people, specifically in the five aforementioned areas.

Another qualitative study “Challenges Faced by Parents of Children diagnosed with Autism Spectrum Disorder” by Ludlow, Skelly, and Rohleder, explores the day-to-day hardships and main challenges faced by parents that are raising a child on the spectrum. This research proves to be especially insightful because the authors sought to find out from parents of autistic children what areas in which they needed more support, as well the types of resources that had been the most helpful. Relevant findings include the fact that parents found social and professional support to be extremely useful in helping them cope with the challenges of raising their child. Many found it helpful when this support came from other parents of autistic children; not only did the support come from a non-judgmental positionality, but it was also constructive in that parents could learn from one another:

Nine parents spoke about how the support of other parents of children diagnosed with autism was an important and valued source of support. Given that so many parents found the judgments and lack of understanding from others difficult, other

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parents who are experiencing similar issues provided a source of understanding, support, and advice...What parents found particularly helpful, is that ideas and strategies for coping and dealing with challenges could be shared.  

Parents in this study also spoke of a sense of privilege they experienced when finding out about challenges that other parents confronted--circumstances that happened to be more severe than their own. The authors considered this to be another coping strategy that was utilized because it made parents grateful for the abilities of their own children. For all of these reasons, parents of children on the spectrum in this study cited social support as something that was necessary for their emotional and physical well-being.

Coping strategies of parents with autistic children also were highlighted in Lei and Oei’s 2014 review of literature. Interestingly, the authors found evidence from other studies that suggested a general shift in the nature of coping over time, from “problem-based coping”, which included looking for treatments and social support systems, to “emotion-based coping”, which was based in religious coping and personal acceptance of their child. This suggests that the specific stressors and subsequent coping mechanisms utilized by parents of autistic children change over time, most likely as their children progress in age.

Since this research concerns the mothers of autistic children, it is also important to look at societal gender norms and feminist theories on motherhood. Existing feminist scholarship and theory concerning the social and biological construction of motherhood

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48 Ibid., 708.
49 Ibid., 706.
frequently examines topics such as the gendered roles of parenthood, biological 
essentialism, the societal obligation versus the personal desire for motherhood, the 
feminization of caretaking roles, heteronormative family structures, and various other 
subjects.

Motherhood is a socially constructed concept -- an ideal for those with female-
gendered bodies to live up to. In this study, we examine the unique ways that 
motherhood is constructed when a Jewish woman is mother to an autistic child. 
However, it is useful to have a broader idea of the construct of “ordinary” motherhood – 
in this case, non-Jewish mothers with children who do not have special needs. Literature 
concerning motherhood as a biological construct includes the idea that women are 
biologically nurturing, and therefore all that is needed to be a mother is to possess a body 
gendered as female. Susanne Gannon and Babette Muller-Rockstroh demonstrate this 
idea by illustrating how the female breast becomes a symbol of female nurture, 
“...nurturing often gave the sense that a woman no longer owned her body; rather it 
became the realm of the baby and its (culturally constructed) needs as perceived and 
policed by society,\textsuperscript{51} and also a physical symbol of motherhood itself: “The source of the 
milk, the nurturing breast, becomes a metaphor and symbol for love, life, and mothering 
in a more general sense.\textsuperscript{52}

What happens when individuals do not live up to this culturally constructed ideal 
of motherhood? Horowitz and Long suggest women, whether they are mothers or not,

\textsuperscript{51} Susanne Gannon and Babette Muller-Rockstroh, “Narrating Breasts: Constructions of 
Contemporary Motherhood(s) in Women’s Breastfeeding Stories,” in \textit{Motherhood: 
Power and Oppression}, eds. Andrea O’Reilly, Marie Porter, and Patricia Short (Ontario: 
Canadian Scholars’ Press, 2005), 50.
\textsuperscript{52} Ibid., 52.
face significant amounts of stress about living up to society’s standards, and they explore this idea using societal discourses surrounding maternal stress. They find four main discourses concerning female stress: that a mother’s stress can harm her child’s health, that stress is damaging to a mother’s health and well being, that stress can affect mothers’ interpersonal relationships, and that mothers should be able to cope with their stress because there are so many options available. From these themes, we can see that society generally has very negative perceptions of stress in mothers, but does not recognize that not all women have the same access to coping mechanisms or solutions to alleviate stress. Societal norms suggest that because of their inherent femininity, women are especially nurturing, and meant to be mothers. Here, we introduce the question of whether women become mothers out of personal desire, or to fulfill a necessary societal niche -- whether that niche is existing as a mother within a patriarchal family structure, or having children to build and strengthen a population. And who exactly, controls the desire of the people to become parents – why is this a socially constructed need in the first place? To address this question, Michel Foucault lectures extensively about the idea of biopolitics and biopower in “The Birth of Biopolitics” -- the concept that the state or other overarching powers control birth, reproduction, and the like, in order to exert power over its people.

We can draw the conclusion that Jewish mothers of children with autism are faced with almost a double standard. They are required not only to embody the general ideals of feminized motherhood describing, but also to serve other roles that come with the

construct of the ideal Jewish mother, as well as the ideal mother of a child with special needs. As we can see from the small number of relevant and available data, research within the realm of disability -- specifically autism -- and religion is a fairly new, but expanding field of study. Combining these ideas with existing gender and feminist theory produces an interesting and novel combination that will be further explored in this research.

Methods

Data collection was implemented through one-on-one interviews with 20 participants. All of the participants were individuals who fit the following criteria:

- Female-identified
- Has at least 1 child with a diagnosis of autism or an autism spectrum disorder (ASD)
- Is Jewish and/or has kids and family who are Jewish

Some individuals who took part in the interviews found the information about this project from a posting on an email list-serve or online group. Others were recruited via snowball sampling: after participating in an interview, respondents passed on the information for the study to others in their communities who also fit the desired respondent profile. Participants had children with autism ranging in age from 5 years old to mid-thirties, and were located in various places throughout the United States. The participants varied in Jewish affiliation – self-identifying within Orthodox, Conservative, Reform, Reconstructionist, secular, and cultural denominations of Judaism.

Respondents were asked to take part in a single interview lasting anywhere between 30 minutes and 1 hour. Interviews with participants were administered either
over the phone or in person, depending on individual preference. 17 participants were interviewed via telephone, and 3 were interviewed face-to-face. All were able to choose whether or not they consented to being recorded, and whether or not they consented to having their direct quotes used in the writing of this project. The informed consent sheet detailing the conditions of the study is included in the appendix.54 For any individuals who did not want me to use their direct quotes, I have simplified their statements to protect their confidentiality while preserving the usefulness of information gathered from them.

There were no specific questions that were to be asked on a mandatory basis, but rather, an interview guide was used, which was meant to guide conversations in order to cover a wide variety of topics relevant to the research. This guide is provided in the appendix.55 All participants were able to skip any questions that they did not wish to answer, and had the opportunity to add any information they saw fit that had not been previously asked of them.

Interviews consisted of a series of questions aimed at understanding the participation of the respondents’ family—especially of their child with autism—in Jewish community life and religious ritual, as well as support systems inside and outside of the Jewish community that proved either helpful or lacking. In order to collect this information, respondents were asked about their family structure, their religious identity, Jewish organizations and groups that they belonged to, and various therapies or groups in which their families had participated.

These individuals were interviewed with the purpose of collecting qualitative

54 Page 84.
55 Page 87.
rather than quantitative information. This explains the reason for the small sample size of n=20; rather than looking to collect research that can be applied to an entire population through generalization and statistical analysis, I sought to find information specific to a small pool of individuals in order to apply existing theory to my findings, and come up with new ideas and directions for the inclusion of children with autism in Jewish religious, family, and communal life. Using data from interviews alongside existing theories of feminism and disability, this study explores the ways in which Jewish mothers with autistic children are simultaneously revolutionary and traditional.

**Ethical Considerations**

No identifying information other than religious affiliation was specifically asked for, in order to keep the respondents’ identities confidential. Any identifying information that was voluntarily given by the participants was not used in the write-up of this study. All the names of respondents have been changed to pseudonyms in order to protect their identity. This research was approved by the university’s institutional review board.

**Limitations**

By nature of the sampling methods that were used, there are a few “clusters” of respondents who belong to similar groups -- such as the same synagogue, school, or other community organization. However, since n=20 is already such a limited sample size, and this study is qualitative rather than quantitative this does not pose a significant problem -- but nevertheless must be acknowledged. There is the possibility that by virtue of existing within similar social climates, respondents from similar clusters face similar challenges as well as hold similar opinions on certain issues. However, since the Jewish community
is already quite small, and the number of families within this community who have children with autism is even smaller, this is not as much of a concern as it would be with research applying to a larger population.

Due to the scope and focus of this project, only mothers were interviewed. Fathers and other guardians were not included or recruited. Although this, of course, limits the amount of information that is received, it does allow for the ability to focus on a specific group. In this specific case, it also allows us to draw gendered conclusions from the data, which is vital to understanding the already highly-gendered idea of motherhood.

Although not often acknowledged as a limitation and often assumed to be a strength, it is also important to analyze how a researcher’s positionality may affect their questions as well as their findings. As a Jewish woman, my positionality within this research must be considered in terms of its epistemological connotations. By virtue of my gender and religion, I fit within the group of respondents. However, given that I am not a mother, and given that we know the experiences of women even within a small community or religious subset are completely diverse and varied, I cannot claim full knowledge of anyone’s experiences. However, the fact remains that since I am familiar with the vocabulary, traditions, and other generalized knowledge of the American Jewish community, my positionality can impose what David Takacs refers to as “conceptual shackles – formed by my own identity and experiences.”

While many argue that the production of completely objective work and research does not exist, we can take necessary precautions to make sure that our work is only inspired by our epistemological

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standpoints – and not affected or tainted by them. As with all people, my positionality affects my epistemology, but I tried to be very aware of this and take necessary precautions to remove my “shackles” and make sure that this would not affect my work negatively.

These precautions included engaging in mostly listening, rather than responding to participant’s thoughts and words, as well as following a formulated and standardized interview guide rather than asking my own questions, which could accidentally result in a subconscious attempt to find information that I may inaccurately believe to be true or relevant. It should also be stated that as a partial outsider to this community, I do not believe that I will be contributing new and breaking ideas; rather, I am simply collecting the narratives of so many intelligent and empowered women who are already doing this work, condensing their information and viewpoint, and framing it in a certain way. Any benefits that come out of this are directly due to these inspiring parents who are working so hard to bring changes into Jewish communities throughout the country.

The following chapters will explore the experiences of Jewish mothers of children with autism within religious and secular contexts, and attempt to explain the unique construction of motherhood that results from different types of exclusion in Jewish spaces.
Chapter 2 - Managing Expectations: A Child on the Spectrum in the Jewish World

In her popular memoir, *Ketchup is My Favorite Vegetable: A Family Grows Up with Autism*, Liane Kupferberg Carter describes an early integrated evaluation of her son Michael (Mickey) who was twenty months old. Responding to the doctor’s cold comments such as “Positive Babinski on the left; right is equivocal,” and command “You can dress him” as though he “were an inanimate object,” Kupferberg Carter blurted out a sentence she would never forget:

P陋 winter light leaked through a sooty sliver of window as Marc and I pulled clothes on our son. The silence felt heavy. Seeking to lighten it, I next said something so ignorant and cringe-inducing to me now that I am ashamed to remember it. “Well, as long he’s not going to vocational school.” To her dismay, the doctor made her sit down and declared, “Don’t expect higher education for your son.”

In one moment, her expectations of normative middle-class temporality were shattered.

According to Judith Halberstam, heteronormative temporality is governed by “strict bourgeois rules of respectability and scheduling” that involve a “desired process of maturation” that leads from childhood to university, marriage, and family. For mothers like Kupferberg, this trajectory is often not a given, and is made even more complicated by ingrained neuronormativity. Neuronormativity, a series of assumptions and social expectations that structure societal interactions based upon presumed neurotypicality, leaves no room for deviation from the norm. This poses a problem for individuals who are neuroatypical -- like many people who are on the autism spectrum -- and behave in ways that are demarcated as “unacceptable” or “inappropriate.” In this way, seemingly simple aspects of family and communal time and space pose specific challenges for

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mothers with children on the spectrum.

This chapter will explore how Jewish mothers navigate expectations about their children within a Jewish cultural and religious context, arguing that although certain expectations about Jewish children are common to the general population, specific historical experiences unique to Jews have shaped a desire to foster learning and “normative” physicality. Not simply a serving as a shield to protect their autistic against awkward stares, Jewish mothers have found ways to integrate them into Jewish time and space with the weight of history on their shoulders.

**Jewish Space and Time**

Jewish space and time in which autistic Jewish children seek to be integrated include a combination of both secular and religious spaces. Some spaces like the synagogue are modern buildings in which practices of ritual, memorial, and the spiritual take place. Other “spaces”, like texts set in varying times and places -- the Torah and Jewish literature, for example -- are equally important to collective Jewish identity and life. As Heinrich Heine once wrote about “the Jews”: “A book is their fatherland, their possession, their ruler…They live between the boundary markers of this book, here they exercise their inalienable civic rights, here nobody can chase them away” (1840). Yet, as we will see, displaying the “correct” and “appropriate” behavior for the environments in which one learns about Judaism and the Torah is not always possible for children on the spectrum. Over the course of the interviews that I conducted, a common theme that repeatedly arose was the fact that some mothers who had children with autism did

not feel welcomed in Jewish spaces like the synagogue which had unspoken expectations about “appropriate” behavior.

**Navigating behavioral expectations in the synagogue**

Often, congregants expected “acceptable behavior” to include a modicum of bodily control, in the form of being quiet, sitting still, and the like. Many respondents mentioned the fact that they and their families were not capable of attending events such as services in the sanctuary, or Shabbat dinners at their synagogues, due to the fact that their child would not be able or willing to sit still throughout the duration of the event. Children with autism engage in self-stimulating behavior, or what psychologists have called “stimming”\(^\text{59}\). This usually involves a repetitive behavior, such as moving the hands in a certain way, rocking or moving the body, making sounds, or repeating a phrase. In a quiet setting, such as a prayer service, this is often not welcome behavior. Moreover, limited attention spans and anxiety due to an overload in sensory stimuli can prevent autistic children from sitting for an entire service.

In a moving blogpost about his son Isaac, Matt Davis describes the hazardous space of the synagogue for his autistic child: “Synagogues are bustling, busy places with singing and chanting that can become exuberant and painfully loud to ears, sensitive or not . . . Welcoming is ubiquitous I know that. But instinct, sociability, and illogical rituals are the dominant currencies in synagogue environments, making the batter for someone

with autism appear demanding." Davis recalls attending a niece’s bat mitzvah ceremony with his son, who was so puzzled by the separate seating of men and women that he resorted to “leaping between my wife and me.” Disoriented in the new space, Isaac did what calmed him: “The mechanism of manically moving about a new location is one he often sets in motion on first visits. It is a method of focusing and stabilizing—something with success, sometimes not.” David recalls, that although most people treated Isaac with compassion, there were a “few reprimanding voices in the congregation that agitated me.”

This topic came up repeatedly while talking to mothers who were wary of bringing their children to services, worried that they would interrupt in an unacceptable way, or that their constant movements or noises would prove to be disruptive and anger the other congregants. One mother, Evelyn, mentioned that she never tried to take her son to services, because she knew that she would have to take him out of the room at times, causing a disruption. Katie recalled a painful memory of attending Temple along with her son in order to say kaddish for a family member. When her son began making sounds, a woman turned around to glare in an unfriendly way, and noted that she was [also] there to say kaddish, and asked Katie to “control her son.” Although these women were both grieving in a similar way, Katie felt that there was no sympathy or support due to the insensitive comments about her son. Another mother, Deborah, said that at the

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60 Matt Davis, “Can Judaism Play a Role in Isaac’s Life?” My Son Isaac (blog), April 11, 2016.
61 Ibid.
62 Ibid.
64 Also referred to as the “mourner’s kaddish”; a Jewish prayer of mourning.
65 “Katie”, Interview, March 14, 2017
synagogue her family previously attended, she would feel self-conscious when her son would make noise, because everyone would turn around and stare. She feels much more comfortable at a new synagogue; the atmosphere there is more “laid back,” does not require “fancy clothes” and “no one cares if you’re loud during the service.” In fact, her current synagogue even holds Shabbat activities once a month that are meant to encourage participation from those who would not necessarily want to attend a prayer service – participants engage in mediums such as art, drumming, or cooking.66

Even autistic children of Jewish clergy were not always immune from negative judgment. Natalie recounted a story she heard from a rabbi who used to work at her synagogue; at the time, he had a young son who was on the spectrum. When this rabbi’s wife brought their son to a prayer service, and he made noises during “inappropriate” times, members of the congregation told the rabbi and his wife that they were not welcome to bring their son into the sanctuary anymore. The rabbi’s wife felt so unwelcomed by this statement that she never again set foot in that particular synagogue.67

A history of decorum in the synagogue

When did the notion that Jewish worship could only be conducted in a certain manner emerge? Synagogues and sacred Jewish spaces did not always have these unspoken rules about social decorum. In fact, the Hasidim—a sect of Judaism that emerged in eighteenth century Ukraine and emphasizes the value of prayer on par with Torah studies—encouraged swaying, bowing, bending, running around the synagogue, and even turning somersaults. Their early opponents mocked their bodily gestures. For

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66 “Deborah”, Interview, March 14, 2017
67 “Natalie”, Interview, March 1, 2017
example Rabbi Jacob Emden of Altona, who had heard about Hasidic prayers, wrote in 1768: “I trembled when I heard only recently that a new sect of foolish Hasidim had arisen in Volhynia and Podolia, …These men perform strange movements, weird and ugly, in the prayer of the Eighteen Benedictions. They clap their hands and shake sideways with their head turned backwards and their face and eyes turned upwards….“68

These movements continued to develop and became an integral part of Hasidic worship. One traveler described his first encounter with prayer at a Hasidic court in Belz on a Friday evening in the 1920s. When the old rabbi of Beltz went up to the reading desk to lead the Hasidim in prayer the congregation went wild:

The crowd which till now has been completely quiet, almost cowed, suddenly bursts forth in a wild shout. None stays in his place. The tall black figures run hither and thither round the synagogue, flashing past the lights of the Sabbath candles. Gesticulating wildly, and throwing their whole bodies about, they should out the words of the Psalms. They knock into each other unconcernedly, for all their cares have been cast aside….They are seized by an indescribable ecstasy…69

The Amdurites (Hasidim from Amdur) were best known for their somersaults in the prayer house and on the streets reciting: “For the sake of God and for the sake of the rebbe.” Their explanation was that “when a man is afflicted by pride, he must turn himself over.”70

The rise of the Reform movement in Germany in the nineteenth century sought to distance Judaism from the “chaos” of traditional services. German-born reformers sought to instill decorum and order by forbidding congregants to talk during services, adding a rabbinic sermon, and other innovations like the addition of the organ to bring the

69 Ibid., 355.
synagogue closer to the manner of the Protestant church. The synagogue became a contested space during the years of mass migration of Jews from Eastern Europe. German rabbis who had immigrated to the United States and introduced Protestant aesthetics into synagogue life were alarmed by the complete lack of decorum among their East European Jewish coreligionists. However, changes were already underway to “civilize” the East European synagogue space. One scene from Abraham Cahan’s immigrant novel, *The Rise of David Levinsky*, in which a recent Russian Jewish immigrant is bewildered at the strange customs of American Judaism, is telling:

He told me that the synagogue was crowded on Saturdays, while on week-days people in America had no time to say their prayers at home, much less to visit a house of worship. ‘It isn’t Russia’, he said, with a sigh. ‘Judaism has not much of a chance here.’ When he heard that I intended to stay at the synagogue overnight he smiled ruefully. ‘One does not sleep in an American synagogue,’ he said. ‘It is not Russia.’

The historian Jonathan Sarna notes in his discussion of mixed seating in synagogues that many reforms which took place within Jewish spaces of worship during this time – often old churches bought and repurposed into synagogues – were inspired and somewhat modeled after the style of mainstream American Christianity. In reference to the specific change of desegregating gendered seating, Sarna remarks that “Pragmatic reforms aimed at improving decorum and bringing the synagogue more closely into harmony with the prevailing American Christian pattern were nothing new,

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even if this particular reform had not previously been introduced . . . .”74 These efforts to assimilate a version of Jewish religious life into America that did not clash with the country’s Westernized, majority Christian culture often resulted in “reforming” Jewish places of worship into more “civilized” and “controlled” spaces, much like the atmosphere of a Protestant church. This is demonstrated by early American Reform synagogues’ preference for the presence of a choir, organ, and pew seating.75 Sarna also discusses the case of a New York City synagogue known as B’nai Jeshrun, whose trustees sought to reform many existing Jewish practices in order to improve decorum in the synagogue as they “worried more and more about the image projected by the congregation to the world at large”.76 These changes often did affect how the physical body was used during prayer, including the location of the physical body (in the female vs. the male section of the synagogue), whether or not the priestly blessing was recited straightforward or chanted (reforms called for reading rather than melodic chanting or singing), and the change to the general atmosphere of the synagogue. Sarna comments that the prayer services became laden with performativity, as the congregation modeled themselves into a “showpiece synagogue”.77

This aspect of performativity is one reason that in reform and conservative synagogues, disrupting the services with any sort of noise or movement is not permitted, being that the etiquette requirements regarding behavior are similar to that of a performance in a theater. This is also demonstrated by the change of moving the place in which the Torah reader is located from the center of the sanctuary to the front – similar to

74 Ibid., 276.
75 Ibid., 280.
76 Ibid., 279.
77 Ibid.
a stage performance. This level of performativity is not as important in many Orthodox shuls, in comparison.

Apart from decorum, the “proper” and acceptable boundaries for the presentation of Jewish bodies in public spaces has been indirectly and directly shaped by antisemitic discourses. These discourses emerged in Western Europe and served to cast Jewish bodies as uncontained, uncontrolled, weak, and deviant—a stereotype that Jews are still fighting today in the form of muscular Zionism. As discussed below, the lasting impact of these discourses have contributed to the Jewish discomfort with imperfect, abject bodies and the lack of bodily control.

**Jewish Masculinities and the Construction of the “Ideal” Jewish body**

Historically, Jews have been a largely diasporic people, often cast as the Other in the communities within which they resided. In modern Europe, they had to contend with powerful, often competing discourses about the Jewish bodies and gender that sought to define them as separate from “normative” Aryan bodies. According to Benjamin Maria Bader, notions of a Jewish masculinity were modeled after a highly desired Jewish version of femininity, and Jewish men were differentiated from non-Jews by their allegedly feminine, caring, and tender disposition. Rather than being discriminated against for this, this ideal of “feminine masculinity” was held up as a strength of the German-Jewish population by Jewish and non-Jewish leaders alike, in particular, two Jewish leaders:

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Samson Raphael Hirsch, who is often considered the founder of modern Orthodoxy in Germany, and the Reform rabbi Adolf Jellinek in Vienna took this exaltation of the female to another level by claiming that femininity constitutes the principle of the Jewish religion and that Jewish men stand out because of the character traits Hirsch and Jellinek called feminine. In the middle of the nineteenth century, these Jewish leaders argued that Jewish culture and Jewish civilization rested on foundations that were domestic, spiritual, and feminine rather than political and manly, and according to Hirsch, Jewish manliness was not grounded in military and political power, but in domestic and feminine virtues. Jellinek postulated that Jewish women and Jewish men had a greater inclination toward gentleness, morality, and domesticity than other populations. He compared Jewish men favorably to non-Jews, praised their devotion to family life, and encouraged them to continue cultivating their tender and compassionate disposition.  

These Jewish leaders asserted that Jews made themselves distinct from other people by “embodying feminine principles and character traits.” However, as one may expect, qualities possessed by Jewish men deemed “feminine” eventually led to discrimination based on the view that the Jew was a weak member of society, which Baader acknowledges.

Racial science and hygiene movement in fin-de-siècle Europe cast the Jewish body as “diseased and degenerate, an entity that literally required healing.” Like many of his contemporaries, the Russian Jewish doctor Max Mandelstamm, accepted the “science” of the Jewish body but sought to find a silver lining: “Weak muscles, badly developed respiratory organs, weak bone structure, slight physical strength, little capacity for physical labor. Only the skull is highly developed among them: the cranial capacity of the Jew is on average greater than that of non-Jewish population.” By stressing the biological predisposition to higher intellect, Mandelstamm sought to

79 Ibid., 50.
80 Ibid.
82 Ibid., 276.
offset the other negative qualities.

In response the racial discourse of the time, the notion of “muscular Judaism” emerged as an integral part of the Zionist movement. Zionists leaders like Max Nordau called for “regeneration”—the creation of a “New Jew” whose body was healthy, fit, and strong, a body that would fulfill Zionism’s desired aesthetic to generate a robust Jewish state. The beginnings of this so-called muscle Judaism stemmed from the goals of the Zionists to “achieve a decidedly European concept of nationality.” The new program spawned the gymnasium movements among Jews who became preoccupied with exercise and the regeneration of the body and later, in popularized imagery of strong, muscled, male IDF soldiers grinning while holding weapons.

As sociologist Harry Brod explains, many of these factors also led to the American Jewish man toeing lines between boundaries of masculinities:

Forced to affirm the value of the life of the mine, which is indeed traditionally valued in Jewish culture, against anti-Semitic attacks on it, many Jewish men have been forced into an overly rigid identification with this ideal to the extent that they perpetuate an overly zealous denial of the complementary life of the body...The idea of the intellectual Jewish male is held to so strongly because it emerges both from within the intellectual traditions of Jewish culture and as a defense mechanism against attacks on Jewish men for not conforming to dominant, more brawny standards of masculinity...as a means of perpetuating specifically Jewish patriarchal norms within a culture that valorizes intellect over physical prowess.

Brod argues that conflicting Eastern-European masculine ideals of intellectualism combined with Western ideals -- which placed more value on physical strength --

84 Ibid., 58.
85 Ibid., 13.
produces a “culture of resistance” where hegemonic masculinity is produced through intellectualism. However, instead of possessing the aforementioned “feminine” qualities desired by nineteenth-century German leaders, this masculinity embodies a very similar space to that of Western, body-focused masculinities. The implications of this are both patriarchal and ableist. First, it creates new societal norms within Jewish culture, which act to control masculine bodies, but in a different though nonetheless still harmful manner. Additionally, it leaves no space for Jewish individuals who possess anything less than strict control over their bodies. It only provides space to individuals dedicated to and entrenched in intellectualism, in a way that does not include individuals with intellectual or physical disabilities.

We can see that the body politics of Jews have been fraught in modern history. A need to both distinguish themselves from the norm and to avoid discrimination through racist or eugenic stereotypes has led to a shift in some Jewish communities and cultures from desired intellectualism to desired physical strength and control, and in many cases, a combination of the two. What does it mean when a religion and culture call for such strict control over one’s body, and what does it mean when bodies exist that do not fall into either of these desired categories? To answer these questions, we must examine modern-day constructions of the ideal Jew, which include a heavy focus on intellectualism and control over one’s body.

**Views of disability by the Jewish community: navigating expectations of intellectuality**

Examining the Jewish community’s understanding of disabilities such as autism
would be incomplete without the acknowledgement of the high value that Judaism places on intellectualism. Learning, scholarly pursuits, and intellectualism are highly valued in Jewish culture, however, this is not a modern-day phenomenon. Jews often held the positions of scribes, bankers, and other skilled professions throughout history. For example, in medieval Spain, the Crown relied heavily upon Jews for administrative and financial tasks, who received royal protection -- necessary due to their minority status -- in exchange for their loyalty and services. 87 We can see that there is a long history of education as an important value in Judaism. As early as 200-600 CE, Jews followed the religious and community norm of sending their young male children to attend lessons at a school or a synagogue at the age of six. 88 The importance literacy for Jews was the ideal of Torah study and public reading. 89

“The Temple and particularly the Torah were the driving forces behind the development of Jewish educational institutions. The Torah highlights the importance of study throughout life and establishes a father’s duty to teach his children the laws of Judaism. However, it does not contain an explicit ruling or law requiring Jewish fathers to send their children to school to learn to read and to study the Torah. An important step in making reading a central feature of Judaism took place when the priestly scribe Ezra inaugurated public reading of the Torah as a new element in Jewish life. Henceforth, the Torah was read and explained on regular occasions in public. Before Ezra, most parts of the Torah were under the exclusive control of the high priests.” 90

This emphasis on education has led to a high value placed on intellectualism among Jewish communities. In traditional contexts, this meant studying to be a scholar of the Torah and other Jewish religious texts. Today, these expectations have changed so

89 From the 9th/10th century BCE through 586 BCE.
90 Ibid., 68.
that the ideal is to become a white-collar professional, but the emphasis on intellectual achievements remain important. This poses a problem for some individuals with disabilities, including autism. It could be the case that someone has a learning disability, and the unique way that they learn is not typically considered to be compatible with the way society defines intellectual success. Or, perhaps a person with autism has a lower than average IQ\textsuperscript{91} and therefore might have a life trajectory that is different from the high-school-to-college-to graduate school-to a career that is normalized and put on a pedestal in many Jewish communities. In these cases, mothers have to navigate these social expectations.

Annie Lubliner Lehmann, whose son Jonah was nonverbal, found it disconcerting to be asked about her “dreams and visions for Jonah’s future” by a psychologist who had just informed her that her nine-year-old son “functioned at the development range of six to eighteen months with an IQ that numerically, wasn’t much higher.” Tempted to say, “Hoping for Harvard,” Lehmann articulates what one might call “autistic temporality”: “Without much choice, we had to be completely rooted in the here and now without the luxury of musing about ‘dreams and visions’ for Jonah’s future.”\textsuperscript{92} Her memoir captures the “here and now” associated with parents facing the uncertainty of their children’s future.

One way in which parents cope is through affirming their pride in their children. For example, Evelyn found that some members of her Jewish community were

\textsuperscript{91} According to Jon Baio of the CDC, less than one-third of people with autism spectrum disorder are intellectually disabled, although a greater proportion of individuals with autism have learning disabilities that are often mistaken for intellectual disabilities.

uncomfortable with her pride in her son’s accomplishments, due to their own expectations. She said, “I’m so proud of my son who is in community college. If I say this to others, it’s hard for them to understand that this is something I’m proud of, and they look away and don’t ask further. But this is important to my child, and I AM proud!”93

There are also many expectations for a family with an autistic child to navigate as the child reaches their early teenage years and has the opportunity to become a bar or bat mitzvah. This event often takes years of preparation, and can serve as a showcasing of Jewish knowledge and mastery of Hebrew that a child has amassed throughout years of Jewish education. This can be a stressful time for a child and their family, but mothers with autistic children must also take on the additional task of assuming responsibilities for modifying the prayer services, teaching their children Hebrew prayers or Jewish stories to supplement their Jewish education, and using unconventional or unusual strategies to make sure that their child’s bar or bat mitzvah is fulfilling and meaningful to the child as well as enjoyed by family and friends.

Three respondents, Katie, Anne, and Ellen, mentioned that their children became a bar or bat mitzvah during prayer services on a Sunday, during a Rosh Chodesh94 celebration, and Krista recalled that her son’s bar mitzvah took place on a Monday, during Martin Luther King Jr. Day. Reasons for choosing other days besides Saturday -- usually, children become bar mitzvah during a Saturday prayer service -- included the fact that Sunday services would draw a smaller crowd, making their child feel less overwhelmed, and also so that a smaller chapel, rather than the large sanctuary, could be

94 Jewish celebration marking the start of a new lunar month.
used to lessen the amount of surrounding stimuli. Instead of relying on Jewish Sunday school and Hebrew school teachers, mothers often assumed the gargantuan responsibility of teaching their children Hebrew prayers, as well as supplementing the education they were already receiving with additional help. Paula noted that she created a special book for her son that contained the prayers and his Torah and haftarah portions, along with smiley face stickers and words of encouragement written by her throughout; he used this book during the prayer service. Ellen helped her daughter learn the blessing over the Torah so that she could have an aliya, and assisted her in writing a brief d’var torah that she would be able to read for the congregants.

For some children, who cannot hold a bar mitzvah ceremony at all, mothers have no choice but to find “untraditional” ways to mark the transition to adulthood. Rabbi Rebecca Einstein Schorr recalls the painful moment when she realized that her son could not participate in the traditional ritual: “A piece of my soul died when we decided that my son Ben’s autism would necessitate a reexamination of a conventional bar mitzvah.” As a reform rabbi who had guided so many young Jewish children through this ritual, she had a special longing to go through the bar mitzvah with her son: “I yearned to have the unique privilege of preparing my own son, my firstborn, the way my father, also a rabbi,

95 “Paula”, Interview, March 6, 2017.
96 The honor of being called up to read the Torah -- often involves saying the blessing that comes before the reading of the Torah.
97 A “sermon” interpreting a text -- at a bar or bat mitzvah, the child typically writes a short speech in which they talk about the meaning of the Torah portion that they have read.
had prepared me.”<sup>99</sup> Although they decided to participate in their local “Walk Now for Autism Speaks” in lieu of the traditional ceremony, Rabbi Schorr was moved by some moments that made up for the lost ritual. As they were kindling the Sabbath candles, she asked her son if he would like to start the Kiddush:

> Ben had certainly started the Kiddush many times at home, but his fear of speaking in public is typically so anxiety producing that it never occurred to me that he would agree to lead any of the prayers. In a clear, strong voice, he began. I wondered if his voice might taper off once everyone joined in the prayer. I wondered if he might stop at the conclusion of the first line. But he kept going. With no visible hesitation.<sup>100</sup>

This narrative does well to reflect the pain that mothers feel when their children are unable to participate in such a formative Jewish life cycle ritual. For Rabbi Schorr, the sorrow was magnified by the two <i>yads</i><sup>101</sup> that were given to her son on his consecration. She expresses a feeling of incomplete yearning:

> So those <i>yads</i> will remain in my drawer, One an intricate design of filigree. The other ceramic in blue hues. Only now, they will stay in the drawer, tucked into the folds of his tallis, the stunning ritual prayer shawl woven by our family’s weavers in Jerusalem with fringes, as in our tradition, finished by my mother, Ben’s bubbe. Like me, they will wait.”<sup>102</sup>

The inability to pass on the ritual objects from generation to generation suggests a break in the family tradition--something that Rabbi Schorr had to come to terms with even as she expressed pride in her son. There were moments in his “alternative bar mitzvah,” however, that were meaningful in a Jewish way. Rabbi Schorr concludes that what made her so proud was that “a lifetime of Shabbat dinners acted as the ultimate

<sup>99</sup>Ibid.<br>
<sup>100</sup>Ibid.<br>
<sup>101</sup>Ritual objects used to point at the Torah text.<br>
preparation” for this brief but immensely moving Kiddush. Moreover, walking for autism became a bar mitzvah experience that reflected Ben’s “strengths and interest.” His team was able to surpass the $5400 goal for research and a cure.

Respondents also discussed how they deviated from the norm of having a large and often elaborate celebration following their child’s bar or bat mitzvah. Many of these mothers were acutely aware that their extended families and friend hoped for -- or even expected -- to be attending this type of celebration after the prayer service. Some chose to throw this party and then removed their child from the environment, as they did not enjoy it, and others chose to forgo this entirely and have a small, quiet dinner with close family members in place of a large, loud event.

As a bar or bat mitzvah tends to be highly attended by family members and friends, there did not seem to be as much worry on the mothers’ part, surrounding expectations of their children at this special coming of age event. However, respondents were made uncomfortable by their counterparts’ lack of understanding about their children’s behavior and capabilities, as well as the expectations of their children’s behavior in many other contexts. They felt that some people within synagogues were often uncomfortable understanding the disabilities and subsequent behaviors or actions of their children. This not only lead to the respondents’ families feeling unwelcome within their Jewish communities, but also to a lack of available resources and programming. This most likely stems from the general lack of education, understanding and acceptance surrounding disability in general – not just in the Jewish community. Research by Farnall and Smith confirm this lack of understanding of disability, in a discussion of attitudes and

\[ ^{103} \text{Ibid.} \]
perceptions about people with disabilities. They find that positive feelings (i.e., acceptance) and a sense of understanding is often dependent on the person’s perception of the disabled individual: “...positive effects are most likely when the nondisabled person perceives the disability as a minor characteristic, judges him or her not to be inferior or incompetent, and understands and copes with the person’s disability.”104

As a result of being excluded by the community, these women have taken it upon themselves to carve out spaces, services, and events that serve to educate their Jewish communities, as well as to ensure that others are not excluded -- and that if they are, that they are supported and not alone.

**Changing communities from within**

A number of respondents that were interviewed actively realized the need for disability and inclusion education within their Jewish communities. Many recognized the lack of understanding about autism – and other disabilities – to be the main barrier to support and inclusion of their families into Jewish life, including religious services, religious education, and other camps and children’s programs. As a result of their exclusion from the community, these mothers made it a priority to become involved in inclusion initiatives that they otherwise may not have been interested in participating in. The fact that eight out of the twenty women who were interviewed were involved in some way with a Jewish inclusion committee or initiative – usually within the context of their synagogue – demonstrates quite well the need for disability education within

Taking part in these inclusion groups benefitted not only the mothers and their children, but the community at large, given that they addressed inclusion issues that were not only specific to autism. Becoming activists within the Jewish community was vital to these respondents’ identities, and was often one of the first things they mentioned when speaking of their involvement with their synagogue. Main topics and areas that these inclusion committees addressed, or hoped to address in the future to increase the Jewish inclusion of families with autistic children included creating parental support groups, and increasing both community support and clergy support.

The vast majority of respondents had sought out support from other parents of autistic children in some context, whether that came in the form of a traditional support group – Jewish or non-Jewish – or an online group like a forum or an email list-serve. Many were fortunate enough to find a community like this; six respondents specifically mentioned being part of a formal or informal support group. For example, Claudia had a small group of parents at her temple that formed a confidential support group, meeting weekly to share resources and referrals with each other and discussing a pre-selected “topic of the week”. Nora also participated in a parent group at her synagogue which she said felt similar to a support group – all of the parents had children with special needs, and when they worked on inclusion initiatives, they also exchanged advice. She enjoyed the informal nature and irregular meetings of this group, noting, “as far as groups

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105 This does not include the number of respondents who were involved in disability/inclusion programs outside of the Jewish community.
106 “Claire”, Interview, February 27, 2017.
go, you almost don’t have enough time”.\(^{107}\)

Claire however, felt that her needs were not being met with the informal Jewish support group that she belonged to, which only met once a year, and desired to be a part of something more constant and ongoing. Though she identified as Orthodox, she was frustrated with her Orthodox community’s lack of outreach to Jews from other denominations, regarding support groups: “They were more worried that their children might see a woman in pants than anything else! And I wear pants! Why must we quibble over these things?” She felt more satisfied when she created her own group, consisting of around 10 Jewish and non-Jewish women, with the feeling that their religion didn’t matter to her, only that they all had “a bond in fighting.” She said, “You have to be able to sit with a group of humans struggling with the same thing, and I remember I did not have that. I wanted to meet people in person, not just online.”\(^{108}\)

While Claire found utility from in-person support groups, online groups were perfect for other respondents. Eileen valued being a part of an online list-serve of parents from a school district. Through the use of the medium, she and other parents of children with autism could communicate about education strategies that had worked for each of them, and discuss possible advocacy strategies to make changes in their district.\(^{109}\) All evidence points to the fact that support groups are a useful and often necessary tool for mothers of autistic children to gather recommendations for therapy and healthcare providers, seek emotional support, and strategize or organize.

Dealing with a child’s initial diagnosis of autism can be a trying time for parents.

\(^{107}\) “Nora”, Interview, March 1, 2017.  
\(^{108}\) “Claire”, Interview, February 27, 2017.  
Respondents noted that they often felt lost, scared, and “in the dark” when receiving a diagnosis, and would have appreciated receiving advice, resources, and guidance from within their Jewish community. Krista, who has a teenage son with autism, recalled the time of his diagnosis—many years ago—as extremely stressful and devastating. Looking back, she wished that there had been some support from her Jewish community around this initial diagnosis period.\textsuperscript{110}

When Krista was diagnosed with breast cancer several years later, the \textit{chesed}\textsuperscript{111} committee from her family’s synagogue was quick to respond with help for her and her family—they brought over food, visited, sent cards, asked if there were other ways that they could assist. She compared this to the lack of support she received during her son’s diagnosis, with the logic that a disability diagnosis can be just as trying as a diagnosis concerning physical health. She sensed that there was less discomfort around a cancer diagnosis than around an autism diagnosis, and hopes that will change in the future, citing \textit{bikur cholim}\textsuperscript{112} as a value that she hopes will translate to visiting and supporting families who have received an autism diagnosis.\textsuperscript{113}

Eileen felt similarly, noting that her family did not receive the kind of support she would have hoped for: “We told our rabbi about the diagnosis, but you don’t bring people meals when someone is diagnosed with autism. It also isn’t a one-time event, we’ve been dealing with it for so many years. No one from the \textit{chesed} committee comes for this kind

\textsuperscript{110}“Krista”, Interview, February 22, 2017.
\textsuperscript{111}“Loving-kindness” -- A \textit{chesed} committee at a synagogue is a group that typically comes together to support a community member who is in mourning, sick, housebound, or otherwise in need.
\textsuperscript{112}The Jewish commandment to visit the sick.
\textsuperscript{113}“Krista”, Interview, February 22, 2017.
of thing…It’s the issue of chronic versus acute conditions”.^{114} Diane also wished that her synagogue community had provided her family with “intense short-term support”, and also compared the situation to that of support given in cases of cancer diagnoses. She was hopeful that this will change for the better in the future, and mentioned that the inclusion group at her synagogue is working with the chesed committee on this issue.^{115}

A qualitative study of religious coping mechanisms conducted by Tarakeshwar and Pargament found that 40% of parents of children with autism that were interviewed by the researchers looked to clergy for support, and that 30% felt as if they were abandoned by their religious community, or not receiving satisfactory support from their clergy.^{116} Although Jews only accounted for 2.4% of their study’s sample^{117}, this is an important fact to keep in mind. Over the course of the interviews, some respondents also noted their disappointment (or praise) regarding support from clergy, suggesting that there is room for improvement in this area. Krista expressed her desire for these improvements, and offered examples of the forms that they could come in:

“I think that Jewish clergy should know, and be able to recommend support groups in the area, as well as start a parents’ support group. They also should be able to connect parents of special-needs kids to others who also have special-needs kids that might be further along in the process and able to help out”.^{118}

As far as positive experiences in this area go, Ellen felt that the rabbi at her synagogue always tried to make her and her daughter feel welcome during services, even during the times that her daughter would scream, offering affirming words of “It’s OK!”

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^{114} “Ellen”, Interview, March 1, 2017.
^{117} Ibid., 249.
and “We love you [name]!” Some of the clergy in Natalie’s community also had children on the spectrum, which she said helped them to be supportive and not become flustered when a child was behaving in an atypical manner. Another particularly positive and supportive measure came from Eileen’s rabbi, who visited her son when he was in the hospital – she noted that they had a good relationship and that her son was always happy to see [the rabbi].

**Feelings of welcome and unwelcome**

I have also observed that among the group of mothers whom I interviewed, those most likely to say that they felt uncomfortable or unwelcomed bringing their autistic children to prayer services belonged to Conservative, Reform, or Reconstructionist synagogues. It is worth noting that two respondents, who self-identified as Orthodox Jews and belonged to Orthodox congregations, did not feel this way. Rebecca found that her Orthodox Jewish community was and is extremely welcoming and supportive to her son; one of the ways in which they expressed this support was complete acceptance of any atypical behaviors during prayer: “Everyone wants him to enjoy synagogue to the best of his ability, so no one stops him if he wants to go bang on the bimah or go climb up to the ark to see the [Torah] scrolls”. While her son may have not been able to participate in prayer in typical ways, such as with his voice, he stayed engaged in ways

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120 “Natalie”, Interview, March 1, 2017.
122 Elevated area in a synagogue’s sanctuary from where the Torah is usually read.
123 The receptacle/ornamental closet where Torah scrolls are contained -- typically considered to be the holiest place in the synagogue.
that he found enjoyable. Rebecca did not find that people in her community disapproved of her son’s unique behavior during services – rather, people liked that he was taking part in the services, and would also help to make sure he felt included in other ways. For example, a family in Rebecca’s community was disappointed when she didn’t bring her son to the family’s bris\(^{125}\) – Rebecca was worried that her son would cause a disruption on the family’s special day, but they said that they would rather have him there, no matter what.\(^{126}\)

Claire, another Orthodox Jewish woman that I spoke to, also did not feel like her family had been excluded from community life at their synagogue on the basis of her son’s autism. She talked about how she, her husband, and her son belonged to a small Orthodox shul\(^{127}\), and that they were “welcomed there, because everyone was needed.” She appreciated that there were no “bells and whistles”, as she referred to it, surrounding her son’s duties and participation in religious life. He was often honored with the duty of opening the ark. Claire felt that there was a lot of respect given to her son – he was encouraged to go to daily prayers in order to make a minyan\(^{128}\) – and that he wasn’t given anything “silly” to do on account of his disability.\(^{129}\)

This is not to say that Orthodox Jewish congregations were the only settings in which families with children on the autism spectrum felt welcomed and affirmed – respondents of Reform, Conservative, and Reconstructionist denominations often noted

\(^{125}\) Jewish ceremony of circumcision, often celebrated with the presence of family and friends present.
\(^{126}\) “Rebecca”, Interview, March 8, 2017.
\(^{127}\) Yiddish for “synagogue”, often used in place of the English word in Orthodox and Chasidic communities.
\(^{128}\) The minimum amount of people needed (ten) for Jewish communal prayer services.
\(^{129}\) “Claire”, Interview, February 27, 2017.
that when they felt uncomfortable in the environment of their synagogue and switched their attendance to a different synagogue of the same denomination, they felt much more welcome. Therefore, we must not come away with the assumption that congregations of these types are notably intolerant of disability, but rather that all will vary from one another. Like Deborah, other respondents also felt that it was the unique atmosphere of their synagogue that made their families feel welcome. Morgan noted that she didn’t feel comfortable at the first synagogue she joined after her family moved to a new area. She felt as if everyone was constantly judging her son’s behavior, and if he would act out in any way, no one was ever sympathetic or willing to offer any help. At the synagogue that her family now belongs to – a conservative congregation – has more “quirky kids”, as she referred to them, which makes everyone much more willing to be understanding about unique behaviors that might be displayed by children with autism.\(^{130}\)

A possible reason for the demonstrated higher levels of acceptance of disabled individuals within Orthodox Judaism could be because of the high value that the reform and conservative movements place on individuality. Some have commented that this relatively newfound sense of individuality among Jews is actually dangerous, due to the fact that religion as a whole, especially Judaism, requires a collective consciousness, and that when the collective is no longer represented due to a shift toward desired individuality, religion faces a crisis\(^{131}\). Interestingly, scholars of disability theory also criticize the “individualizing” of disabled individuals, as belonging to the niche group of the “disabled.” However, as Murugami writes in “Disability and Identity”, since the

\(^{130}\) “Morgan”, Interview, March 21, 2017.

designation of “disabled” is societally constructed as negative rather than positive, it is more desirable to ascribe disability unto the collective, rather than onto an individual:

Society needs to acknowledge the sometimes elusive boundary between having impairment and being able-bodied. It should acknowledge that very few of us qualify as fully able-bodied along all dimensions of functioning throughout all of our lives. Hence, impairment should be seen as part of the human condition rather than a basis for setting someone apart, or a characteristic diminishing one’s humanness.¹³²

She believes that in an ideal world, disabled people – or, to specify – those whom we currently would mark as disabled, would not need to define themselves or be defined as “other.” In this sense, disability would not be conflated with the self or the individual, but instead seen as an innate human quality.

In this way, it is possible that one of the reasons that Orthodox Jewish mothers who have children with autism felt consistently more welcomed by their communities than some others did is because of Orthodox traditions that can favor the collective over the individual. Psychologists and social scientists note that when members of religious groups are “committed” to their faith, they “shift their self-interest to the welfare of the collective”.¹³³ These children would not automatically be “othered” and thought of as disabled, because they are first and foremost thought of as belonging to the collective. This is not to say that individuality in any sense is a negative concept for communities to emphasize. In fact, this is a factor that leads to diverse and vibrant communities of Jewish people. It is indeed important for people to establish their own beliefs, style, and thinking patterns, and to contribute to a group by virtue of being a

unique individual, having a personhood that no one else can embody. This includes children with autism in the Jewish community.

We can see that the Jewish community has unique conceptions of disability and ability, on account of the Jewish people’s long history of emphasis on intelligence and literacy, as well as the construction of the “ideal” Jew. As a result of these understandings of disability, respondents, whether they felt welcomed or unwelcomed by their communities, often felt motivated to work on improving inclusion in their synagogues and Jewish communities. This was demonstrated in their notable community involvement in inclusion initiatives as well as by their extensive visions of what an inclusive Jewish community should look like.
Chapter 3 - Jewish Mothers: Advocates, Reformers, Activists

“Judaism's way of grappling with Torah is central, and the fact that any question can beget any answer and the fact that those answers evolve, is also central. This aspect of coming to different conclusions from reading the same text gives a message that we are all different and how you look at life is different. This informs my parenting, because my kids are all different and I have a different approach with each of them just as all parents do. Being Jewish makes me grapple with things and think about them differently…” - Evelyn

According to Evelyn, her approach to parenting relies on the Jewish tradition of asking questions. As a mother of an autistic child, Evelyn finds meaning in the evolving nature of Judaism, exemplified in reading texts that beget new questions and “different conclusions” with each engagement. Her statement about questioning is reminiscent of passages in the Torah -- “Parshat Bo” in Exodus 10:1-13:16 -- which address the necessity of children’s questions and the duty of the parent to educate them. For example, “And when your children ask you, ‘What does this ceremony mean to you?’ then tell them, ‘It is the Passover sacrifice to the Lord, who passed over the houses of the Israelites in Egypt and spared our homes when he struck down the Egyptians.’”¹³⁴ These passages make their appearance in the Passover Haggadah, personified as the “Four Sons” -- one wise, one wicked or rebellious, one simple, and “one who does not know how to ask questions.”¹³⁵ Like the child who asks the four questions on Passover, or the proverbial questioner -- the figure of Job in the Hebrew Bible -- Evelyn questions how to raise a child to be Jewish and to find inclusion in Jewish spaces.

Today, the exclusion of children with autism from Jewish spaces, overt or accidental, often also results in the inability their family to participate as well. Many

¹³⁴ Exod. 12:26-27
¹³⁵ Ibid.
respondents noted that they did not feel welcomed with their children in Jewish spaces, and some even felt openly scorned. Katie mentioned a time when her son was acting out in the synagogue, and she had to take him outside the sanctuary. Openly weeping, she felt emotionally overwhelmed, and was later surprised to realize that no one passing by had offered to help, or even asked her what was wrong. Additionally, respondents found themselves either missing out on or being excluded from religious experiences, education opportunities, and celebrations due to their inability to have their children present in certain social and religious spaces, for fear of the child violating social norms with atypical behaviors, such as loud noises or meltdowns.

What happens when mothers of autism take matters into their own hands, reconstructing their family’s Jewish traditions and religious observances as a result of exclusion? This chapter argues that Jewish mothers of children with autism have found themselves in the role of intermediaries between their families and Judaism. In this role, they constantly think of ways to make Jewish ritual, education, and observance meaningful and accessible to their autistic children, both inside and outside of the private sphere.

**Working within and apart from the system**

Women have been making reforms to all facets of society since before the idea of feminism even existed. There are usually a few ways in which people effectuate societal change. Activism and social movements rely on two key strategies: they either seek to overthrow an oppressive system entirely and create a new, more inclusive one in the

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process, or make changes and reforms within an existing system to make that specific structure less oppressive. Depending upon who one asks, women reforming traditions for their children resort to both of these processes. On one hand, some insist on strict interpretations of halakhah, which does not allow for much innovation outside of tradition. Using that framework, mothers making changes in their ritual practices may be viewed as radical in their attempts to reform existing structure of halakhah to fit the needs of their children. However, it is also true that because of its analytical and interpretive nature, Judaism by definition allows and even encourages making changes to accommodate a person or community’s need. Through this lens, the given situation is a very good example of working within the existing structure of Judaism to figure out possible ways to make religious practices and observances more accessible to children with autism -- to find new ways of making old traditions meaningful again. The mothers interviewed in this study occupy the space between revolutionary and reform movement; they seek to change aspects of Judaism that are amenable to innovation but they also call for the complete overhaul of a certain elements that they feel are no longer relevant for their families. These mothers are being radical, yet traditional at the same time.

This blend of working within Jewish structures and advocating for revolutionary changes is unsurprising, given a long history of Jewish mothers as the organizers and implementers of Judaism in the domestic realm. In this study, mothers reimagine Jewish rituals that are central to the home and immediate family. They accomplish this in ways

137 Types of social movements are differentiated by David Aberle in his 1982 book “The Peyote Religion Among the Navaho.” Revolutionary movements constitute a complete overthrow of an existing system, while reform movements seek to make changes to norms within an existing system.
that ensure their children with autism will be able to enjoy, participate in, and derive meaning from religious practices along with the rest of the family, while also preserving the observance of holidays and celebrations. In this way, Jewish mothers with autistic children take on two more important roles: the religious “reformer” of the family, and the “translator” of Judaism for their child.

Exclusion from the Jewish public sphere

Jewish rituals and observances that take place in the public sphere are particularly challenging for families who have children with autism, mainly due to the knowledge that children with autism are prone to violating social norms at any given time, which respondents often cited as a reason for not bringing their child to participate in prayer services. This resulted in many respondents feeling as though they were missing out on religious practices that they would have otherwise wanted to participate in, or otherwise being an outsider during these events. This includes important religious milestones like bar and bat mitzvahs. For example, Katie did not want to risk the possibility of her son causing an audible disruption during his brother’s bar mitzvah service, so she had to sit alone with him in the balcony of her synagogue.138 Similarly, Ellen was not able to stay for the entirety of her daughter’s bat mitzvah luncheon, having instead to take her daughter home when she lost interest in being in a social environment.139

In addition to being excluded from events like prayer services, respondents also noted their inability to participate in activities like adult Jewish education and prayer services in general as frequently as they wanted to, distancing them from Jewish

139 “Ellen”, Interview, March 1, 2017.
observance and identity. As a result of needing to take her daughter to a Sunday school program that would provide for her special needs that was far away from her family’s synagogue, Natalie was unable to attend the adult Jewish learning that were held during the same time as children’s Sunday school programs at her synagogue.\textsuperscript{140} Evelyn also mentioned her disappointment at not being able to attend adult classes or high holiday services at her temple.\textsuperscript{141} This exclusion from Jewish adult life affected these women’s identities, and may have even served to make them more interested in preserving Jewish rituals within the home as a result.

A particularly relevant model to understand how mothers of autistic children create a new form of “domestic Judaism” to meet the needs of their families is the role of bourgeois Jewish women in imperial Germany as “priestesses of the home.” According to the historian Marion A. Kaplan, “Whereas Judaism relegated women to a peripheral role in the synagogue, it placed them on a pedestal in the home.”\textsuperscript{142} As German Jewish men began to assimilate into the broader bourgeois society, their involvement in public worship in the synagogue began to decline. Though women had little power in synagogue life as leaders, they were critical to the continued observance of Judaism in the home:

The informal transmission of Judaism -- affective, private, and personal, including foods, family, and the hearth -- was in large measure women’s domain, and that, among traditional families, women were accorded social power and status for their religious adherence. Women fashioned the fabric of daily life which enveloped their children. They shaped the social and cultural milieu in which traditional sentiments were reinforced… Looking back over a lifetime, children seem to have been more affected by their mother’s faith as revealed in the home and kitchen (whether positive or negative) than by their fathers’ attendance at

\textsuperscript{140}“Natalie”, Interview, March 1, 2017.
\textsuperscript{141}“Evelyn”, Interview, March 7, 2017.
\textsuperscript{142}Marion A. Kaplan, \textit{The Making of the Jewish Middle Class} (New York: Oxford University Press, 1991), 70.
German Jewish women continued to perform Jewish rituals according to the Jewish calendar, maintain family networks through the observance of holidays such as Passover, and provide special foods that reminded their children of Judaism and life cycle events. As public observance declined, they became the sole guardians of Judaism and the “significance of women’s religion moved from the periphery to the core.”

In the case of mothers of autistic children today, their exclusion from the synagogue comes not because of gender bias. Rather, they feel like unable to participate because of the subtle [or overt] ostracism of their families due to their autistic child’s deviation from standards of behavior in the synagogue or their inability to participate even in a welcoming environment. This exclusion from the synagogue has functioned as a catalyst for Jewish mothers to create new ways of observance in the home, transforming them into guardian of Judaism within the family.

Noticeably, many of the ways that respondents modified Jewish traditions in the home -- and created new ones -- revolved around two themes. First, they sought to make the rituals something that their autistic children would enjoy and cherish, no matter how much that affected the observance or “holiness” of the holiday or occasion. Second, many of the new traditions that were created were made with the intention of honoring their child, and valuing their unique differences.

\[143\] Ibid., 71.
\[144\] Ibid., 84.
\[145\] This is in no way to say that Judaism has eradicated gender disparities within the synagogue -- women are often separated from men and made to sit far away from the prayer service, or given less honorable roles than men -- but there has been some improvement in the mere fact that women are now accepted as more active members within the workings of the modern-day Jewish synagogue.
Many mothers used their children's' interests, hobbies, and sensory habits in order to fashion new ways of being Jewish in the home. For example, Helen wanted her family to celebrate Shabbat and havdalah\textsuperscript{146} each week, but quickly realized that her son grew bored and restless throughout the process. Since he was very interested in cameras and photography, she had him take pictures of the Shabbat candles, the kiddush cup, the challah, and other religious items during the prayers. This engaged him and made him more interested in Shabbat; he and his father would post these pictures weekly to their Jewish-themed social media page. Although the use of electronic devices like digital cameras are generally prohibited during the sabbath, Helen knew that allowing her son to take pictures was his own unique way of observing Shabbat.\textsuperscript{147}

Similarly, Rebecca, who described her family as \textit{shomer shabbat},\textsuperscript{148} allows her son to have occupational therapy sessions on Friday nights, because, in her words, “that’s what he needs in that moment.”\textsuperscript{149} Regarding her son’s therapy sessions, she said, “The first thing he learned in therapy was to put his yarmulke on. A non-Jewish therapist knew this was important to us, and focused on teaching him this as an everyday skill. . . .It’s one direction that he will always follow, when we ask him to pick up his kippah and put it on.”\textsuperscript{150} This demonstrates that since Rebecca recognizes that since Judaism is so present in this area of his life, it makes it very acceptable, and even positive, that he engages in therapy sessions on Shabbat.

Rituals were also created or modified by mothers in order to include their child as

\begin{footnotesize}
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\item \textsuperscript{146} Prayers marking the end of the Jewish sabbath.
\item \textsuperscript{147} “Helen”, Interview, March 2, 2017.
\item \textsuperscript{148} Observant of the Jewish sabbath
\item \textsuperscript{149} “Rebecca”, Interview, March, 8, 2017.
\item \textsuperscript{150} Ibid.
\end{itemize}
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well as honor them as a unique individual. It is often customary for parents to offer blessings to their children on Shabbat, and a particularly relevant example specific to mothers of children with autism comes from Karen Webber Gilat. While she was not a respondent in this study, excerpts from her havdalah prayer are specifically related to the special needs of the autistic child:

Blessed are You, Creative Source in the Universe, who bids us share, in joy, this cup of sweet sweet wine, rather than drink from it alone. May we recognize that ___’s need for connection and community is different from ours. Help us help her communicate more clearly, make better eye contact, and more fully read faces and emotions. May we honor and bless ___’s different understanding of relatedness, while at the same time praying for her to join all of us - her "team" - in the hard work ahead of forging connections: with herself, with her family, and with her community. AMEN.

Blessed are You, Creative Source in the Universe, who bids us delight in our senses - smelling, tasting, seeing, touching, hearing. May we recognize that ___’s sensory experience is different from ours: Rain feels like bullets, a fly sounds like a 747, and textured food touching her lips overwhelms her. May we honor and bless ___’s different sensorium-lying on the floor with her, watching the fan overhead-but also lovingly prod her to engage with the world more fully. We pray for ___ to join all of us - her "team" - in the hard work ahead of heightening her tolerance for sensory experience.

Blessed are You, Creative Source in the Universe, who bids us, through the ceremony of Havdalah, to relish difference. In the light and the shadows cast by these intertwined wicks, may we celebrate what has been brought "into the light" about autism-and also recognize how much we still need to uncover. May we honor and bless those exploring autism’s mysteries, and pray that their research brings us increased understanding. Speedily and in our day.151

This prayer highlights several elements of the autistic child’s challenges to operate in the neurotypical world: first, the prayer recognizes that the child’s sense of sociability is different and needs to be respected. In some respects, this is a reminder to the family that they should not push the child to socialize in “neurotypical” ways even as they seek to

help the child with social interaction.

Matt Davis, while blogging about his autistic son Isaac, provides powerful insights on his son’s sociability. Sometimes, Isaac is a “roaring and adoring, larger than life social animals.” However, just as quickly as sun turns into rain, his social mood changes: “It’s just that he can retreat into the solitude from the social swiftly and alarmingly. His universe-falling-apart meltdowns may appear indiscriminate, immediate, and scary.”

Like the havdalah prayer that reads “May we recognize that ___’s need for connection and community is different from ours,” Davis ponders on his son’s difference: “Maybe friendships are and could remain too onerous for him. The codes impossible to decipher. Intuitive and conflicting. It explains why he seeks the solidity of inanimate objects rather as opposed to the unpredictability of animate ones. Stuff over folk.” Yet, at the end of the day, Davis wonders if it the “neurotypical” individuals who need to change by “entering and immersing oneself” in Isaac’s world.

The havdalah prayer also addresses the difficulties of communication among autistic children--their problem with eye contact and ability to read “faces and emotions.” Like Davis mentions above, “codes” that are intuitively easy to decipher for the neurotypical are frustratingly impossible for autistic children. By asking God to help the family assist the autistic child to communicate better, the prayer seeks to reduce the frustration that comes with the inability to interact based on social cues. Sensory issues -- whether it be touch, sound, or smell -- are also addressed at length in the prayer. It reminds the family that for the autistic child “rain feels like bullets, a fly sounds like a

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153 Ibid.
747, and textured food touching her lips overwhelms her.”

The child’s therapeutic goals are also included, perhaps giving the family hope that the prayer will help the child become more accustomed to sensory issues. It is notable that the havdalah prayer, which marks the end of the Sabbath -- separating sacred time from secular time -- can also help acknowledge and appreciate the differences of a neurotypical child. These havdalah blessings are an example of how a Jewish tradition can be modified not just to fit the needs of autistic children with autism, but also to honor them.

Another example of transforming Jewish tradition came from Diane, whose young children were initially bored and strangely bothered by their parents’ efforts to say blessings over them on Shabbat:

We have a ritual that we created for our family. My husband and I wanted to do blessings over the kids on Shabbat, but when they didn’t want to be blessed, we created a “blessing cup.” We put candy in it, pass it around the table. When it’s your turn, you can say any kind of blessing for the family and then you get the candy...They could choose between saying “Shabbat Shalom” or “I love my family”. By crafting a tradition that was both accessible and rewarding for her child and heartful for herself, Diane acted as a keeper of Judaism in the domestic realm. Holidays such as Passover can also be challenging; Matt Davis eloquently describes the challenges of this holiday for his autistic son:

But Passover is so bound up with trip wires. Familiar family houses lose their familiarity; people jovially jostling for space and sound. Dinner tables become sinisterly ceremonial with plates and dishes, color and spice, and much mystique. Groaning—literally for Isaac—with foreign foods that fizz and froth at him. Cutlery, crockery, glass—clinking, smells overriding, people shouting, picture books of cartoonish death and destruction howling him. Not just a sensory sickness. The scalding blur of all this clutter, audibly and visibly also blighting any order, any uniformity he yearns. Comprehension can collapse like a house of

cards. The change of routine and social interactions that Davis describes is familiar to Jana Banin, who wrote about “How I Prepare My Son for Passover” in the online magazine Kveller. The change in his diet during Passover was extremely daunting for her nine-year old Benjamin, who has “an incredible difficult time with change:” “No soy bacon in the morning. No grilled cheese on Wednesday night. No restaurant pizza Sunday night.” This led her to sigh, “It’s going to be a long eight days.” Banin tries to include Benjamin in the preparations for Passover to help him acclimate to the change: taking him shopping to buy matzah and helping him find substitutes.

Henny Kupferstein, a doctoral student of psychology who uses music therapy to help autistic children, published an innovative version of the “Four Questions” for Passover, written by a boy with Asperger’s Syndrome. In many ways, it addresses the concerns that Matt Davis and Jana Banin raise about the changes to diet, routines, and hypersensitivity to sensory stimuli (which can lead to sensory overload). For instance, the first question deals with food selectivity, which is a problem for many autistic children:

Mah Nishatana Halayla Hazeh... Why is this night different from all other nights? On all other nights I can eat my rice cake that I eat every night, this time. But tonight, and on this night only... (Ma! We eat matzah the entire Pesach, why do I have to say this night only?!)... more than any other night, why do we eat potato? You know it’s soft and mushy and I hate the way it feels in my mouth? and then when I swallow it, I can’t drink again until after the next Kos [cup], after saying mah nishtanah.

156 Matt Davis, “Isaac’s New Hobby is Music to Our Ears?” My Son Isaac (blog), March 10, 2017.
In this question, the children acknowledge their limited repertoire of foods and process the new foods that are causing them anxiety because of their texture. Although a mother did not compose these questions, the issue of food selectivity would be something familiar to her. A cluster of studies found that over 50 percent of children between 3 to 10 years old in the U.K. ate fewer than 20 foods and were reluctant to try new foods. The subsequent questions also address other sensory sensitivities such as tactile discomfort with a certain texture of clothing: whereas on other nights the child can wear a “comfortable shabbos shirt . . .,” “he asks “why on this night do I have to wear this itchy glittery shirt that I made with the O.T by therapy.” Another question in these unique Four Questions includes a line about colors that make the child uncomfortable--the “very old apples are already brown, and brown is my worst color.” According to new research in journal *Molecular Autism*, autistic individuals are more like to “also have synaesthesia” -- that is a mixing of the senses. The study found that 31 out of 164 adults on the autism spectrum experienced “either tastes, pains, or smells triggering a visual experience of color.” The final question allows the child to express anxieties about space: “On all other nights, I can sit on my special chair by the wall in the kitchen, where nobody can touch me or breathe near my plate, but tonight, and also tomorrow, we

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163 Ibid.
have to eat reclined, and that means I would be touching Ari’s chair….” While composed by an autistic child, the inclusion of the “Four Questions” on a website is intended for Jewish parents of autistic children, giving voice to their children who struggle with sensory overload during Passover and many other Jewish holidays alike.

Through their actions, these women whose narratives have been included above bring to light the idea that Jewish mothers are redefining religious rituals in the home in ways that make them meaningful to their children with autism. Because they are attuned to the special needs -- from challenges in communication to the painful experience of sensory overload -- Jewish mothers can make religious rituals in the home and create prayers that are sensitive and comprehensible to their children.

Activism outside of the Jewish realm

In addition to figuring out how to include their children in Jewish life, Jewish mothers with autistic children find themselves balancing other responsibilities that, as numerous respondents noted, feel like full-time jobs. Liane Kupferberg Carter recalled the conversation with her husband Marc after meeting Stanley Greenspan, the creator of the “Floortime” method of play therapy in her novel. Her husband took her hand and said, “Unfortunately, the burden is going to fall mainly on you. Are you okay with this?” Kupferberg Carter had no idea at that moment what this burden would entail, but she soon found out what it meant to carry over the play therapy into the home: “Play became

my vocation. Play as work. Mind-numbing, tedious play, but moments of connection and joy too.”

In addition to parenting and continuing play, speech, and other therapies at home, mothers also must engage in advocacy for their children, especially during their child’s school-age years. They must gain expertise in multiple areas to provide the best educational experience for their children, who might otherwise miss out on critical services, therapies, and educational opportunities. Without intending to do so, mothers of autistic children end up being caregivers, advocates, organizers, and activists. An excerpt below from Women Transforming Politics: An Alternative Reader describes the many duties spanning across political realms that mothers with disabled children are responsible for:

“In recent years the women’s movement, recognizing that mothers, too, are working women, has given priority to such issues as child care in setting working agendas. However, the child care needs of mothers of disabled children are virtually invisible in the development of consciousness and policy. It is estimated that 10 percent of children under the age of twenty-one are disabled (Gliedman and Roth 1980)...The reality of the lives of mothers of disabled children radically extends the traditionally perceived boundaries of motherhood. Mothers of disabled children must not only become experts in education and medicine; they must also become advocates and organizers in order to ensure the most basic rights and services for their children. The need to become an advocate and organizer is especially true for the mother who tried to secure an appropriate education for her disabled child. This process is inherently politicizing. It forces women to deal with the system. It is assertiveness-training boot camp. The experience of these women is of critical importance to the women’s movement, for mothers of disabled children have all the issues of other mothers and more. The women’s movement cannot ignore these women. As with all disabled people, families with disabled children too often become isolated – out of sight and out of mind. Not only do these women need the support of the women’s movement, they also have much to contribute to it.”

166 Marian Blackwell-Stratton, Mary Lou Breslin, Arlene Byrne Mayerson, and Susan Bailey, “Smashing Icons: Disabled Women and the Disability and Women’s
The idea of “being an activist” is associated with very specific imagery and connotations within an American societal context. Perhaps this phrase would cause one to imagine a loud, demanding figure – holding a sign, or protesting in a march or picket line. As we know, activism often takes place well outside the boundaries of these highly visible situations, and at times, is not voluntary, but rather necessary for individual and familial well-being. This is the case with many of the participants who were spoken to over the course of this study. Many mothers, without having any previous desire or inclination to speak out or be activists, found themselves advocating on behalf of their child and family’s needs. As a result of having a child with autism, respondents created their own versions of themselves as activists, whether they referred to themselves as such or not. Becoming an advocate for their children meant that mothers had to educate themselves on their children’s rights including laws on Individualized Educational Plans (IEP), Individuals with Disabilities Education Act (IDEA), financial resources, and other legal protections.

One respondent, Anne, described how difficult it was to get the services that her son needed – and should have been provided under the law – within the public school system that her family was a part of. She mentioned that it is not even an option for parents to be unfamiliar with the laws surrounding special needs before entering a meeting to discuss their child’s needs with school administrators, explaining that it is preferable to hire an advocate on one’s behalf to make sure that the school was not withholding any services that they are obligated to provide. However, she noted, it is not

feasible for families without financial means to hire professional advocates or lawyers.  

Given the critical importance of having adequate services for autistic children in the public school system – ranging from having classroom aides trained in special needs education, to occupational or speech therapists – respondents felt like they were constantly fighting an “uphill battle” with schools just so that their children would be able to have access to a public education. Claire joked, “I would say, ‘hmm, what can I have for lunch today? Ah yes, the school district!’ And then my husband would write a scary letter that would put the school district on its knees, and I would yell and scream and scare everybody.”  

In addition to being fierce advocates for their children, the lack of services provided in public schools inspired many women to start their own parent groups and engage in other similar forms of activism. For example, Ellen fought to bring a new behavior analysis program into the public schools in her area that had not previously existed there, and another respondent, Eileen, helped to form a parents-only group that would talk about strategies that had worked for them to secure the services and therapies that their children were entitled to through the public school system.  

Some women felt that needing to be an advocate for their child changed them as people, by removing them from their comfort zones and pushing them into adopting an activist mindset. As Diane eloquently stated, “When you have a disabled child, you don’t

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168 “Claire”, Interview, February 27, 2017.  
Another respondent, Ellen, felt that spending numerous years fighting for her child’s needs left her much more outgoing and willing to speak up than she had ever been in her life. Sometimes, being an activist is a choice. Many of these women did not make an active or conscious decision to become an activist in the realm of special needs and disability, but did not think twice about it when it became clear it would be necessary on behalf of their children. Ellen referred to this concept as her “Mama-bear claws”, noting that they “came out” when she had to fight for anything that her daughter needed. Having their children’s rights denied and left unrecognized by the public school systems – excluded from the rights of neurotypical children -- caused these mothers to become advocates on their child’s behalf. In most cases, this was a social niche that they had previously not occupied.

**The “dreaded” Jewish Mother**

Acting as Jewish activists and speaking up to make reforms in their children’s lives that also serve to help other children in similar situations, the respondents interviewed often fit into the stereotypes and ideals of “The Jewish Mother.” That is to say, acting as a fierce and loyal advocate and protector of their children is “stereotypically” Jewish; but at the same time, displaying certain traits is portrayed negatively in the media and can harm Jewish mothers as advocates in the school system. In *You Never Call! You Never Write! A History of the Jewish Mother*, Joyce

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173 Ibid.  
174 At least one respondent mentioned that she was a social worker, which she said added to her breadth of knowledge and experience regarding advocacy on behalf of her child.
Antler offers the image of the “grasping, omnipotent Jewish matriarch.”\(^{175}\) According to Antler, this image stemmed partly from the second-wave feminists’ disdain for the nuclear family structure, and even their vitriol for motherhood that sometimes extended to other women who bore children of their own.\(^{176}\) Although this belief was certainly not held by all feminists at the time, it was a philosophy popularized by Shulamith Firestone, a radical feminist whose strict Orthodox Jewish upbringing contributed to her outright rejection of childbearing and the traditional family unit.\(^{177}\) Even other women at the time, writes Antler, held a deep disdain for their own mothers, who, while being matriarchal, independent, and possessing many of the values later prized by third-wave feminists, were “stuck” as some saw it, in their small familial unit of patriarchy.\(^{178}\) As the ideal of Jewish family life during this time called for close-knit families with married parents and children, this proved particularly hard for some women, and some of the stereotypes we have about Jewish mothers emerged out of the second-wave movement.

Struggling to find role models, second-wave feminists had to pioneer ways to reconcile their ambitions to become independent women within traditional social structures. For those who were mothers, the task could be especially difficult. In the women’s movement, mother remained an “explosive divide”, as Alix Kates Shulman put it. With the birth of her two children, born in 1961 and 1963, Shulman’s whole life changed. Feminists pitied her for her new responsibilities, and she felt excluded, “humiliated and vulnerable.” But surprisingly, she found that in her own life, motherhood and feminism “were integrated from the start”, with motherhood providing new opportunities for personal and professional development.\(^{179}\)

So, while feminists in this era did often recognize their mothers’ abilities to be


\(^{176}\) Ibid., 154.

\(^{177}\) Ibid.

\(^{178}\) Ibid., 152.

\(^{179}\) Ibid., 160-161.
strong, independent, and work as well as raising families, they also resented the fact that their mothers and later, they themselves, were expected to bear children and raise children, carving out an existence within the boundaries of the nuclear family. Even worse, in their minds, was the fact that this was a process that their own mothers had willingly participated in. This idea is exemplified further in Antler’s analysis of Jane Alpert’s\textsuperscript{180} description of the rejection of her own mother (along with Robin Morgan, another radical feminist): “Like Firestone and Morgan, Alpert rejected her mother’s values and found her power over her to be constricting and oppressive. All three feminists saw their mothers’ strength and will as negative forces. For each, rage against the mother was an important ingredient in the mix of motives that led to radical activism, and then feminism.”\textsuperscript{181}

In this way, and with the help of derisive images of “vicious” and “controlling” Jewish mothers popularized via media such as the writings of Philip Roth, and plays such as \textit{Awake and Sing!}, “The Jewish Mother” is constructed as the controlling and stifling matriarch of the nuclear family.\textsuperscript{182} It can be argued that this occurs as a result of the power and control usually granted to the masculine head of household -- the patriarch -- being diminished, and masculine hegemony at once challenged and disassembled. When one considers the feminization of the Jewish man that we have seen throughout time, the idea of a “family matriarch” becomes particularly threatening.

Jewish mothers who have children with disabilities often have no choice but to be assertive, strong, and determined -- characteristics that might be misinterpreted as

\textsuperscript{180} A far-left radical and feminist, best known for conspiring to bomb governmental and commercial buildings in New York City.
\textsuperscript{181} Ibid., 160.
\textsuperscript{182} Ibid., 142.
“pushy, entitled, and demanding”: the negative stereotypes of the despised, Jewish mother in the media. In her memoir, *The Accidental Teacher: Life Lessons from My Silent Son*, Annie Lubliner Lehmann recalled the moment when she stopped being the “deferring negotiator” and to press hard for results. It involved the toilet training of her son Jonah in an integrated elementary school program. She met with his teachers before school began, “wrote out the details of what we’d accomplished that summer, and made clear that Jonah’s number one educational goal for that year had to be toilet training.” Every visit to the school revealed that her son was “sitting alone, unsupervised,” coming home with a “bag full of soiled pants and a note to send more clothes and perhaps some diapers.” Lehmann experienced a surge of anger and began to advocate for her son more passionately. “My answer to their request that he wear a diaper to school was ‘absolutely no.’” Reflecting back on this time, she explained that she felt empowered by her knowledge about what Jonah needed: “I was also beginning to appreciate my power as an advocate. Even without a degree in teaching or psychology, I began to see that I was the Jonah expert, the one who could, besides adding heart, add substance to any conversation about him.” Rejecting old stereotypes and ethnic caricatures, mothers like Lehmann point to their unique position as disability activists who know best for their children, because they are the experts in the subject of their child’s well-being. They desire to create an environment in which their children can flourish, be happy, and be as independent as possible while also knowing that their children can always fall back on them to be their fiercest and most loyal advocates.

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184 Ibid., 68.
185 Ibid.
Jewish parenting and “parenting Jewishly”

What exactly does it mean to these women to be a Jewish mother, and to “parent Jewishly,” specifically in the context of raising a child with autism? Overwhelmingly, over half of respondents affirmed that their Jewish identity plays a large role in the ways that they parent. Three mothers noted that to them, being Jewish means that they want to make sure their children are nurtured, loved, and supported in order for them to build the confidence and skills to someday live as independently as possible. A quote by Ellen exemplified this sentiment: “The more I learn about Judaism the more I figure out how to parent in a Jewish way. It’s about giving kids what they need in order to be independent”. Two respondents mentioned that one aspect of “Jewish parenting” that they find important is being protective and advocating for their children. While we can assume that many parents, both Jewish and non-Jewish, would express this desire, it is noteworthy in this case because it was among the examples offered respondents when asked how being Jewish affects their parenting style. It is clear that these mothers find the types of protective desires they display to be based within their individual understandings of Judaism.

Most commonly cited by the respondents as an effect of Judaism on their parenting style was “Jewish values.” Each respondent mentioned different values and qualities of Judaism that they find meaningful -- including leadership, community, honesty, sympathy, performing mitzvot, giving tzedakah, and tikkun olam. One

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187 A religious obligation to do what is righteous; often used in reference to giving charitable donations.
188 Repairing the world; often used in reference to actions that promote societal and environmental well-being.
respondent, Helen, said that her family combined *tzedakah* with activism by raising money for autism-based organizations as well as donating clothes and toys, noting that it was a good way to involve both of her children, one who has autism and one who does not.\(^\text{189}\) Another story reported by *The Mercury News* described an eight-year-old girl with autism, Raquel Jarson, who learned about a *tzedakah* box after reading the book *How Dalia Put a Big Yellow Comforter Inside a Tiny Blue Box* and wanted to contribute something for the poor.\(^\text{190}\) Her mother MariaElena Jarson explained, “That’s how she decided that any money would spend on a Hanukkah present for her she wanted to give to *tzedakah*, so we could buy warm blankets and a warm jacket for people who didn’t have them.” Her mother was especially proud that her daughter told her that “she loved being Jewish” at a time when “Christmas is so prevalent.” Raising her daughter Jewishly meant teaching her how to give: “I love that we give *tzedakah*. For any kid, that’s awesome, but especially for a kid with autism. To have a child who wants to give more than receive, and who’s helping make the world a better place . . . .”\(^\text{191}\) They selected their items to donate -- blankets, bedding, a jacket and an umbrella -- and dropped them off at their synagogue.

Many of the respondents’ sentiments about how Judaism affects their parenting had to do with teaching their children to treat others with the kindness and respect that they, as mothers of disabled children, did not always receive from everyone around them. Morgan said, “I’ve learned to be more sympathetic to people, because I always wished people would do that for me. You have no idea how hard it is to be a parent to a kid with

\(^\text{189}\) “Helen”, Interview, March 2, 2017.


\(^\text{191}\) Ibid.
special needs until you have one.” This further exemplifies how exclusion from certain Jewish and non-Jewish spheres of life influenced the maternal identity formation of these women, constructing them as not just caring mothers, but also activists and advocates. This is specific to Jewish women because of the unique way that these mothers took it upon themselves to fashion new rituals for their children and families -- becoming Jewish leaders and “reformers” in the process.

Conclusion

“It definitely affects women’s identity to have a special needs child; it almost erases your identity because it’s all you’re doing. They talk a lot about depression, you know, in moms with kids on the spectrum but I feel like there’s not time. You’re so distracted by having to do stuff that you don’t even have time to sit and think about yourself...I do think that it definitely plays a role in how much women can be themselves -- even having a normal job is nearly impossible because you’re constantly getting called out of work and going to appointments.” 193

In the above quote, Nora candidly described the erasure of her own identity, which seemed so intimately tied up with her autistic child that she had no time to think of her own needs. Similarly, Rabbi Rebecca Einstein Schorr, whose story about her son’s alternative bar mitzvah has previously been described, describes an ordinary yet overwhelming day in the life of a Jewish mother of child with autism in “A Day in the Life: Rebecca Einstein Schorr, Mother of a Child with Autism & Tourette’s.” She recounts her exhausting daily routine, which includes negotiating with insurance companies about her son’s extensive medical bills for various therapies, transporting her son to and from therapies, as well as taking care of her two other children, all while lacking the time to cook meals and get adequate rest. Schorr ruefully acknowledges that she “became” a stay-at-home mom upon realizing that her three kids -- one who is on the autism spectrum -- “needed more from her” 194, suggesting she has sacrificed parts of her life that form her identity as an individual in order to take care of her son. Even the “relaxing” part of her day is tinged with the responsibility of caring for her son:

9:00 p.m. I can barely see straight. I had been hoping to sit with [my husband] and catch up on last week’s episode of “The Big Bang Theory.” We often use the

show with [my son] to help him understand social pragmatics, but always watch it first in case there are situations that might not be appropriate for him. However, tonight is not the night. A soak in the tub and a cup of tea are sorely needed… 9:45 p.m. Lights out. *Shema* recited. *Laila tov* to me.¹⁹⁵

Jewish mothers not only have the responsibility of caring for their child’s special needs, but also have to navigate Jewish spaces and religious rituals very carefully in order to raise their children as Jews. Despite the best intentions and openness of congregations, mothers cannot completely shield their children from awkward stares or rude remarks made by individual congregants. Unspoken expectations about proper behavior in the synagogue as well as general attitudes toward intellectual achievements and misunderstandings of disability can lead to the isolation of these mothers and their families as they attempt to avoid situations in which their children may “cause a scene”.

The very nature of Jewish rituals can overload the sensory sensitivities of autistic children, making holidays like Passover a hazardous undertaking. As a result of their children’s specific sensitivities, Jewish mothers have become their own reformers of Judaism in the public and private spheres, as well as keepers of Jewishness in their own homes. Prayers like the havdalah for an autistic child or the autistic child’s Four Questions show how Jewish rituals can be reimagined to personalize the holidays for families with children on the spectrum.

Not only do Jewish mothers have to contend with the ins and outs of religious life, but like other parents of special needs children, they need to become experts in disability and law as they serve advocates for their children. As this study has shown, women who never previously imagined themselves as leaders find themselves fighting for inclusion initiatives and advocacy within their public school systems. The unique experiences of

¹⁹⁵ Ibid.
exclusion that Jewish mothers of autistic children face in the public and private spheres -- secular and religious -- lead them to be fearless activists, fierce advocates, and passionate reformers of Judaism.
Appendix

Informed Consent Form

You are invited to participate in a research study being conducted by Rachel Gabrilowitz, an undergraduate student at Brandeis University. The study is being conducted under the supervision of Dr. ChaeRan Freeze, Professor of Women’s Gender, and Sexuality Studies and Near Eastern and Judaic Studies at Brandeis University. Please read this form carefully. We encourage you to ask questions if you want more information about any part of the form or the study. If you decide to participate in this study you will be asked to sign this form. A copy of the signed form will be given to you to keep for your records – it has important information, including whom to contact if you have questions in the future.

What is this study about?
We are conducting this research study because we are trying to learn more about how Jewish families with autistic children, specifically mothers, engage in Jewish family and community life, ritual, and celebration.

What will you be asked to do if you participate?
If you decide to participate in this study, you will be asked to participate in a one-on-one interview with the lead researcher of the study. We would like to audiotape you during this interview. However, if you would prefer not to be audiotaped, that is okay – you may still participate in the research. We will ask for your consent to be audiotaped at the end of this form. The interview will take 45-60 minutes and can be conducted at Brandeis University or at a location convenient to both you and the interviewer, such as a coffee shop or library.

Are there any possible risks to you?
You may feel uncomfortable answering some of the questions. If a certain question or topic makes you feel uncomfortable, you are free to skip the question or ask the interviewer to move onto another topic. You can also withdraw from the study completely at any time. There is always the risk that your information could be accidentally disclosed to people not connected with this study; however, we will do our utmost to secure your information so this does not happen.

Will you benefit from participating in the study?
We hope that the study will explore new and unique ways that families with autistic children engage within the Jewish community. There is always the chance that strategies that have worked for other unique families will work for you, and vice versa. This study is a chance for beneficial information to be shared within the Jewish community upon completion.

Will it cost you anything to participate in the study?
The only cost to you will be your time.
Will you be compensated or receive anything for participating in this study?
You will receive a $15 gift card to either Starbucks or Target – your choice – as compensation for participating in an interview.

How will your information be kept private?
All information obtained in this study that can be identified with you will be kept confidential to the extent permitted by the law. If you consent to audio recording of the interview, the audio recording will be transcribed without any information that could identify you, and the audio file deleted immediately after.

When data and findings from the study are reported – in presentations and possible future publications – your information will not be separable from the findings as a whole. Pseudonyms will be used when reporting data and quotes from interviews; your real name will not be used. We will ask for your consent to use direct quotes from your interview at the bottom of the form. If you prefer that the study does not use any direct quotes from you, this is fine. Additionally, all data collected will be destroyed after the completion of the study.

What if you don’t want to participate or change your mind partway through?
Participation in interviews for this study is completely voluntary. You have the right to refuse to participate in all or a part of this study. Even if you decide to participate now, you may change your mind and withdraw from the study at any time without penalty or revocation of compensation. You may also refuse to answer any questions you like – just ask the interviewer to move onto another topic.

Who can you call if you have more questions?
If you have any questions about the research being conducted or your participation in the research, feel free to contact the supervisor of the study at (781) 736-2987 or at cfreeze@brandeis.edu.

If you have any questions about your rights as a subject in this research, would like to speak with someone other than the researchers about concerns you have regarding the study, or if you cannot reach the researchers, please contact the Brandeis University IRB (the University’s Committee for the Protection of Human Subjects) at 781-736-8133 or at irb@brandeis.edu.

Subject Consent
I have read the contents of this consent form, have been encouraged to ask questions, and have received satisfactory answers to my questions. I understand that my participation is voluntary and that I may withdraw my participation at any time without penalty. I voluntarily agree to participate in this study.

I do
I do not give my permission to make an audio recording of me during this interview.

I do
I do not give my permission to use my direct quotes from this interview in the written portion of this study.

Participant’s Signature ____________________________ Date ____________

Investigator’s Signature ____________________________ Date ____________
Interview Guide

The following is an interview guide that will be used for the one-on-one interviews. The bulleted points underneath each question are so that the interviewer can guide the conversation to ensure that it covers as many of the points as possible while making sure the conversations flows naturally. Participants may skip any questions at any time.

Pre-interview: Can you tell me a little bit about your family structure? How old are your kids, who lives in your household, etc.

1. Can you tell me a little bit about what your “Judaism” looks like?
   - Denomination
   - Connection to religion
   - Dedication to passing down to children
   - How does it influence your ways of thinking

2. If you belong to a synagogue, can you talk about what is it like?
   - Denomination
   - Children’s programs
   - Attendance of services or other activities

3. Do you and/or your family belong to any other Jewish groups or institutions? (Community groups, day schools, summer camps, youth groups, Chabad, etc.)
   - Who in your family participates

4. What was your experience like when you found out your child was diagnosed with autism?
   - Reaction of self
   - Reaction of spouse and other children (if applicable)
   - Coping mechanisms
   - Using Judaism to understand diagnosis
   - Reaction to initial diagnosis vs. how feelings have changed

5. Did you receive support after the diagnosis from anyone?
   - Experience with asking for and/or accepting help
   - Jewish or other support networks
   - Family or friends

6. Does your child participate in activities such as physical/occupational/speech/behavior therapies either within or outside of school?
   - IEP
   - Who brings the child
   - Gender of therapists
   - Early intervention
   - Other services received
   - Serving as an advocate for your child
7. Can you talk about any times where you have changed your traditions/observances/rituals, or created new ones, for Jewish holidays and celebrations to make them more inclusive/accessible for your child?
   - Shabbat observant
   - Passover, Hanukkah, Sukkot, others
   - High holidays

8. Can you tell me about some non-holiday-based Jewish practices that you, your child, and your family take part in, such as rituals or everyday practices?
   - Jewish books or stories
   - Bar and Bat Mitzvah
   - Sunday school or Hebrew school
   - Jewish education

9. What are some of the ways that you and your family feel either welcome or unwelcome by your synagogue or other Jewish institution?
   - Accommodations for your child during
     - Services
     - Hebrew/Sunday school
     - Events or meals

10. Can you describe a typical day’s routine for you and your family/child?
    - Role of ritual and repetition
    - Challenges of discipline
    - Division of labor for both parents (if applicable)

11. Could you tell me a little bit more about your child?
    - What do they like to do for fun
    - Things they are interested in
    - Things they dislike
    - Any favorite stories you like to tell about your child
    - Any stories relating to Judaism/ritual practice
    - The child’s connection to/feelings about Judaism/being Jewish

12. What are your personal conceptions of motherhood and parenthood?
    - Does being Jewish inform these concepts
    - Did these conceptions change with the birth of your child/children
    - Goals of parenthood
    - Most important things you wish to teach your child
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