Experiences of Jewish American Mothers of Children with Autism Spectrum Disorder

by

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For my children, Micah Talor, Asher Elazar, Elijah Benjamin, Caleb Jude, Eden Atara Shani, Nessa Yael Shai, Simon Jedidiah, Halleli Shirah, who taught me everything I know about love.

Abstract

This study examined the experiences of Jewish American mothers of children with autism spectrum disorder (ASD), and the extent to which they experienced affiliate stigma. The overall research question was: What are the experiences of Jewish American mothers relating to their child diagnosed with ASD? The following sub question guided the scope of this study: To what extent do these mothers report feelings of affiliate stigma? This study is a qualitative, phenomenological study as defined by Braun and Clarke (2022), Creswell and Poth (2018), Miles et al. (2020), Padgett (2017), and Terry and Hayfield (2021). The data were gathered through semistructured interviews and then analyzed using thematic analysis (TA), as described by Braun and Clarke, with coding facilitated by ATLAS.ti software. The sample consisted of 16 mothers of children with ASD who identify as Jewish American and live in Northern New Jersey. The themes of the mothers' experiences were *belonging matters, mothers' emotions and behavioral consequences, the need for friendship, affiliate stigma precludes belonging,* and *making meaning, meeting challenges, and personal growth.*

The findings of the study contribute greatly to all areas of social work practice by informing social work professionals about the nuanced experiences of mothers of children with autism within a Jewish American community. The study findings add to scholarship by delving into the unique cultural perspectives and lived experiences of this population. Furthermore, the study findings can be used to inform future qualitative research in other cultural contexts and broader quantitative research.

Table of Contents

List of Tables

Chapter 1: Study Overview

This study examined the experiences of Jewish American mothers of children with autism spectrum disorder (ASD), and the extent to which they experienced affiliate stigma. Affiliate stigma is the self-stigmatization process of family members, or affiliates, of a stigmatized person (Mak & Cheung, 2008). Family members of children with ASD are known to experience affiliate stigma (Mak & Kwok, 2010). Mitter et al. (2019) brought awareness to how others' perceptions of atypical behavior and development may be influenced by a cultural lens. Although previous research had been conducted on how parents of children with ASD experience affiliate stigma within many specific cultural contexts, this is the first known study exploring how Jewish American mothers of children with ASD experience this phenomenon. The specific aims of the study were to explore the experiences of Jewish American mothers of children with ASD and to determine if and how they experience affiliate stigma.

Scope of the Study

The overall research question was: What are the experiences of Jewish American parents relating to their child diagnosed with ASD? The following sub question guided the scope of this study: To what extent do these parents report feelings of affiliate stigma? To answer these questions, this study examined in depth the experiences of a small sample of Jewish American mothers of children with ASD living in northern New Jersey. The findings of this study lay the foundation for a large-scale research project with Jewish American parents of children with autism in other communities.

Significance and Contribution to the Social Work Profession

According to the National Association of Social Workers (NASW; n.d.) Code of Ethics, "Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural and ethnic diversity” (Ethical Principles Section). This study adhered to that code by exploring experiences of parenting a child with neurodiversity within the context of cultural and ethnic diversity. This is the first known study to explore the experiences of Jewish American mothers of children with autism with a specific focus on affiliate stigma. The findings contribute to the field of social work by examining the unique experiences of mothers of children with autism within a particular cultural context within the United States. This research contributes to a deeper understanding of this phenomenon, guiding social workers who work with this population in any capacity.

Methodology Overview

This study is a qualitative, phenomenological study as defined by Braun and Clarke (2022), Creswell and Poth (2018), Miles et al. (2020), Padgett (2017), and Terry and Hayfield (2021). The data were gathered through semistructured interviews and then analyzed using thematic analysis (TA), as described by Braun and Clarke, with coding facilitated by ATLAS.ti software. The sample consisted of 16 mothers of children with ASD who identify as Jewish American. The sample size was in accordance with similar studies using TA (Blanche et al., 2015; Broady et al., 2017; Gill & Liamputtong, 2011). The study was carried out in northern New Jersey. Participant recruitment began with parents known to the Friendship Circle of Bergen County. The director of the Friendship Circle granted permission to recruit and sent an email invitation to parents. Several mothers volunteered and introduced the researcher to other mothers, who then also volunteered. Participants read, discussed, and signed an informed consent letter. Interviews lasted 30–60 minutes and the researcher asked questions about the participants’ families, experiences in their Jewish community, and experiences with affiliate stigma.

Study Limitations

The reader should bear in mind that the study is based on Jewish American mothers of children with autism who are already affiliated with a specific Jewish community. Because only mothers volunteered, the experiences of fathers are not represented. Furthermore, these mothers were willing to talk to the researcher about their experiences, meaning they were willing to identify themselves as mothers of a child with ASD. These participant characteristics limit the scope of the study's findings because they do not include the perspectives of some parents.

Contributions

The findings of the study contribute greatly to all areas of social work practice by informing social work professionals about the nuanced experiences of mothers of children with autism within a Jewish American community. The study findings add to scholarship by delving into the unique cultural perspectives and lived experiences of this population. Furthermore, the study findings can be used to inform future qualitative research in other cultural contexts and broader quantitative research.

Chapter 2: The Study Problem

The aim of this study was to illuminate the experiences of Jewish American mothers of children with ASD, especially with affiliate stigma. Being a parent of a child with a disability may come with personal struggles such as stress, depression, loss of personal identity, and increased self-doubt and self-criticism (Werner & Shulman, 2013). Researchers have found that parents of children with ASD experience these symptoms more profoundly than parents of children with other disabilities (Mak & Cheung, 2008; Mak & Kwok, 2010; Werner & Shulman, 2015). These experiences are further intensified by society's stigma against those with ASD and, by association, their parents. Cultural standards, religious beliefs, and popularized theories and perceptions may heighten these experiences. It is important for social workers to design practice strategies to treat families of children with autism (Bishop-Fitzpatrick et al., 2019); thus, social workers need to understand the process and effects that stigma can have on family members. This chapter examines the challenges faced by Jewish American parents of children with ASD, specifically parents' experience with stigma by association with their disabled child and the internalization of that stigma.

What is Autism?

ASD, or autism, is categorized as a lifelong developmental disability. Symptoms impact social behavior and communication and include repetitive, restrictive, and stereotypical behavior patterns (American Psychiatric Association, 2013). Autism is a spectrum of varying levels of severity and presentations (Weitlauf et al., 2014), and is considered an invisible diagnosis because the outward physical appearance of a person with ASD is typical, whereas their behavior may deviate mildly to severely from the norm. Maenner et al. (2021) reported that, in 2018, the prevalence of ASD in children aged 8 and older in the United States was 1 in 44. In 2000, the prevalence was 1 in 150 (Centers for Disease Control and Prevention, n.d.). The increase in diagnoses over time may be due to the changing diagnostic criteria, increased awareness, changing acceptance of the diagnosis with the understanding of a wide range of outcomes, or perhaps, more cases. ASD occurs in all racial, ethnic, and socioeconomic groups; however, ASD is diagnosed four times more often in boys than in girls (Maenner et al., 2021).

The Experience of Parenting a Child with Autism

For every child diagnosed with ASD, there is at least one parent, caregiver, or guardian dedicated to raising that child. Researchers agree that these parents experience high levels of stress (Barroso et al., 2018; Keenan et al., 2016). Additionally, poor parental self-perception and feelings of failure are associated with a weaker child–parent relationship and lead to reduced developmental outcomes for the child into adulthood (Twomey & Shelvin, 2017; Woodman et al., 2015).

Upon receiving their child's diagnosis of ASD, parents initially need help understanding the disorder and then require an overview of available treatments and interventions (Gentles et al., 2019). There are many interventions available, and the parents are tasked with accessing an appropriate treatment protocol. Often, parents feel pressure to start any kind of rehabilitation therapy for their child as soon as possible (Gentles et al., 2019). Parents of children with ASD can easily feel overwhelmed and often feel unsupported when finding unique methods to cope and adjust, not only with the process of setting up a treatment program, but also with their own internal stressors (Davis & Kiang, 2020; Shepherd et al., 2018; Vernhet et al., 2019; Zaidman-Zait et al., 2018). Parental burden is significant because parents need to provide care and support to further the developmental, cognitive, and educational growth of their child with ASD (Frame & Casey, 2019; Picardi et al., 2018). The challenges and barriers that parents face in addressing the needs of a child with ASD vary depending on the severity of the child's symptoms and the coping skills of the parent (Gray, 2006). Parenting a child with ASD requires learning facets of development, tools for growth, and management skills specific to the disorder (Siller et al., 2014). Additionally, these parents must navigate the intricacies of the special-education system and the laws that govern it (Mire et al., 2017).

The process of assessment culminating in receiving a diagnosis can be stressful for parents. Ooi et al. (2016) observed that the "myriad of emotions experienced upon diagnosis followed immediately by a feedback session were overwhelming for parents" (p. 758). Twomey and Shevlin (2017) noted, "the assessment process is reported to be difficult for parents due in part to professional inadequacies, parental uncertainties and misrepresentations of the role of the parent" (p. 159). Furthermore, McLaughlin et al. (2005) found that poor communication between parents and professionals in the stages of assessment can leave a "legacy of mistrust that confirms for parents that this indeed is a truly awful thing that is happening to them and their child" (p. 285). After learning of an ASD diagnosis, parenting is fraught with determining the appropriate interventions and therapies. Parents in Frame and Casey's (2019) study reported that information about ASD treatments was confusing and conflicting. When selecting a treatment to try, the parents considered child-specific goals for treatment, concerns about safety of some treatment options, and concerns about mixed testimonials. Moreover, once a treatment was selected, parents experienced multiple challenges with accessing and implementing therapies (Frame & Casey, 2019). For Ooi et al.'s participants**,** even after services were secured, "some parents perceived therapies as difficult to access, a burden financially, difficult to implement, and not all to be effective" (p. 758). The service system can be disjointed, difficult to navigate across educational transitions, and sometimes perceived as intrusive and overwhelming, all of which are characteristics affecting parental psychological well-being (Hodgetts et al., 2017). Parents get sucked into a vortex of autism information and misinformation, hope and despair, fear over prognosis, and elation over small accomplishments.

Not surprisingly, parental stress is a critical factor in families of children with ASD. The daily interaction and constant intervention can often be wearing on a parent and can be chaotic and volatile. A parent must constantly be on the alert for a vast array of situations. Thus, it is not surprising that parental mental health issues are numerous (Baykal et al., 2019). In addition to stress, the literature highlights multiple negative impacts on parents of children with ASD, including depression and anxiety (Chan & Leung, 2021). Parents can develop destructive coping mechanisms, such as self-blame, isolation, negative feelings, and fear of speaking to professionals (Zaidman-Zait et al., 2018; Zhang et al., 2013). Potential isolation, both self-imposed and as a result of the stigma of their child's ASD diagnosis, is also a major concern (Kinnear et al., 2016; Myers et al., 2009). Parental self-perceptions include feelings of failure, shame, inadequacy, and hopelessness (Zhou et al., 2018).

Parents of children with ASD have been shown to be more stressed than parents of typically developing children, and parents of children with autism typically have increased levels of attachment-related anxiety (Keenan et al., 2016). Research has found that stress is higher for parents of children with ASD than for other clinical groups, such as children with mood disorders or chronic illness (Werner & Shulman, 2015). Parents of children with autism have been shown to have high levels of depression, which can be especially true for the parents of younger children (Manan et al., 2018). Furthermore, stress and depression are correlated, and thoughts of how the public perceives their parenting ability leads to increased depression and lower quality of life (Manan et al., 2018). Hopelessness and feelings of shame and embarrassment can be exacerbated by the internalization of felt and enacted stigma toward people with ASD and their families (Chan & Lam, 2018; Papadopoulos et al., 2019; Zhou et al., 2018).

The process of parenting a child with ASD is complex and unique for each parent and child dyad, and ultimately a challenging lifelong experience (Twomey & Shevlin, 2017). The increased challenges of parenting a child with ASD result in parental reports of poor self-perceptions and an inability to manage their child's needs (Chen et al., 2021). Lack of interventions, poor support, and increased stress are critically linked to parental perceptions of failure (Shepherd et al., 2018). Pity for and blame of parents of children with ASD can have a significant impact on parental feelings of failure and must be mitigated by positive reinforcement from professional and social support systems (Hingley-Jones, 2005).

Historical Perspectives on Parenting a Child with ASD

The diagnosis of ASD has been, and still can be, devastating for the child and family. In the past, mothers were blamed for their child's autism. The negative impact on mothers over the course of time cannot be calculated. In 1943, Leo Kanner, a child psychiatrist at Johns Hopkins University, first identified a syndrome he called *infantile autism*. This disorder was characterized by social and communication impairment, which could range from mild to profound, obsessive–compulsive repetitive behavior, and self-injurious activity. Kanner perceived that the parents of children with autism were suspiciously cold and aloof. In 1967, Bruno Bettelheim published *The Empty Fortress,* in which he purported that autism was a psychological disorder caused by bad mothering. Thus, the term *refrigerator mother* came about (Cohmer, 2014). Psychoanalysts attempted to treat children with ASD to help them overcome the psychological trauma of supposed poor mothering (Maurice, 1994). Challenging Bettelheim's theories, Rimland began shifting perceptions of the cause of autism from psychogenetic to a mix of genetics, environmental toxins, and neurological deficits (Rimland & Ney, 1974; Volkmar & McPartland, 2014). Still, the troubling impression of parental causation remained prevalent until the early 1990s, at which time there was an explosive increase in diagnoses, beginning what is now seen as the autism epidemic. Catherine Maurice, a pseudonym, was a mother of two children with autism; her children reportedly recovered after receiving applied behavior analysis (ABA) therapy. Maurice detailed her experience in the 1994 publication of *Let Me Hear Your Voice*, critiquing "bad parenting" and other purported psychological causes of autism and introducing parents to an alternative: a bio-neurological etiology. Maurice further popularized the demand for modern autism treatment when she brought awareness to Ole Ivar Lovaas' techniques (Lester & O'Reilly, 2021).

Lovaas (1981) published his experiences in teaching developmentally disabled children in the *Me Book*. Using discrete trial training, Lovaas' ABA became the only evidence-based, scientific treatment for autism. With ABA, Lovaas initially asked the parent to provide behavioral intervention and redirection around the clock to "recover" their child from autism. This matured into one of the major treatment modalities for this condition. ABA was expensive, time consuming, and demanding for parents, but it held promising outcomes; 47% of children receiving the treatment appeared neuro-typical by the age of 6 (Lovaas, 1981). Parents became obsessed with the goal of recovering their children and engaged in all means necessary to make that happen. Although the blame of causation was no longer placed specifically on the mother, responsibility for fixing this neuro-genetic syndrome was placed on the parents. Mothers of children with ASD were offered the opportunity to redeem themselves by rectifying the problem and recovering their child. Often, parents sacrificed financial security and their own mental well-being in pursuit of this goal (Maurice, 1994).

Over the last decade, perceptions surrounding autism shifted yet again, this time away from blaming or pressuring parents to “fix” their child, and toward encouraging the acceptance of the differences in their child’s neurological development. The neurodiversity movement was launched by Judy Singer in the late 1990s (McGee, 2012). According to McGee (2012), neurodiversity is

> less an example of academic jargon than a political naming. It suggests that the discourse of individual rights, and the celebration of diversity that accrues to the categories of race, gender, ethnicity, and sexual orientation, ought to apply to individuals whose neurological predispositions are not typical. (p. 12)

McGee observed that many outspoken advocates for neurodiversity are people who have been diagnosed with ASD. Conceptually, the acceptance of neurodiversity could ameliorate the negative perceptions that parents of children with ASD experience.

Affiliate Stigma, Courtesy Stigma, and General Stigma

According to Goffman (1963), stigma is the experience of a person who is disqualified from full social acceptance. This disqualification is based on an attribute that is deeply discrediting, which can be one of three types: body, character, or tribal. The disqualification is enacted when self-perceived “normals” discriminate against the person with stigma. Reviewing the stigma literature since Goffman’s work, Pryor and Reeder (2011) identified four manifestations of stigma: public stigma, self-stigma, stigma by association, and structural stigma. Public stigma, which is at the core of the model, is the perceiver’s reactions to the stigmatized person. Self-stigma is the impact of possessing a stigma, with the potential of internalizing the perceived stigmatizing negative attributes. Stigma by association (Goffman's [1963] courtesy stigma) is the reaction to stigmatization based on association to the stigmatized person. Structural stigma is the "legitimization and perpetuation of a stigmatized status by societies, institutions, and ideological systems" (Pryor & Reeder, 2011, p. 4).

Self-stigmatization of family members is known as affiliate stigma (Mak & Cheung, 2008), and its roots have been explored throughout the literature (Mak & Cheung, 2008; Mak & Kwok, 2010; Mitter et al., 2019). Mak and Kwok (2010) explored the process of how family members of children with ASD internalize courtesy stigma (another term for stigma by association), resulting in affiliate stigma. In some literature (Bos et al., 2013; Mak & Cheung, 2008; Pryor & Reeder, 2011), courtesy stigma is synonymous with affiliate stigma; in other literature (Mitter et al., 2019), courtesy stigma is understood to preempt affiliate stigma. Mitter et al.'s (2019) synthesis of literature resulted in a theory of a circular process termed *circle of stigma*. This circular process begins with the experience of courtesy stigma. Parents then identify with the negative perceptions expressed by others. This negative identification, when internalized, develops into affiliate stigma. Parents then fear future discrimination and rejection. Often, this daunting response to stigma elicits behaviors, such as social isolation, that feed back into the start of the cycle.

Based on Mitter et al.'s (2019) description of the circle of stigma, one can see how cultural nuances are woven throughout the process. The cycle begins with courtesy stigma, which is the awareness of others' perceptions of difference in behavior and development; those perceptions may be culturally influenced. Research has documented profoundly different public views about autism in different cultural settings, specifically in China and the United States (Yu et al., 2020). Furthermore, the internalization of courtesy stigma resulting in affiliate stigma can be influenced by culture because cultural norms apply to navigating the process of shame; shame-proneness has been found to be more prevalent in some cultures, and therefore more significant for parents in that culture (Zhou et al., 2018). Moreover, the extent to which parents feel affiliate stigma and shame is culturally driven (Papadopoulos et al., 2019). For example, several studies in specific cultural contexts have documented some of the variations within the stigma process, including how religious beliefs play into perceptions about autism and parents' response to it (Bos et al., 2013; Chu et al., 2020; Kwok & Kwok, 2020; Shaked & Bilu, 2006; Tilahun et al., 2016).

Parents' Experiences with Multiple Stigmas and ASD

Families of children with ASD may experience multiple stigmas in addition to the stigma of ASD. Attributes such as race, ethnicity, religion, and economic status can also be stigmatized. Coupled with the stigma of being a parent of a child with ASD, additional stigmas can intensify the experience. As discussed above, Goffman (1963) defined stigma as disqualification from full social acceptance based on a body, character, or tribal attribute. Based on this definition, it stands to reason that someone can be stigmatized for more than one of their attributes (e.g., disability and race or disability and socioeconomic status).

Being a minority or member of another oppressed group may exacerbate the challenges faced by parents of children with ASD (Singh & Bunyak, 2019). Zuckerman et al. (2018) found that Latinx parents of children with ASD in the United States were more likely to experience increased stigma, especially those who were further marginalized because they did not speak English and/or were undocumented. These parents had greater difficulty navigating the healthcare system and obtaining knowledge related to ASD, and had decreased trust in providers.

Research has documented significant racial and ethnic disparities in the frequency of ASD diagnosis (Mandell et al., 2009). Providers may interpret parents' concerns about their child's behavior differently based on the family's race and cultural background. For African American parents, pediatricians may be more likely to interpret parental concerns as consistent with the diagnosis of oppositional defiant disorder or conduct disorder rather than ASD (Donohue et al., 2019). Implicit bias may be at play in shaping these diagnostic experiences. For instance, Obeid et al. (2021) found that White undergraduate students implicitly associated White children with a less stigmatized diagnosis and Black children with a more stigmatized diagnosis; however, this pattern did not hold true for explicit biases, when participants had time to think. Although Obeid et al.'s research participants were not professionals, it is possible that implicit bias shapes providers' diagnoses, preventing minority children with ASD from receiving valuable therapies and services early on. The literature documents disparities and differences in both diagnosis and receipt of services based on race, ethnicity, parental income, and parental education level (Dallman et al., 2021; Smith et al., 2021). These disparities suggest that the experience of parents of children with ASD with multiple significant societal stigmas can be much more complex than the experience of their counterparts with fewer or less significant societal stigmas.

Interventions and Support for Parents of Children with ASD

Researchers have explored multiple interventions for promoting the well-being of parents of children with ASD (Frantz et al., 2018). Frantz et al. (2018) reviewed studies of interventions that targeted stress, depression, or self-efficacy as outcomes for parents of children with ASD. The interventions included psychoeducational programs, cognitive behavioral therapy (CBT), mindfulness-based stress reduction (MBSR), behaviorally based interventions, psychotherapeutic intervention, online journal writing, occupational therapy, and progressive muscle relaxation therapy (Frantz et al., 2018). The authors concluded that parents may see improvements in stress, depression, and self-efficacy from many of these interventions, but feel that more research is needed to fully understand what makes each intervention most effective.

There is very little literature documenting interventions specifically geared toward treating the affiliate stigma experienced by parents of children with autism. As described above, in the case of parents of children with ASD, courtesy stigma is the parents' awareness of outsiders' perceptions of their child's disability, outsider judgement, and related distressing emotions. Courtesy stigma, when internalized, is referred to as affiliate stigma, which includes negative self-evaluation, self-blame, depressive symptoms, self-isolation, and lack of self-compassion. Any intervention designed to ameliorate these issues must take the stigma process and its internalization into account.

One intervention specifically targeting affiliate stigma is SOLACE, developed and tested by Lodder et al. (2019, 2020). SOLACE is a facilitated, online support group for parents focused on the multifaceted experience of affiliate stigma, specifically addressing the unique attributes of ASD parenting. Participants were 17 parents who were randomly assigned to SOLACE (nine participants) or control (eight participants). Parents in the SOLACE group had improved mental health scores and reduced courtesy and affiliate stigma scores compared to the control group. Participants also had decreased self-blame scores and increased self-compassion scores. In focus-group interviews, parents reported the value of learning about self-compassion, the importance of being part of the group, and concern about the group ending. A larger trial is necessary to know if this intervention is safe and effective. Lodder et al.'s (2020) results demonstrate that professional intervention decreases the detrimental effects of affiliate stigma experienced by parents of children with autism while providing other mental health benefits. At the same time, this group-based intervention may not be appropriate for all parents of children with autism. It is imperative that parents of children with autism have access to their own mental health treatment if they choose to seek support. Multiple types of interventions may be beneficial, and those resources could be invaluable.

Social Work, Affiliate Stigma, and Parents of Children with ASD

Given the reality of affiliate stigma, what do parents of children with ASD want and need from social workers? Parents' experiences and perceptions will vary, so social workers will have to ask individual parents to learn what they need. Kwok and Kwok (2020) provided some guidance on parents' needs based on their research with parents in Hong Kong. Kwok and Kwok used the construct of emotion work (Hochschild, 2019), or the effort involved in managing emotions in oneself or others, to explore how emotion can be purposefully managed in parenting children with ASD. Kwok and Kwok identified five domains of emotion work to be addressed: diverting discomfort through managing annoyance, shame, or loss; avoiding hurt feelings through mediating and negotiating in the family; surviving stigma and social rejection; surviving institutional barriers and disregard; and negotiating identity. Kwok and Kwok found several implications for social work practice. First, their findings confute the assumption that parents' emotional experience is limited to stress. Additionally, the researchers also found that the parents' emotional needs were not confined to comfort versus discomfort; parents also required support for advocating for themselves and for their child. Though Kwok and Kwok's suggestions are based on data from parents in Hong Kong, and thus might not be generalizable to other cultural contexts, they give a fresh look on how social workers can and should work with parents of children with autism.

Policy Deficits Limiting Access to Appropriate Treatment

Thus far, this chapter has demonstrated the necessity and benefits of mental health care for parents of children with autism, whether their needs stem from affiliate stigma or other stressors that constitute their experience. It is now necessary to focus on the policy deficits limiting access to appropriate treatment. First, it is important to recognize that parents of children with autism must navigate the murky waters of accessing autism treatment, often depending on the generosity of an insurance provider. Not all states mandate autism coverage and the coverage mandated varies greatly. According to Callaghan and Silvester (2019), as of 2017, 46 states had mandated coverage, yet the generosity of benefits mandated differed significantly. Furthermore, the generosity of these mandates is precarious, as Callaghan and Silvester demonstrated that generosity is tied to partisan control of state legislatures. Additionally, a mandate does not equal implementation, or utilization (Callaghan & Silvester, 2019).

It is well documented that parenting a child with ASD is financially burdensome. Liao et al.’s (2019) literature review found that parents of children with ASD, especially mothers, faced job losses and greater expenses. When faced with the financial expenditure of accessing mental health services, parents might need to forfeit their own treatment to free up funds for treatment for their child. These parents’ experience with affiliate stigma includes depression, low self-esteem, significant shame, and decreased family functioning (Chan & Leung, 2021; Zhou et al., 2018). Unfortunately, mental health services may be difficult to access for parents of children with autism. Mental health services are expensive, and insurance often does not cover long-term mental health support, even though these parents experience ever-changing stressors in the long term. There is wide variability state to state in what mental health services are required to be covered (Willison et al., 2021). Support and mental health treatment may be critical to positive outcomes for both parents and their child or children with ASD (Frantz et al., 2018; Lodder et al., 2020); however, this treatment may be difficult to access and is quite costly.

Conclusion

It is now well established that parenting a child with ASD is difficult. Multiple stressors affect parents of children with ASD, including affiliate stigma. How parents perceive themselves in their role of parenting can affect the outcome for both the child with ASD and the entire family unit. It is well documented that the internalization of courtesy stigma, also known as affiliate stigma, has a significant effect on parental well-being. Social workers can ameliorate the negative experience and stress of affiliate stigma that parents of children with ASD may encounter. Given the evidence that culture affects all stigma processes, it is important that researchers explore the experience in a wide range of cultural settings. This is the first study to examine the experiences of Jewish American parents of children with ASD with a special focus on if and how they experience affiliate stigma.

Chapter 3: Literature Review

This chapter focuses on published literature that explores the experience of affiliate stigma for parents of children with ASD. A selective review of both quantitative and qualitative research conducted since 2015 has been organized thematically. One key quantitative study published in 2008, which validated the most commonly used measure of affiliate stigma, is also included, as it sets the precedence for most quantitative research conducted in this review. Key themes presented in the quantitative literature include measuring affiliate stigma, outcomes of affiliate stigma, mediating variables affecting affiliate stigma, and processes of affiliate stigma. Viewing the quantitative and qualitative literature together, relationships between culture and religious beliefs and affiliate stigma was a key theme. Furthermore, the lack of qualitative literature published in the last 5 years will be highlighted and examined. Gaps in research will be discussed. Last, contributions of this study to fill those gaps will be reviewed**.**

Methods

A search was completed in the following eight electronic databases: Academic Search Complete, Health Source Nursing Academic, Health Reference Center Academic, Medline, Psych Articles, Science Direct, Springer Link, and Social Science Full Text Complete. The initial query evaluated the depth of research on stigma, courtesy stigma, and affiliate stigma as experienced by parents of children with ASD.

An initial search was conducted using the terms *parental stress* and *autism* or *ASD* and *stigma* as a baseline. Academic Search Complete produced 501 results, Health Center Academic produced 98 results, Health Source Nursing produced 132 results, Medline produced 219 results, Psych Articles produced 44 results, Science Direct produced 601 results, Springer Link produced 906 results, and Social Science Full Text produced 50 results.

The search was then modified to include *parental stress* and *children with ASD* and *affiliate stigma*. This search yielded limited results. Health Source produced nine results, Academic Search Complete produced 23 results, Psych Articles produced two results, Health Reference Center produced one result, Medline produced 15 results, Springer Link produced 97 results, Science Direct produced 36 results, and Social Science Full Text produced zero results. The comparative lack of published research that focuses on the connections between raising children with ASD and stigma suggests prior research focused heavily on stress or mental health issues and paid relatively little attention to additional factors, such as stigma. There is great potential to develop a holistic understanding of the family unit when considering the daily struggles with communal stigma, courtesy stigma, or affiliate stigma and the stress that is created for parents of children with ASD. Consequently, the body of research collected speaks to many issues of stress and mental health disorders and exhibits little consideration to additional causes of stress such as affiliate or courtesy stigma. This researcher considered 61 articles for further analysis.

Inclusion criteria included peer-reviewed articles where the search terms were found in the article abstracts. The located articles focused on stress, stigma, and other additional factors supporting the research question. These factors included affiliate stigma, courtesy stigma, coping with the experiences of stigma, self-stigma, and internalized stigma processes. Exclusion criteria included non-peer-reviewed literature, articles not available in English, and theoretical articles. Further exclusionary criteria included research on extended family members and siblings and research that considered infants.

Regular replication of articles in the eight databases were identified. Based on these exclusionary criteria, only 34 peer-reviewed articles were selected for further examination. It is noteworthy that Social Science Full Text and Psych Articles did not yield as many results as the more general health-related databases. Five additional articles relevant to this research were obtained after thoroughly examining the 34 original articles and their reference pages. The themes that were further examined included measuring affiliate stigma, outcomes of affiliate stigma, mental health and stress, mediating variables affecting affiliate stigma, the processes of affiliate stigma, and culture and religious beliefs and affiliate stigma. After conducting this literature review and determining that this study would focus on Jewish American parents, additional literature on the Jewish American community and Jewish parents of children with autism was also reviewed.

Jewish American Parents of Children with ASD

Jewish American identity can be viewed as a construct of both religious and cultural affiliation, with large potential variations in how individuals identify with either the religious or cultural components of being an American Jew (Friedlander et al., 2010; Friedman et al., 2005). Scholars have urged counselors to recognize American Jews as ethnic minorities (Schlosser et al., 2009). No studies of Jewish American parents of children with ASD were located in the literature search.

Although autism is considered a neuro-biological, developmental disorder, the behavioral manifestations of ASD may mimic or exist comorbidly with profound mental illness. For this reason, literature on mental health stigma and mental health needs in Orthodox Jewish communities in the United States can inform this study. The Jewish American community is comprised of multiple denominations and subgroups (Friedlander et al., 2010), with some Orthodox subsets experiencing profound stigmatization of mental illness of any kind. Schnall (2006) highlighted the need for multicultural competence in counseling with the Orthodox

Jewish population. The population has many subgroups, and mental health professionals must be careful not to make assumptions about their clients. Furthermore, religious difficulties may be effects of and not causes of a client's emotional difficulties (Schnall, 2006). A mental health professional needs to understand a community's explanatory models of illness; for example, the illness may be seen as G-d's reproof for nonadherence to religious mandates or as a divine test. Schnall also articulated that within Orthodox communities, stigma is attached to individuals seeking mental health services. This means individuals seeking services are likely to be very concerned with confidentiality and the possibility of *loshon hora* (speaking negatively about another individual). Finally, Schnall also noted the likelihood of rabbinical involvement in all decisions related to mental health treatment.

Baruch et al. (2014) found elevated depression stigma amongst Orthodox Jews demonstrated by elevated secrecy, treatment-seeking stigma, fear of family/marriage stigma, and other stigmatizing experiences. Interestingly, Pirutinsky et al. (2010) found that biomedical explanations for mental illness increased stigmatization toward mental illness in the Orthodox Jewish community. This finding was tied to a focus in the Orthodox Jewish culture on the consequences of mental illness on family status, stability, and children. While studying mental health needs in the Orthodox Jewish community, Schnall et al. (2014) also found evidence of stigma and mistrust of the mental health field. Because people with ASD may demonstrate bizarre behavior and because ASD is currently understood to be caused by an unknown genetic "flaw," ASD is likely to be stigmatized in the Jewish American population.

Measuring Affiliate Stigma

Within the last decade, quantitative researchers have used several scales to measure internalized, affiliate, or courtesy stigma. In the set of studies reviewed, the Affiliate Stigma

Scale (Mak & Cheung, 2008) was the most frequently used measure of affiliate stigma (Kabiyea & Manor-Binyamini, 2019; Recio et al., 2020; Werner & Shulman, 2015; Wong et al., 2016; Zhou et al., 2018). The Affiliate Stigma Scale measures internalization of stigma, and was the first scale created specifically for affiliate stigma. Exploratory factor analysis suggests the scale is unidimensional, internally consistent, and has good predictive ability for subjective burden (Mak & Cheung, 2008).

Mak and Cheung (2008) defined affiliate stigma as the self-stigmatization process of family members, or affiliates, of a stigmatized person. By internalizing stigma, these affiliates may develop negative self-beliefs and detrimental or negative emotions. Behaviorally, those experiencing affiliate stigma may withdraw or conceal their affiliation with the stigmatized person. What was defined by Erving Goffman (1963) as courtesy stigma in his seminal work on the topic is referred to as affiliate stigma when internalized. However, in the existing multinational literature, the two terms are either used in conjunction to label different parts of the same experience or simply interchangeably. The intrapsychic processes of courtesy and affiliate stigma have been further investigated in the reviewed literature within this chapter. There has been significant research conducted on the affiliate stigma or courtesy stigma processes that parents of children with mental illness experience (Link et al., 2015). Additionally, there is much literature on the experiences of parents of children with general behavioral disturbances, intellectual disabilities, and physical disabilities (Eaton et al., 2019; Kabiyea & Manor-Binyamini, 2019; McLean & Halstead, 2021). The body of literature that examines affiliate stigma for a parent or caregiver of a children with ASD, either quantitatively or qualitatively, points to the importance of culture and religious beliefs in the experience of affiliate stigma and to a need to further explore unique cultural and religious perspectives of parents of children with ASD.

An individual with ASD lacks the physical abnormalities that those with overt physical disorders possess. In fact, a child or adult with ASD seems completely typical in outward appearance (Werner & Shulman, 2015); thus, ASD has been described as an invisible disability (Chu et al., 2020). When the individual with ASD exhibits bizarre, destructive, or surprising behaviors consistent with the diagnosis, it can be shocking to onlookers in public places and deeply embarrassing to the parent or caregiver accompanying them (Broady et al., 2017; Gray, 2002a; Ng et al., 2020). In a groundbreaking quantitative study, Werner and Shulman (2015) discovered that parents of children with ASD experienced more affiliate stigma than parents of children with physical or intellectual disabilities. As noted above, the literature search found no studies specifically on affiliate stigma experiences of Jewish American parents of children with ASD. Thus, this literature review thoroughly details the most current literature on the affiliate stigma experiences of parents of child(ren) with ASD within any ethnic group.

Other measures with slightly different focuses have been developed to assess stigma. The Self-Stigmatizing Thinking Automaticity and Repetition Scale (STARS; Chan & Lam, 2018) is a measure of the self-stigma process. Although researchers have distinguished between the content and the process of self-stigma, Chan and Lam (2018) noted that there were no measures for the process of self-stigma. To fill this gap, Chan and Lam sought to validate a self-stigma scale (STARS) while also collecting data from a sample of parents of children with ASD. In Chan and Lam’s study. most of the parents were mothers with male children with ASD and a concurrent intellectual disability. The authors determined that the scale was internally consistent and maintained content validity, criterion validity, and incremental validity.

Another measure of parent self-stigma focused on parents of children with mental health disorders. Eaton et al. (2019) developed the Parent Self Stigma scale for this purpose. Eaton et al.'s scale breaks down self-stigma into self-shame, self-blame, and bad parenting. This scale is relevant to the present literature review because an ASD diagnosis can be concurrent with a mental health diagnosis and intellectual disability diagnosis. Furthermore, there are significant issues with differential diagnoses for children with average or above average intelligence, high functioning autism, or the former diagnosis of Asperger's Syndrome.

Other researchers have used an existing internalized stigma scale modified to reflect a parent's experience. A modified version of the Internalized Stigma of Mental Illness (ISMI; Hammer & Toland, 2017) scale was used by Öz et al. (2020) to study relationships between anxiety and depression and internalized stigma for mothers of children with ASD. The modified ISMI reflected the experience of affiliate stigma by changing the personal expressions to reflect the parent's relationship to their child. It is important to note that perceptions of the presentation of mental illness can differ significantly from perceptions of the presentation of ASD, so it must be noted that this scale was developed for parents of children with mental illness.

Regardless of whether it is internalized stigma or perceived stigma, the experience of stigma still affects parents' ability to function effectively. The literature review revealed additional measurements used to examine perceived stigma rather than affiliate/self/internalized stigma. Zuckerman et al. (2018) created a bilingual English–Spanish measure of parent-perceived ASD stigma. The authors aimed to fill gaps about (a) perceived stigma in families with children with ASD, and (b) how that perceived stigma might limit families' desire to access healthcare services and therapies. Zuckerman et al. successfully validated this measure of parent perceived stigma and determined that the scale showed sociodemographic variation in perceived stigma. This measurement of parent-perceived ASD stigma, which asked participants to report their perceptions of their community’s attitudes toward ASD, is noteworthy because it is specific to parents of children with ASD and because perceived stigma is the antecedent to internalized stigma. Following Zuckerman et al., Harrison et al. (2019) examined the psychometric properties of the Autism Stigma and Knowledge Questionnaire (ASKQ)—which also measures perceived public stigma—in multiple cultural contexts. Similarly, Čolić and Milačić-Vidojević (2021) developed the Parental Perceptions of Public Attitudes Scale (PPPAS) to measure perceived stigma by Serbian parents of children with ASD and physical disabilities.

Although the existing quantitative measurements allow researchers to capture a substantial amount of data using a standardized and validated process, several scholars have noted that qualitative research captures the nuances of parents’ experiences in a way that quantitative data collection cannot (Mak & Cheung, 2008). Because of the impersonal nature of a survey, the nuances and subtleties of one’s experience may be overlooked or underestimated. The remaining sections of this review highlight the themes present in this body of literature, summarizing within each theme what has been learned through both quantitative and qualitative methods.

Outcomes of Affiliate Stigma: Mental Health and Stress

Affiliate stigma has been associated with significant outcomes related to parental stress and parental mental health. These outcomes can also impact the child with ASD. Furthermore, stigma adds to caregiver burden and negatively affects quality of life (Mitter et al., 2019). In their systematic literature review, Mitter et al. (2019) sought to explore the documented consequences of affiliate stigma. In Mitter et al.’s review, the consequences of affiliate stigma for family members included emotional distress, burden of care, and social isolation. Similarly, Papadopoulos et al. (2019) found that autism stigma significantly impacts caregiver mental health. In this review, Papadopoulos found that the damage autism stigma can cause for a caregiver is presented with a causative through-line.

Stigma plays a significant role in predicting how difficult life is for parents of children with ASD (Kinnear et al., 2016). Noting that previous stigma studies were either large-population quantitative studies or small, qualitative studies, Kinnear et al. (2016) asked questions about stigma and its consequences. To what extent do families experience stigma? What are the key features of stigma? How do these aspects of stigma contribute to how difficult family caregivers feel it is to care for a child with ASD? Kinnear et al. delineated the process by which affiliate stigma contributes to the stress levels and well-being of parents of children with autism. First, the child's behaviors start the stigma process. Then, others' perceptions and assumptions as they observe the child's behavior continue the process. When parents experience rejection by these others, the experience leads to isolation and seclusion. Finally, the parents internalize the stigma to varying degrees.

Kinnear et al.'s (2016) sample consisted of 502 American and Canadian parents of children with autism. Via telephone interviews, the authors asked parents about their child's autism-related behaviors, their perceptions of public stereotypes (concerning competence of social roles), the causes and characteristics of autism, frequency of rejection of their child by peers, isolation from family and friends, exclusion by family and friends, the impact of autism on parents' work hours, their overall assessment of difficulty of stigma in their lives, and the overall difficulty of raising a child with ASD. Kinnear et al. findings imply that stigma plays a significant role in predicting how difficult life is for parents. They also found that almost all parents experienced stigma, but the extent to which they experienced stigma varied.

Kinnear et al. (2016) explained their conceptual model and some of the variation and its consequences. This model included how the external symptomatic behaviors of the child with ASD induce the social processes of stereotyping, rejection, and exclusion. Kinnear et al. concluded that, of all the variables, stigma and the child's autism-related behaviors play the largest roles in making parents' lives challenging overall. Stereotypes and peer rejection were not significant predictors of the difficulty of caring for a child with ASD; however, the difficulties that parents experienced internally with stigma was predictive of the difficulty they reported in parenting their child with ASD. In conclusion, parent perception of stigmatization may have a significant impact on the well-being of parents of children with autism. Because Kinnear et al.'s study was published in 2016, it adhered to the DSM-4 TR criteria for ASDs, which differ from the current DSM-5 criteria. The authors recommended further study with racially and culturally diverse participants.

Most of the affiliate stigma outcomes studied and documented in the literature focus on the heightened stress, decreased well-being, and clinical mental health challenges experienced by parents of children with ASD. These parents have been found to be more stressed when experiencing affiliate stigma and may benefit from mindfulness training to reduce the stress they associate with parenting a child with ASD (Wong et al., 2016). Although Öz et al.'s (2020) study of mothers in Turkey did not determine causation, they found that mothers with moderate depression and/or anxiety symptoms also experienced moderate levels of internalized stigma. Additionally, quality of life and life satisfaction were reportedly low in most mothers studied. Chan and Leung (2021) also identified parent depression and anxiety as an outcome of enacted and felt stigma; the stigma served as a link between a child's autism symptoms/behaviors and the parents' mental health outcomes. Mitter et al. (2019) described the circle of stigma, which also explores the circular relationship involving child behavior and parent mental health. Finally, low self-esteem is an outcome for parents who experience affiliate stigma (Recio et al., 2020).

Affiliate stigma can also result in behavioral outcomes for both children and parents. Ng et al. (2020) found that the experiences that parents of preschool-aged children had with affiliate stigma negatively impacted children's involvement in overall community participation and participation in one activity at home. Parents who have internalized stigma may be reluctant to seek help (Wong et al., 2016), although cultural influences may also contribute to help-seeking behavior. As noted in Mitter et al.'s (2019) review, there are also some positive aspects of caring for a child with ASD. The authors observed that research has shifted from a negative view to an increased focus on positive experiences in caregiving (Mitter et al., 2019).

Mediating Variables Affecting Affiliate Stigma

Mediating variables are also being explored in the quantitative literature. Some studies identify parent/caregiver characteristics that could be predictors of affiliate stigma. For example, stigma level decreases as education levels increase (Öz et al., 2020). Self-esteem, shame-proneness, and family functioning predict affiliate stigma and depression (Zhou et al., 2018). Moreover, nonpartnered caregivers are more likely to experience affiliate stigma (Lovell & Wetherell, 2019). Additionally, caregivers with less sleep are more likely to experience affiliate stigma and to somaticize their reactions (Lovell & Wetherell, 2019). Somatization and stress may be mediated by sense of stigma (Kabiyea & Manor-Binyamini, 2019).

Other studies identify variables that mitigate or protect against affiliate stigma. Self-compassion is a potential buffer (Wong et al., 2016); parents who are hopeful and self-accepting are less affected by affiliate stigma. Trait mindfulness mitigates the adverse psychological impacts of public and courtesy stigma, such as depression, anxiety, and caregiving burden (Chan

& Lam, 2017). In addition, Recio et al. (2020) found a moderating and protective role of social support. They examined internalized stigma while acknowledging the antecedent, perceived discrimination. Recio et al. found that social support partially protects the parent's self-esteem and perception of discrimination. Further exploring the processes leading to affiliate stigma outcomes, Cheung et al. (2019) found that parenting stress mediates the relationship between parent characteristics (mindful parenting disposition and affiliate stigma) and behavioral difficulties of children with ASD. In other words, mindful parents are less likely to get stressed trying to avoid stigma (Cheung et al., 2019).

Papadopoulos et al. (2019) observed that some parent variables correlating to affiliate stigma are changeable through intervention, whereas others are not. For example, changeable phenomena include caregiver burden, divine punishment attribution, emotional support, family functioning, feelings of shame and embarrassment, hopelessness, parent confidence, perceived controllability, positive meaning for caregiving, proneness to shame, self-blame, self-compassion, self-esteem, and social isolation (Papadopoulos et al., 2019). Nonchangeable phenomena include gender, culture, financial burden, and time since diagnosis (Papadopoulos et al., 2019). Lodder et al. (2020) conducted a feasibility trial of an intervention called SOLACE, which centered around a parent support group. Parents in the SOLACE group had improved mental health scores and reduced courtesy and affiliate stigma scores compared to the control group. Parents valued learning about self-compassion and reported the importance of being part of the group, demonstrating concern about the group ending.

The Processes of Affiliate Stigma

Although quantitative researchers agree that affiliate stigma, or courtesy stigma, is a process (Chan & Leung, 2021; Kinnear et al., 2016; Mitter et al., 2019; Zhou et al., 2018), a consistent explanation of the process has not yet been articulated. Kinnear et al. (2016) sought to test a model of stigma processes among parents, beginning with child behavior and moving through stereotyping, rejection, exclusion, and isolation. The researchers found that stigma played a significant role in predicting how difficult life was for parents. In evaluating their conceptual model, Kinnear et al. found that almost all parents experienced stigma, but the extent to which the experienced stigma varied. The conceptual model explains some of the variation and its consequences. The behaviors of the child with ASD induce the social processes of stereotyping, rejection, and exclusion. Of all the variables, stigma and the child's autism-related behaviors played the largest roles in making parents' lives challenging overall. Stereotypes and peer rejection were not significant predictors of the difficulty of caring for a child with ASD; however, the difficulties parents experienced internally with stigma was predictive of the difficulty they reported in parenting their child with ASD. In other words, parent perception of stigmatization influences difficulties in parenting. It is possible that future qualitative research could enhance the understanding of the nuances of these processes.

Chan and Leung (2021) described a process of enacted stigma leading to felt stigma. Their goal was to test a model that child behavior symptoms may heighten parent affective symptoms by evoking stigma. In their analysis, specific child behaviors were linked positively with both vicarious and courtesy stigma and parental stigma. Both kinds of stigma were associated with depression and anxiety. As Chan and Leung stated,

> Consistent with our hypotheses, child autistic symptoms were linked to higher levels of parental affective symptoms through two pathways: via parental perceptions of public stigma and feelings of vicarious stigma and/or via parental perceptions of courtesy stigma and feelings of self-stigma. (p. 533)

Mitter et al. (2019) discussed the circle of stigma, providing a model of how the experience of courtesy stigma feeds into affiliate stigma and then how caregivers respond and the consequences they experience. Mitter et al. also noted the role of culture in the stigma circle, especially the distinction between how stigma unfolds in collectivist versus individualist cultures and how caregivers cope with stigma, particularly through religious or spiritual practice. Stigma processes and the roles of these cultural and religious influences emerged in the researcher's review of both quantitative and qualitative research on affiliate stigma experienced by parents of children with ASD.

Culture and Religious Beliefs and Affiliate Stigma

For parents of children with ASD, the experience of affiliate stigma is often determined and exacerbated by the culture, traditions, and customs of the society in which they live (Mitter et al., 2019; Salleh et al., 2020). In the literature on affiliate stigma, culture refers to the shared ideas influencing those living in a group of people, such as their values, beliefs, ideologies, language, communications, and norms (Papadopoulos et al., 2019).

Multiple sociocultural settings were represented in the literature reviews by Papadopoulos et al. (2019), Mitter et al. (2019), and Liao et al. (2019), and in a meta-analysis of qualitative research prepared by Salleh et al. (2020). In their literature review, Liao et al. specifically noted that parents from different cultures all struggle with stigma. Furthermore, Liao et al. recommended that cultural tailoring should be considered in research designs to acknowledge the relevance of language, customs, and religious beliefs. Selman et al. (2018) examined an immigrant cultural group in Britain using a qualitative approach. Papadopoulos et al. also encouraged qualitative researchers of affiliate stigma experiences to include statements of their own cultural backgrounds. Last, Zuckerman et al. (2018) pointed out that public perceived stigma of ASD, which plays a part in the processes of courtesy and affiliate stigma, also varies with cultural and sociodemographic factors. Furthermore, Zuckerman et al. found that marginalized groups are likely to have higher ASD perceived-stigma scores. It stands to reason that the process of internalization of public stigma is also impacted by cultural and sociodemographic factors, leading to the experience of courtesy and/or affiliate stigma.

Some of the literature that focuses on cultural factors influencing affiliate stigma amongst parents of children with ASD noted how religious beliefs play a role. These beliefs may be factors in the affiliate stigma process or in the ways parents cope with affiliate stigma. These beliefs can also impact how parents interact with professionals to receive care for their children or for themselves. There is evidence that religious beliefs impact a parent's and society's understanding of disability in general and ASD in particular. In their systematic review, Papadopoulos et al. (2019) noted several examples in the literature of ways religion also plays a role in how communities understand the diagnosis of autism.

Among the studies included in this review, four main sociocultural categories emerged: Middle Eastern, Asian, African, and Western. Table 1 displays the studies' sociocultural settings and study designs. The high number of studies from Chinese cultural settings is important because, as Mak and Cheung (2008) noted, affiliate stigma can be related to Chinese cultural beliefs. Shame-proneness is common in Chinese culture and also predicts affiliate stigma (Zhou et al., 2018). Additionally, face-preserving Chinese culture may impact the experience of stigma (Wong et al., 2016). Yu et al. (2020) also found that culture affects the perception and prevalence of autism stigma. Coming from a Saudi Arabian context, Alshaigi et al.'s (2020) findings also suggest that the prevalence of stigma among parents may be impacted by culture, as the authors connect their participants' experiences of self-stigma to conservative culture in the Kingdom of

Saudi Arabia. Though the prevalence of affiliate stigma or self-stigma seems to be impacted by culture, there is room for further exploration of cultural characteristics that might lead to higher prevalence. Papadopoulos et al. (2019) called for additional qualitative research to understand the nuances of the vulnerabilities leading to the experience of affiliate stigma.

Table 1

Literature Review

Author(s), year	Sociocultural setting	Study design
Middle Eastern		
Alshaigi et al. 2020	Saudi Arabia	Quantitative
Werner & Schulman, 2015	Israel	Quantitative
Kabiyea & Manor-Binyamini, 2019	Bedouin community/Israel	Quantitative
Öz et al., 2020	Turkey	Quantitative
Asian		
Chan & Lam, 2018	Hong Kong	Quantitative
Chan & Leung, 2021	Hong Kong	Quantitative
Wong et al., 2016	Hong Kong	Quantitative
Chan & Lam 2017	Hong Kong	Quantitative
Cheung et al., 2019	Hong Kong	Quantitative
Ng et al., 2020	Hong Kong	Quantitative
Mak & Cheung, 2008	Hong Kong	Quantitative
Zhou et al., 2018	Mainland China	Quantitative
Chu et al. 2020	Malaysia	Quantitative
African		
Tilahun et al. 2016	Ethiopia	Mixed methods
Oti-Boadi et al. 2020	Ghana	Qualitative
Selman et al., 2018	Somali immigrants/UK	Qualitative
Western or European/North American		
Gray, 2002a, 2002b	Australia	Qualitative
Broady et al., 2017	Australia	Qualitative
Recio et al., 2020	Spain	Quantitative
Lovell & Wetherell, 2018	USA and UK	Quantitative
Kinnear et al., 2016	USA and Canada	Quantitative

Author(s), year	Sociocultural setting	Study design
Zuckerman et al. 2018	Latinx and White non-Latinx/USA	Quantitative
Eaton et al., 2018	Australia	Quantitative

Furthermore, many researchers note that the understanding of autism in the community varies by culture (Alshaigi et al., 2020; Yu et al., 2020; Zuckerman et al., 2018). Chu et al. (2020) found that their sample of Malaysian parents did not experience high levels of stigma or stress, and thus suggested that cultural and religious beliefs may play a part in the acceptance of children with autism. There is also some evidence that mediating factors or coping strategies may be influenced by cultural characteristics and practices. Wong et al. (2016) found that factors of Chinese culture may lead parents to seek family support rather than support from other sources. However, family support is not always available, especially around the time of diagnosis (Broady et al., 2017; Gray, 2002a, 2002b).

An example of ingrained cultural perception may be present in Chu et al.'s (2020) examination of the relationship between affiliate stigma, parenting stress, and quality of life for Malaysian parents of children with ASD. Most participants were Malay (93.6%) and Muslim. Thus, the authors noted that the results may reflect Malay religious and cultural values. Survey participants reported low levels of stigma and moderate levels of stress. The quality-of-life challenges reported were relational problems with the child. For these participants, affiliate stigma did not play a role in quality of life, although stress had a moderate negative correlation with quality of life. Chu et al. noted how cultural and religious beliefs may play a part in the acceptance of the child's condition, as Malay Muslims see a child's ASD as a test from G-d and may develop positive ways of responding to this test. The authors further noted that Malay parents may feel cultural pressure to present a positive perspective on raising a child with ASD.

Despite the described acceptance of autism and reported abundance of information available in the Malay culture, it is interesting to note that the response rate for the study was only 17.4%. Chu et al. pointed to the need to further examine how culture and religion influence the experience of affiliate stigma.

Mixed-methods research also provides insight regarding how culture and religion are part of the experience of stigma for parents of children with ASD. Tilahun et al. (2016) found stigma was higher among caregivers who had sought traditional help, provided supernatural explanations for their child's condition, and for those of Orthodox Christian faith. The authors noted that the direction of causality was unknown. Participants were 102 caregivers of children with developmental disorders attending two clinics in Addis Ababa. Within the study, 66.7% of the participants' children were diagnosed with an intellectual disability, and 33% were diagnosed with ASD. Participants completed a structural questionnaire and face-to-face interview. Many caregivers expressed experiences of stigma consistent with research in higher income settings and other low- and middle-income countries. Rationalizations for the child's illness were a mix of supernatural and biomedical explanations. Tilahun et al.'s study findings suggest the possibility that religiosity and belief in the supernatural may have a negative impact by supporting perceptions of affiliate stigma.

Few qualitative studies on affiliate stigma for parents of children with ASD were published after 2015. Qualitative studies have been set in Ghana (Oti-Boadi et al., 2020), Australia (Broady et al., 2017), and among Somali parents in the United Kingdom (Selman et al. 2018). In addition to prevalence, the experience of affiliate stigma may be impacted by culture. Papadopoulos et al. (2019) observed that the experience of affiliate stigma seems to differ between individualist and collectivist cultures.

Oti-Boadi et al. (2020) focused on mothers of children with ASD in Ghana. The authors provided background on the understanding of ASD in Ghana and other West African countries, where the conceptualization has a spiritual dimension. Oti-Boadi et al. specifically studied stigma and forgiveness, and found that the participants' need to forgive outsiders for their experience of perceived affiliate stigma had religious significance for them. When dealing with affiliate stigma, the parents in this study found forgiveness as a coping resource that aided their well-being. The parents who participated in the study all self-identified as Christian, which is the predominant religion in Ghana. Oti-Boadi et al. posited that forgiveness was a coping resource for the parents' experience of stigma. The authors emphasized understanding the participants' experiences in the context of their spiritual and religious beliefs. The mothers in the study felt forgiveness under the guise of religious necessity, which empowered them to overcome affiliate stigma.

An additional qualitative study in a different context further highlights the influences of culture and faith. Selman et al.'s (2018) aim was to understand the nature of stigma experienced by Somali parents of children with autism who had migrated to the United Kingdom and how they coped with or resisted it. The authors used a community-based, participatory research approach, conducting in-depth interviews with 15 participants, 12 of whom were mothers and three of whom were fathers. The interviews were conducted with Somali–English simultaneous translation. The authors noted that there is little Somali vocabulary to describe the condition of autism. Furthermore, there is little vocabulary to describe the experience of stigma. The authors found that Somali parents may not use the term *stigma,* but still experience it. The parents described the nature of the stigma they experienced as including labeling, stereotyping, separation, emotional reactions, discrimination, and the power of their perception of affiliate stigma. For these Somali parents in the United Kingdom,

> Related to the difficulty of categorising autism was the lack of consensus on and understanding of its aetiology and trajectory. Parents received conflicting messages from members of their own community … the suspicion that parents might in some way be implicated in causing their child’s autism influenced other people’s responses to them as well as parents’ self-perceptions. (Selman et al., 2018, p. 12)

The parents in Selman et al.’s (2018) study also described coping and resistance; they specifically spoke about the power of language, faith as a resource, and learning about autism, as well as peer support and community relationships. The parents specifically used faith as a resource in that their “Understanding of Allah as ultimately responsible for one’s life helped parents resist shame or guilt about their child’s condition” (Selman et al., 2018, p. 20). It is notable that, for these parents, Somali cultural discourses about autism often conflict with mistrusted medical discourses about autism. A limitation of this study identified by the authors was the inconsistent reporting of stressors and difficulties during the interview compared to what one interviewer, who was familiar with the participants prior to the study, knew from prior interactions with the participants. This study is important because it examines Somali culture within the British Western culture.

The qualitative study from a Western, English-speaking (Broady et al., 2017; Gray, 2002a, 2002b) setting seems to exclude cultural influences, whereas studies from non-Western, non-English-speaking settings include cultural influences. Broady et al. (2017) identified the negative outcomes of caring for children with ASD, such as stress, financial, mental health issues, and negative experiences. The purpose of Broady et al.’s study was to explore the experiences of caregivers (anyone who provided unpaid care) of children with high-functioning autism. Broady et al. used semistructured interviews, taking an exploratory approach to understand how caregivers understood stigma in their caring role. The study was conducted in Australia, and a convenience sample of participants was recruited through autism support groups. Participants were 15 caregivers (nine female and six male) of children diagnosed with high-functioning autism. Of these participants, 12 were married, including six who were married couples, one who was separated, and two who were divorced. The children were aged 5–19. The authors did not provide information about participants' cultural backgrounds.

Through a TA of interview transcripts, Broady et al. (2017) identified four domains of stigmatizing experience: lack of knowledge, judgment, rejection, and lack of support. The domains encapsulated felt, enacted, and courtesy stigma. The experiences occurred in four contexts—in school, in public, among family, and among friends—and the dynamics of each experience played out differently across the contexts. Participants also demonstrated resilience and coping. Support groups were identified as an important resource, and additional supportive people in communities were also mentioned. Advocacy for children was a common experience for these participants. Participants talked about love for and positive relationships with their children. Broady et al. concluded that the experience of stigma started with lack of knowledge and moved through the other domains; this was a common pathway. Caregivers perceived pervasive stigma, and this inhibited their participation in multiple contexts. The authors concluded that caregivers who were healthier individuals prior to their child's diagnosis did not get enmeshed in the stigma. Broady et al. also asserted that caregivers' act of educating others can have a positive outcome or become burdensome. Last, the authors postulated that interventions need to consider the four domains of a stigmatizing experience, the pathway that connects them, and the different social contexts. Broady et al.'s study was limited to participants in Sydney and New South Wales with similar sociodemographic characteristics; thus, further research with more diversity in participants might reveal additional domains.

In their meta-analysis, Salleh et al. (2020) sought to present evidence of affiliate stigma across cultures. The authors searched broadly, from publishing years 1940 to 2019. The goal of the research was to demonstrate the prevalence of affiliate (courtesy) stigma across international cultures. Following PRISMA guidelines to identify articles, criteria for inclusion contained the following elements: articles available in English, published between 1940–2019, and peer-reviewed. Twelve qualitative studies met the criteria for inclusion, and all were published after 2002. Twenty-five percent were from United States, 25% were from Australia, and the following countries each contributed one study: Egypt, Ireland, Israel, Kenya, Pakistan, and Vietnam. In total, 256 participants were included in this set of studies. The majority of participants were mothers, despite the fact that 67% of studies included both parents' participation. Four common themes were identified: felt stigma, enacted stigma, variations in stigma, and contributors to stigmatizing experiences. Feeling rejected, guilty, or embarrassed by having a child with ASD fell within the first theme, felt stigma, which emerged in all 12 studies. Parents experienced feelings of being blamed or judged. The strength of this set of studies was in the multinational representation within the set, meaning that the set incorporated various cultural contexts.

Conclusion

This literature review has identified the most current literature available on affiliate stigma as experienced by parents of children with autism. The majority of the literature is quantitative. There is a significant lack of qualitative research, especially in the United States. Several studies and reviews indicated that cultural influences are inherent to the affiliate stigma experience; however, only some research reflects religious differences. Authors cited in this review have called for further research on religion and coping strategies (Chu et al., 2020) and for more cross-cultural comparisons, especially between collectivist versus individualist cultures and among parents who have crossed cultural contexts (Mitter et al., 2019).

Further qualitative research should be conducted to explore how parents of children with ASD understand cultural factors, including religion, as part of their experience of affiliate stigma. Specifically, sociocultural contexts that are not yet represented in the qualitative literature need to be added. This study examined experiences of Jewish American mothers of children with ASD living in northern New Jersey, with a specific focus on if and how they experienced affiliate stigma. This contribution is significant because, when working with parents of children with autism, social workers need to be aware of the struggles this population endures and what coping mechanisms they employ.

Chapter 4: Theoretical Framework

The purpose of this qualitative study was to explore experiences of Jewish American mothers of children diagnosed with ASD. Specifically, the study aimed to determine to what extent these mothers report experiencing affiliate stigma. This chapter details theories and concepts of stigma and provides an exploration of the processes of affiliate stigma and how affiliate stigma may be experienced by parents of children with ASD.

Stigma

According to Goffman (1963), stigma is the experience of a person who is disqualified from full social acceptance. This disqualification is based on an attribute that is deeply discrediting, and may be one of three types: body, character, or tribal. The disqualification is enacted when self-perceived "normals" discriminate against the stigmatized individual. Goffman states, "By definition, of course, we believe that a person with a stigma is not quite human" (p. 5). In making this comment, Goffman urges consideration of the damnation of being stigmatized against in a society where others seemingly fit in and belong.

Link and Phelan (2001) expanded Goffman's theory, took a sociological perspective, and redirected research from a focus on micro interaction to macrolevel processes. Link and Phelan responded to critiques asserting that stigma was vaguely defined by Goffman in addition to being overly individually focused. The researchers observed that different definitions existed in the literature because stigma is a concept studied by multiple disciplines with different frames of reference, and determined that the value of their definition of stigma is in its utility. Link and Phelan defined stigma as "the co-occurrence of its components: labeling, stereotyping, separation, status loss, and discrimination, and for stigma to occur, power must be exercised" (p. 363). They went on to expand this definition, saying:

> In our conceptualization, stigma exists when the following interrelated components converge. In the first component people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics—to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of ‘us’ from ‘them.’ In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differentness, and construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination. (Link & Phelan, 2001, p. 367)

The essence of Link and Phelan’s conceptualization of stigma is that it is multifaceted and relies on a power struggle that may be unconscious and therefore unbeknownst to the struggler. However, they examined stigma from a sociological approach rather than a psychosocial perspective.

Link and Phelan (2001) focused on the nature and consequences of stigma rather than its sources. Link and Phelan argued that stigma is likely to become a key determinant in many kinds of life chances, or, in other words, opportunities lost. Because stigmatizing others is a covert and unconscious process, the stigmatizer likely does not understand their motivation to organize their world in this way. Furthermore, the stigmatizer’s behavior toward the stigmatized person could be covert or overt (i.e., intentionally cruel or overwhelmingly polite). Pryor et al. (2004) found that there are dual processes of stigma, one of these processes being how people respond to the stigmatized person. One such response may be coming across as fastidiously kind, leading Pryor et al. to challenge whether kindness itself is stigmatizing. This issue will be discussed below, specifically as it relates to ASD.

The reactions of people in the stigmatization dyad are emotional in nature (Link & Phelan, 2014). In their sociological perspective, stigmatizers' reactions to labeled people may be induced by fear, repulsion, or disgust. The labeled person may feel shame, embarrassment, and humiliation. As a result, the person may experience status loss and discrimination. Link & Phelan (2011) emphasized that this process is all dependent on power and noted that one's medical understanding of mental illness still contains stigma. Link & Phelan (2011) observed that, although treatment for mental health issues may no longer be subject to the same type of stigma that it once was, people who have severe mental illness continue to be stigmatized.

Reviewing the stigma literature since Goffman's work, Pryor and Reeder (2011) identified four manifestations of stigma: (a) public stigma, (b) self-stigma, (c) stigma by association, and (d) structural stigma. Public stigma, which is at the core of their model, encompasses the stigmatizer's reactions to the stigmatized person. Self-stigma is the impact of possessing a stigma with the potential of internalizing the perceived stigmatizing negative attributes. Stigma by association, also termed courtesy stigma (Goffman, 1963), is the reaction to another individual based on their association to the stigmatized person. Finally, structural stigma is the "legitimization and perpetuation of a stigmatized status by societies, institutions, and ideological systems" (Pryor & Reeder, 2011, p. 791). Though the four manifestations of stigma all have importance for the purposes of this research (i.e., affiliate stigma, as discussed below), self-stigma and stigma by association are two particularly important manifestations.

Corrigan et al. (2016) explored the impact of self-stigma, and found that people who are stigmatized often experience loss of self-respect and a "why try" outcome. The process of self-stigma begins with the awareness of being stigmatized, concurring with the loss of status, applying it to oneself, experiencing diminished self-respect, and then asking, “why try?” Or, in other words, why bother trying to fit in, succeed, or flourish in a society where one is considered lesser than?

Pryor et al. (2012) proposed a model of how stigma by association spreads to contaminate others. The authors developed a model of stigma by association, focusing on the processes involved in primary and secondary reactions to stigma. They theorized that the primary reaction is spontaneous or reflexive, which means it is fast, emotional, unconscious, and feels effortless, whereas the secondary reaction is more deliberate, meaning that it is volitional, controllable, and feels effortful. Pryor et al. explained that reactions to stigma involve an interplay of reflexive and deliberate reactions, and therefore asked if stigma spreads based on deliberate reactions or reflexive impulse or a combination of both. Pryor et al. found that a perceived meaningful relationship between the stigmatized person and their companion may elicit more deliberate reactions than would be possible in a perceived coincidental relationship. In this case, stigma may spread through deliberate reactions, as people rationalize their negative thoughts. Parent–child relationships are considered meaningful in this way, as families have entitativity, meaning they are seen as a collective. Pryor et al. elaborated:

> Families are likely to be seen as having common motivations. When people are perceived as bound to a stigmatized person by family ties, consciously held attitudes about the stigma are likely to come into play in how others perceive them. (p. 226)

Basically, Pryor et al. encouraged the consideration of the dual processes of stigma by association/courtesy stigma.

In sum, stigmatization can be covert rather than overt and occurs on societal, interpersonal, and individual levels (Bos et al., 2013). Most definitions of stigma have two components: the recognition of difference and devaluation. All definitions indicate that stigma itself does not exist within a person, but is enacted in a social context (Bos et al., 2013). However, the internalization of stigma exists on an intrapsychic level with negative psychosocial consequences. Stigma theory can help scholars understand the experience of Jewish American parents of children with ASD because this theory illuminates the complicated social, interpersonal, and internal processes involved.

Affiliate Stigma

The study will focus on the concept of affiliate stigma; therefore, it is worth exploring its conceptual definition. As is already evident, a constellation of terminology is used to describe stigmatization experienced by family members of, or others closely associated with, a stigmatized person. These include courtesy stigma (Goffman, 1963), associate stigma (Mehta & Farina, 1988), and stigma by association (Pryor & Reeder, 2011). Affiliate stigma (Mak & Cheung, 2008) and family self-stigma (Deguchi et al., 2021) further incorporate the intrapsychic and behavioral manifestations of internalization of this experience.

Mak and Cheung (2008) defined affiliate stigma as the self-stigmatization process of family members, or affiliates, of a stigmatized person. By internalizing stigma, these affiliates may develop negative self-beliefs and detrimental or negative emotions. Behaviorally, those experiencing affiliate stigma may withdraw or conceal their affiliation with the stigmatized person. Deguchi et al. (2021) defined family self-stigma as “the experience of an individual who internalizes the stigma that marks their family and its corresponding psychological responses” (p. 388). The differences between affiliate stigma and family self-stigma are minimal, and for the purposes of this study, affiliate stigma is used because this term is better established and has a corresponding measure, the Affiliate Stigma Scale (Mak & Cheung, 2008), which has also been used to study parents of children with autism (Mak & Kwok, 2010). This study examined the process of affiliate stigma as experienced by Jewish American families of children with ASD in the northeastern United States.

There are two dimensions to affiliate stigma: content and process. Both affect the experiences and mental health of caregivers (Chan & Lam, 2018). Mitter et al.'s (2019) synthesis of literature theorized a circular process termed the circle of stigma. This circular process begins with the experience of courtesy stigma. Parents then identify with the negative perceptions expressed by others. This negative identification, when internalized, develops into affiliate stigma. Parents then fear future discrimination and rejection. Often, this daunting response to stigma elicits behaviors, such as social isolation, that feed back into the start of the cycle. Mitter observed that culture and family culture underly the stigma and affiliate stigma process.

Stigma, Affiliate Stigma, and ASD

Four major themes were identified in the literature on stigmatization of children and adolescents with ASD and their families (Mazumder & Thompson-Hodgetts, 2019). The first theme, social perceptions of ASD, included two subthemes: (a) invisibility and judgment and (b) diagnostic labels. The other themes were social isolation, well-being and responses to stigma, and stigma reduction. Mazumder and Thompson-Hodgetts (2019) affirmed Pryor and Reeder's (2011) conceptualization of stigma to explain the experience for people with ASD and their families. The themes Mazumder and Thompson-Hodgetts identified resound in this section. The following section first examines the experiences of people with ASD and then explores how their affiliates experience this phenomenon.

Individuals with ASD

The stigma experienced by people with ASD "arises from a complex interplay of individual and structural factors" (den Houting et al., 2021, p. 4). Individuals with ASD make sense of their own neurodiversity and experience with stigma in unique ways. Botha et al. (2020) found that their participants with ASD experienced their autism as value neutral, but perceived that society viewed autism as a negative trait. Milton (2012) proposed the double empathy problem, in which people without autism empathize or sympathize with the difficulties of being an autistic person; however, not all people with ASD experience their neurodiversity as either a disability or problematic (Mitchell et al., 2021). Cage et al. (2019) found that people without autism see ASD as troublesome, challenging, atypical, and abnormal, and can even have dehumanizing perceptions of people with autism. Therefore, people without autism may feel compelled to react with explicit compassion to ward off uncomfortable implicit biases (Jones et al., 2021).

On the surface, it may seem that exposure to ASD helps the general population build tolerance and empathy. However, although autism acceptance training can reduce explicit biases, it does not reduce implicit biases (Jones et al., 2021). According to Thobodeau and Finley (2017), "Findings that suggest benevolent explicit attitudes toward individuals and families affected by ASD could coexist with attitudes that were markedly less positive" (p. 848). This coexistence of contrasting attitudes makes addressing the problem of stigma highly complicated.

In Link and Phelan's (2001) conceptualization, labeling is a precursor to the stigma process. From 1994–2013, the DSM included Asperger's Syndrome as a separate diagnosis related to autism. In 2013, Asperger's was dropped, and all conditions pertaining to autism were included under the umbrella term ASD. Ohan et al. (2015) investigated the result of the removal of the Asperger’s diagnostic label from the DSM-5 in 2013, and how that change in label affected ASD stigma. Surprisingly, Ohan et al. found no difference in the stigma between an Asperger’s label and an ASD diagnosis. In fact, they found neither were stigmatized, as public knowledge about the two labels is plentiful. However, Ohan et al.’s study focused on how participants responded to the two labels rather than exploring lived experiences of stigmatization. Although both Asperger’s syndrome and ASD are familiar terms in the United States, this does not guarantee a reduction in biases and stigmatization.

Offering a critique similar to Link and Phelan (2001), Farrugia (2009) suggested that Goffman’s microsocial focus “sheds no light on the origin of socially devalued stereotypes” (p. 1014) or the conditions for successful resistance strategies. Farrugia emphasized power and subjectivity in his conceptualization of stigma as a sociocultural process, with the idea that the person with stigma is ontologically inferior. As Faruggia put it, enacted stigma is “an overt political/discursive act for the purposes of social control, which attempts to position the stigmatized as spoiled” (p. 1015). On a microsocial level, labeling allows the labeler to avoid discomfort and instead experience power, prestige, and worth. This is possible because of values held on the macrosocial level.

Stigmatization affects individuals with ASD when others behave in ways that accentuate their differences and make them feel inferior. The stigmatization process has multiple components uniquely affecting individuals with ASD. As Gray (1993a) posited, autism is an invisible disorder. The individual with autism has a completely typical outward appearance; there are no unusual facial characteristics, wheelchairs, or other apparatus to signal the person has a disorder of any kind. However, ASD disrupts the social, communication, and sensory processing abilities of those afflicted. For example, someone with ASD may be hypersensitive to noise or completely oblivious to sound. The spectrum of presentations is vast, and there is no way to know what to expect or what the possible triggers may be. To the observing public, an individual with ASD simply appears to exhibit odd, offensive, or oppositional behaviors without any justification. This combination can lead others to believe that the person with ASD is volitionally behaving abnormally or aggressively.

Families of Individuals with ASD

People with ASD and their families experience discrimination and isolation (Bishop-Fitzpatrick et al., 2019). This is compounded by the exceptionality of ASD's presentation: "Autistic children appear to be physically normal yet suffer from an extremely pervasive disability. It is this combination of a pervasive disability and apparent physical normality that gives the stigma experienced by families with autistic children it's unique quality" (Gray, 1993b, p. 114).

Mak and Kwok (2010) detailed the process of internalizing courtesy stigma into affiliate stigma, specifically for parents of children with ASD. They found that internalization was severe for parents of children with ASD and identified three paths of internalization. The first path was a direct link from courtesy stigma to affiliate stigma. The second path was possibly mediated by responsibility and self-blame. The third path from courtesy stigma to affiliate stigma was mediated by perceived controllability. In other words, if a parent feels unable to control their child's adverse or abnormal behavior, they might internalize that failure. Only support from significant others and friends reduced affiliate stigma; family support was not enough, nor was professional support. Mak and Kwok articulated the following:

> The direct link between courtesy stigma and affiliate stigma might be due to the pervasiveness of courtesy stigma in society, such that parents easily agree with the

> negative views of them and their children. Others accepted the attributions of responsibility and blame for their child's condition and accepted stigma, and so internalized courtesy stigma. (p. 2049)

Past theorizations and conceptualizations of ASD have exacerbated the affiliate stigma that parents experience. Following Link & Phelan’s (2011) idea, it may be the case that people accept that children with ASD should be receiving treatment and improving. When a child does not improve from prescribed interventions, the onus may be placed on the parent’s failure to execute the remediation effectively. The expectation that parents can control the outcome of therapies and interventions may result in an additional stigma experienced by the parents of children with ASD. Munroe et al. (2016) discussed the pain parents experience: “the implication that the mothers were to blame appeared to be at the root of many judgments and made these particularly difficult to hear, having a negative impact on their identities” (p. 16).

Farrugia (2009) urged readers to understand how parents of children with autism defend against their otherness. Farrugia found that parents make the child the other by using medical knowledge to defend against the stigma process and to separate themselves from their child. However, this defense is predicated on the parent accepting that their child is ontologically autistic and therefore an autistic subject, and perhaps lesser than their neurotypical counterparts: “if the medical explanation for their child's behavior is not accepted by others, they are treated as bad parents, a stigmatized position” (Farrugia, 2009, p. 1019). Because the child with ASD is physically normal, yet may behave horrendously and bizarrely, it is easy for an onlooker to blame the parent when the medical justification of “my child is autistic, this is why they behave this way” is offered. There may be residual judgement based on previously discounted theories of autism’s etiology, which, although disproven, may linger in the minds of many.

The experiences of parents may be completely different than those of their child because they themselves are not autistic and may or may not see ASD as value neutral (Milton, 2012). In fact, they may perceive that another's empathy is an insult to their child's neurodiversity or perceive that other people view them as deficient for not being able to control or cure their child (Munroe, 2016). In some cultures, having a disabled or poorly behaved child is shameful, and the internalization of that shame can have profound mental health ramifications on parents (Kwok & Kwok, 2020; Salleh et al., 2020; Selman et al., 2018; Zhou et al., 2018).

Kwok and Kwok's (2020) discussion of the emotion work engaged in by parents of children with ASD includes strategies to survive stigma and social rejection. This research underscores that parents of children with ASD experience significant stigma and often attempt to compensate by becoming over involved and overly concerned about their child's emotional well-being. Affiliate stigma is only one of the many dilemmas that cause stress, but it is a significant cause of the emotional stress that parents of children with ASD experience.

There may be several factors impacting how parents of children with ASD experience affiliate stigma. For example, the parental experience of self-stigma may be influenced by the age of their child with ASD. Gray (2002b) conducted a longitudinal qualitative study and found that the experience of stigmatization may be different after the child with ASD is older, or perhaps as time has passed after diagnosis and ASD parenting becomes less of a shock and more of a way of life. This does not account for caregiver burden, as a child that is profoundly difficult may become bigger and harder to manage.

Deguchi et al. (2021) explored dimensions of self-stigma, also termed affiliate stigma, for families of people with ASD and discovered a social misunderstanding element that was unique to families of people with ASD. The social misunderstanding element encompasses both the reactions of others to the unusual behaviors of the person with autism and the parents' responses to and management of the behavior.

Conclusion

In summary, the literature theorizing stigma and affiliate stigma indicates that stigma is multifaceted and dependent on power (Farrugia, 2009; Link & Phelan, 2001; Link, 2011). The researcher's review of how prior scholars applied the theoretical frameworks of stigma and affiliate stigma among parents of children with ASD highlighted several questions that were then explored with participants in the semistructured interviews. The interviews explored meaningful and memorable interactions where the mothers felt stigmatized and how these interactions have influenced them over time. Mothers were asked to discuss how they deal with stigma and what supports would be helpful for emotional management. Moving from micro interactions to advocacy, the mothers were asked about how they conceptualize their child's disability or neurodiversity and if one outlook feels more stigmatizing than the other. Areas of exploration included: How does the mother of a child with autism negotiate respect for their child's right to neurodiversity and at the same time cope with a society that possibly sees their child as nonhuman? How does the experience of affiliate stigma shift in an era where diversity is supposedly celebrated? Have the efforts to change the public's explicit biases made the affiliate stigma experience better or worse for mothers of children with ASD, given the fact that implicit biases respond less well to remediation?

This study was formulated around the broad research question: What are the experiences of Jewish American mothers relating to their child diagnosed with ASD? The secondary question was: To what extent do these mothers report feelings of affiliate stigma? In asking this question, the study used the definition of affiliate stigma developed by Mak and Cheung (2008): affiliate stigma is the self-stigmatization process of family members, or affiliates, of a stigmatized person. The study explored the experience from the mothers' point of view, keeping in mind that the process of stigmatization is multifaceted and involves multiple parties and unique internalizations.

The research contributes to the theoretical understanding of affiliate stigma by adding voices of mothers from a cultural group that has been underrepresented in the literature. Adding data on new cultures to the literature is important because it can help develop an understanding of how culture, subculture, and self-identification are part of the processes of affiliate stigma. Ultimately, this kind of research can contribute to better educational initiatives; researchers note that educational initiatives attempting to remedy stigmatization lack cultural context and may be less effective because of this (Mazumder & Thompson-Hodgetts, 2019; Papadopoulos et al., 2019).

Both stigma and affiliate stigma have been applied to parents of children with ASD. However, this study addresses how identification with a particular cultural group and the need to belong to a greater community impacts the experience of affiliate stigma. Previous qualitative research within specific cultural settings has also shown that this identification can impact affiliate stigma (Salleh et al., 2020; Selman et al., 2018). This study shows how Jewish American mothers of children with ASD experience affiliate stigma alongside their efforts to belong to their Jewish community.

Chapter 5: The Research Question

The study explored the experience of Jewish American mothers of children with ASD, with a focus on affiliate stigma. The fundamental question of the study was: What are the experiences of Jewish American mothers relating to their child diagnosed with ASD? The following subquestion also guided the scope of the study: To what extent do these mothers report feelings of affiliate stigma? Within this exploration, the researcher inquired about how affiliate stigma influences these mothers' emotional well-being and perceptions of themselves as a mother within their community. The study findings inform social workers who may support members of this population. More broadly, the findings suggest a need for future research on how to provide better caretaker treatment, including treatment within specific cultural contexts.

This was a qualitative inquiry; therefore, no hypothesis was developed for the purpose of this study. The questions for this study were developed based on existing research on affiliate stigma, parents/caregivers of children with autism, and Jewish American identity. Extant literature suggests that the members of subcultures experience stigma in varied ways and with different levels of severity.

Data was collected through semistructured interviews. The following interview questions and probes were used:

- Family context/story and demographics
    - Tell me about your family.
        - Children's birth order
        - Parents' marital status
        - Other adults in the home
        - Is there anyone else in your family with autism?

- Tell me about your child with autism.
    - What was it like when they were diagnosed?
- Experiences within Jewish community
    - What does belonging to a Jewish community mean for you and your family?
    - Have your experiences as a parent of child with ASD affected how you behave within your community?
    - Can you describe how being a parent of a child with ASD affects your relationships with other people in your community?
    - How do you think other people in your community see you? Your parenting?
    - What differences do you see between how you are treated within your community versus outside the community?
    - Do you see yourself differently in your community now than you did before your child was diagnosed with autism?
- Experience of stigmatization
    - Can you tell me about a meaningful interaction where you felt inferior/embarrassed/discriminated against/lesser than because your child is autistic?
        - What did that feel like for you?
    - How often do things like that happen?
    - After an experience like that, how are you feeling about yourself?
    - How do these experiences affect how you perceive yourself as a person?

    - As a parent?
    - How you perceive your child?
    - As a member of your community?
- Is there anything else you want to share about your experience?

Chapter 6: Methodology

The purpose of this qualitative study was to explore the experiences of Jewish American parents of children diagnosed with ASD. Specifically, the study aimed to determine to what extent these parents report experiencing affiliate stigma. The research question was: What are the experiences of Jewish American parents relating to their child diagnosed with ASD? The following subquestion guided the scope of this study: To what extent do these parents report feelings of affiliate stigma? This chapter outlines the qualitative, phenomenological design of the study and defines the study's key concepts, including ASD, parents, affiliate stigma, and Jewish American identity. Next, the chapter describes the how Jewish American parents of children with ASD were recruited and introduces the 16 mothers who participated. Then, the semistructured interviews are described. Next, the analysis process using TA (Braun & Clarke, 2022) is described. Finally, the chapter addresses issues of trustworthiness and concludes by discussing ethical considerations, including protection of participants' anonymity and confidentiality.

Design

A qualitative methodology was employed in this study. Hallmarks of qualitative inquiry include responsiveness, adaptability, holistic emphasis, knowledge-base expansion, processual immediacy, opportunities for clarification and summarization, and the opportunity to explore atypical or idiosyncratic responses (Lincoln & Guba, 1985). Qualitative methods are an obvious choice for gaining a personalized, in-depth understanding of something about which little is known (Padgett, 2017). In the case of Jewish American parents of children with ASD, the literature review did not reveal any study documenting these parents' experience with affiliate stigma. This study filled that gap by documenting the experiences of 16 Jewish American mothers of children diagnosed with ASD.

Conceptual Definitions

Autism Spectrum Disorder

ASD is characterized by persistent symptoms that impact social behavior and communication and include repetitive, restrictive, and stereotypical behavior patterns (American Psychiatric Association, 2013). In this study, children with ASD are defined as biological or adoptive offspring who have been diagnosed with ASD by a healthcare professional.

Parents

This study specifically focused on parents, rather than on other caregivers, to narrow the scope of the study. Although both mothers and fathers were invited to participate, only mothers volunteered. All of the mothers were biological mothers of one or more children diagnosed with ASD. Although some literature on affiliate stigma and ASD has referred to caregivers (Lovell & Wetherell, 2018; Mak & Cheung, 2008; Mak & Kwok, 2010; Papadopoulos et al., 2019; Recio et al., 2020; Tilahun et al., 2016), carers (Broady et al., 2017; Lodder et al., 2019), or family members (Gray, 2002b; Mitter et al., 2018), most literature refers to parents.

Affiliate Stigma

This study used Mak and Cheung's (2008) definition of affiliate stigma as the self-stigmatization process of family members, sometimes referred to as affiliates, of a stigmatized person. By internalizing stigma, these affiliates may develop negative self-beliefs and detrimental or negative emotions. Behaviorally, those experiencing affiliate stigma may withdraw or conceal their affiliation with the stigmatized person. Affiliate stigma is an offshoot of stigma, which Goffman (1963) conceptualized as the experience of a person who is disqualified from full social acceptance.

Jewish American

In this study, participants self-identified as Jewish American. In alignment with scholars like Friedlander et al. (2010), Jewish American identity is viewed as a construct of both religious and cultural affiliation, with large potential variations in how individuals identify with either the religious or cultural components of being an American Jew.

Phenomenological Framework

Phenomenological research strives to describe several individuals' common understandings and perceptions of a phenomenon; it also explores how participants make meaning of their lived experiences (Creswell & Poth, 2018). Phenomenological analysis focuses on "deeper meanings, achieved by prolonged immersion" and on finding the "essence" of participant experiences (Padgett, 2017, p. 41). Phenomenology draws attention to participants' perspectives, psychological processes, and thoughts, and has become recognized as linked to the interests of social work (Carey, 2013). This study's research questions delved deeply into the unique experiences of mothers of children with ASD in a Jewish American community. Within the phenomenological framework, this study employed reflexive TA, which is "a method for developing, analysing, and interpreting patterns across a qualitative dataset, which involves systematic processes of data coding to develop themes" (Braun & Clarke, 2022, p. 4). Using reflexive TA, the researcher identified themes in the experiences of Jewish American mothers of children with ASD.

Researcher Description

The researcher is an orthodox Jewish American mother of two children with ASD living in one of the communities nearby the participants' communities. The researcher had prior relationships with some but not all of the participants: one participant was a friend of the researcher, several were acquaintances, and several were unknown to the researcher prior to the study. The researcher had prior knowledge of the communities, organizations, and schools that participants described in their stories. The researcher's children are older than the participants' children, making her experience somewhat different than the participants' experiences.

The researcher's experience raising children with ASD took place before the founding of two community organizations serving Jewish children with special needs. Because these organizations did not yet exist when the researcher's older son was young, he was unknown and unwanted in the community. Other children and their parents were afraid of him. Despite having ASD, he was incredibly social. When he was 11 or 12 years old, the Friendship Circle was introduced, and it was life changing for him and for his siblings. The researcher came into this study with a prior personal understanding of being a Jewish American mother of a child with ASD within the Jewish community. To manage this prior understanding, the researcher shared with participants that she had two children on the spectrum, but did not share other details. She also used a research journal to document impressions, feelings, and insights immediately after the interview and beyond.

The researcher is also a mental health clinician with an LCSW and she is a nationally certified psychoanalyst. This experience means that the researcher has a deep understanding of character development. The researcher collected and interpreted the data using insights from this professional experience. For example, the researcher conducted interviews with keen empathy and drew on her honed skill of facilitating self-expression. Remaining cognizant of her researcher role in this study, the researcher noted when interviews risked becoming too emotionally intense for the participants and gently redirected the conversation back to the interview guide.

Sampling Procedures

The target population for the study was parents of children with ASD who identify as members of a Jewish American community. To be included in the study, a participant had to be a parent (biological or adoptive) of a child or children, of any age, with ASD and had to identify as a member of a Jewish American community.

A purposive sampling strategy was used to find and select respondents who could help answer this study's research questions (Padgett, 2017). Recruitment began with parents of participants of the Friendship Circle of Bergen County, a volunteer program run by the Jewish organization, Chabad, that pairs neurotypical peers with children and adults with developmental disabilities. Friendship Circle also hosts programs and events where neurotypical peers interact with people with disabilities. The Bergen County Friendship Circle program director distributed a study participation invitation (see Appendix A) by email to program parents. Nine mothers responded to this email and agreed to participate. An additional six mothers were recruited through snowball sampling when participants shared the invitation with other mothers they knew. Snowball sampling was advantageous in reaching mothers who might have otherwise been hard to recruit because of their noninvolvement in Friendship Circle, whether because their child could not access the program due to age, severity of symptoms, or level of functioning. A potential limitation in snowball sampling is that participants have familiarity with one another and thus might be likeminded.

Participants were asked if their husbands would like to participate, but none volunteered. This may have to do with the role of mothers as primary caregivers and social organizers. Additionally, it may reflect fathers' reluctance to be interviewed by a woman because, in the Orthodox Jewish community, men are sometimes uncomfortable being alone with a woman who is not their wife. In one case, one participant said she pressed her husband to participate, but after much thought, he refused because his experience with affiliate stigma and his son's ASD was too painful.

Ultimately, 16 mothers participated in the study. This sample size was similar to sample sizes in comparable studies. Other phenomenological and TA studies that have explored experiences of parents of children with ASD within specific cultural or ethnic groups have had sample sizes of eight to 15 (Blanche et al., 2015; Broady et al., 2017; Gill & Liamputtong, 2011; Goh et al., 2021; Minhas et al., 2015; Russell & Norwich, 2012).

Participants and Context

All 16 participants were the biological mother of a child with ASD. Their children with ASD ranged in age from 5 to 28 years. One mother had two children diagnosed with ASD, and two mothers had other children with a different diagnosis under the umbrella of neurodiversity. The mothers had from one to five children. For most of the mothers (n = 10), their child with ASD is their firstborn or only child.

All of the mothers identified as Jewish American. As noted above, there are different levels of observance within Judaism. Jews who consider themselves traditional or culturally Jewish might not observe the laws and regulations prescribed by sages and contemporary scholars. Amongst the observant community, there are different levels of observance. What is considered acceptable may range from completely insular thought and behavior to significant participation in modern life. In this study, 15 mothers identified as observant and one identified as traditional and culturally Jewish. Thirteen mothers lived in a modern Orthodox community. Two lived in *machmir* (strictly Orthodox) communities that were less modern. One mother, although living in a modern Orthodox community, considered herself traditional but not fully observant.

Data Collection Procedures

Data were collected through individual, semi structured interviews. These interviews allowed participants the opportunity to fully express themselves (Terry & Hayfield, 2021), and allowed the researcher the opportunity to probe and ask follow-up questions, resulting in rich and detailed data (Terry & Hayfield, 2021). Demographic information collected included children's ages, the family's community (neighborhood), marital status, and family constellation. Three interviews were conducted in person and 13 were conducted using video conferencing. Interviews were audio recorded with the participant's permission for recording.

Before beginning recording, the participant and researcher completed the informed consent process approved by the university's Institutional Review Board (IRB). The informed consent letter is included in Appendix B. Participants were emailed the consented form to print, sign, scan, and email back to the researcher.

Following guidance for qualitative interviewing in phenomenological studies, the semistructured interviews began with general questions and then funneled down to more specific and emotionally laden questions (Terry & Hayfield, 2021). The interview schedule (see Appendix C) covered three topic areas: the family context, experiences within their Jewish American community, and experiences with stigmatization. Interviews lasted from 30–60 minutes. Participants were given a $20 gift card to thank them for their time and effort.

Data Analysis

Audio recordings of the interviews were transcribed by a professional transcriber. The researcher reviewed the transcripts while listening to the audio to check for accuracy and ensure that the data had been transcribed to an appropriate level of detail (Braun & Clarke, 2022). The researcher filled in some Yiddish and Hebrew words that the transcriber had been unable to transcribe. Each participant gave explicit verbal and written permission to record their interview.

Analysis followed the six phases of reflexive TA described by Braun and Clarke (2022). Phase 1 involves the researcher familiarizing themselves with the dataset. In this study, the researcher read and reread the data, listened to the audio recording for every interview once and, for some interviews, twice, and made notes on participants' stories, family constellation, and self-identification (Braun & Clarke, 2022). Also during this phase, the researcher called two of the participants to verify unintelligible speech and to ask for clarification on specific Hebrew terms that they used in their interview.

Phase 2 is coding. First, the researcher coded every transcript in Microsoft Word by highlighting and labeling anything that seemed relevant to the research questions. Next, uncoded transcripts were uploaded to ATLAS.ti version 22.2.0 and coded again, resulting in over 1,000 codes. To make the set of codes more manageable, the researcher went through the entire dataset again to consolidate codes until the revised code list was 207 codes. For example, the following extract was coded "affiliate stigma:" "it's very hard for me. I'm trying to let go of their opinions, and I'm trying to let go of the stigma and, but it's hard." This example shows how, following Braun and Clarke's (2022) guidance, the coding process employed both inductive (data-driven) and deductive (researcher or theory-driven) strategies and thinking at both semantic (participant-driven, descriptive) and latent (researcher-driven, conceptual) levels. The participant used the term "stigma," and the researcher was looking for examples of affiliate stigma.

Phase 3 is generating initial themes. In this phase, codes were reviewed and placed into groups based on sharing a concept, such as "school," "community expectations," "emotions," and affiliate stigma (Braun & Clarke, 2022). Phase 4 is developing and reviewing themes. Initial code groups were checked against coded extracts to determine the core focus or the central organizing concept of each theme. During this process, code group names were revised, and some were dropped (Braun & Clarke, 2022). For example, codes in the initial group called school were placed into groups with revised names such as "the community has no place for my child," "the consequences of not meeting the expectation to send to Jewish school," and "finding a good fit in public school." Phase 5 is refining, defining, and naming themes. Using guidance for theme development from Braun and Clarke (2022), the final five themes were selected from the groups and given concise names. To illustrate, the groups related to schools listed above became part of a finalized theme called "consequences of having an atypical child when belonging matters."

Phase 6 is writing up. According to Braun and Clarke (2022), writing is a key analytic activity. Through the writing process (drafting, revising, and editing), analysis continued. By weaving the analytic narrative and data extracts together, it became more apparent how participants' personalities played into their experiences and understanding of affiliate stigma and ASD. At least one participant was adamant that she experienced no stigma even though her child did, and others felt they were stigmatized for how they parented their child. Others felt brutally stigmatized for their child's behavior and how they managed the behavior.

Trustworthiness and Rigor

According to Lincoln and Guba (1985), trustworthiness is a quality that persuades readers that a study's conclusions are "worth paying attention to, worth taking account of" (p. 290). Trustworthiness fulfills values of truth, applicability, consistency, and neutrality (Lincoln & Guba, 1985). Hence, trustworthiness establishes verisimilitude. Likewise, Padgett (2017) asserted, “a trustworthy study is one that is carried out fairly and ethically and whose findings represent as closely as possible the experiences of the participants” (p. 50).

This study fulfilled Lincoln and Guba’s (1985) trustworthiness criterion of credibility. The researcher prolonged engagement with participants by conducting in-depth interviews that built trust and rapport and asked participants to speak about varied contexts. The researcher also prolonged engagement with the data by conducting a lengthy analysis process characterized by persistent observation, or “an aura of skepticism surrounding an intention to come to terms called for by the situation” (Lincoln & Guba, 1985, p. 305).

The study achieved Lincoln and Guba’s (1985) trustworthiness criterion of transferability by using thick description. Findings include descriptions of emotionality and verbal discourse in the form of participant quotes. Additionally, the findings include descriptions of the participants’ community contexts to better detail their perspectives and their experiences.

To achieve Lincoln and Guba’s (1985) trustworthiness criteria of dependability and confirmability, the researcher utilized the strategy of auditing. The researcher read and reread materials generated in the research process, including the written notes and interview recordings, summaries of notes and interview transcripts, codes, categories, themes, and findings. The researcher also kept a research journal in which analytical notes, methodological notes, trustworthiness notes, and audit-trail notes were recorded. For example, in this journal, the researcher wrote about how participants sometimes contradicted themselves, or how it seemed they wanted to make either the researcher or themselves believe something. As an additional example, the journal was also a place to record how the interview process evolved when the researcher found that discussing experiences in the Jewish community before asking about experiences with stigmatization worked better for participants. Materials related to researcher intentions and dispositions were be recorded in the research proposal. The journal aided the researcher in being “explicit and as self-aware as possible about personal assumptions, values and biases, and affective states” (Miles et al., 2020, p. 305). The journal gave the researcher the opportunity to review their own emotional responses to what people were saying and then to remove those from the analytic process as much as possible. This strategy increased trustworthiness in this study because “the researcher’s subjectivity is acknowledged and, to varying degrees, managed through reflexivity, or systematic self-awareness” (Padgett, 2017, p. 50). This was particularly important in this study because the researcher is a parent of children with ASD and identifies as Jewish American.

Ethical Considerations

As Reamer (2018) postulated, the researcher’s primary ethical obligation is to protect the well-being of participants. Protecting participants’ well-being means protecting confidentiality and anonymity as much as possible (Padgett, 2017); it also includes an informed consent process, making participants aware of their right to withdraw from the project at any stage, managing potential conflicts of interest, and providing appropriate resources for participants experiencing emotional distress (Reamer, 2018). Participants were provided the informed consent letter (see Appendix B) prior to the interview meeting and completed the informed consent process before or at the beginning of the interview meeting.

Participants’ anonymity and confidentiality have been protected as much as possible. In the findings, participants are given pseudonyms and identifying details, such as names of communities and schools, are omitted. It is possible that someone who is familiar with northern New Jersey may be able to guess which communities these women come from. As Padgett (2017) observed, “Qualitative researchers cannot offer the anonymity or safety in numbers that quantitative researchers can. They must, however, provide virtually ironclad guarantees of confidentiality" (p. 83). To protect confidentiality as much as possible, identifying data is obscured. It must be noted that telling stories of lived experiences within a small Jewish community poses a risk that participants could be recognized by people who know them.

Chapter Summary

This study explored experiences of Jewish American mothers of children diagnosed with ASD. Specifically, the study aimed to determine to what extent these mothers reported experiencing affiliate stigma. To fulfill this purpose, a phenomenological methodology was used. A purposive sampling strategy identified 16 participants to take part in in-depth semistructured interviews. TA strategies (Braun & Clarke, 2002; Terry & Hayfield, 2021) were used to analyze the data. Trustworthiness strategies of in-depth interviews, lengthy analysis, thick description, and auditing were used. Participants' well-being and confidentiality were safeguarded through the informed consent process, use of pseudonyms, and omission of identifying details in the final report. The following chapter will present the results from the analysis.

Chapter 7: Findings

This study explored two research questions: First, what are the experiences of Jewish American mothers relating to their child diagnosed with ASD? Second, to what extent do these mothers experience affiliate stigma? The researcher used data from semistructured, individual interviews with 16 mothers to answer these questions. All participants (*n* = 16) were mothers who responded that their child with ASD was lost in the Jewish community to some extent. Most of these responses were related to Jewish day schools (yeshivas, yeshivot) that could not or would not accommodate their child. Interestingly, schools were the main focus of the responses, even though this topic was not asked about directly in the interviews. The majority of participants (*n* = 13) reported feeling that their child with ASD was currently locked out of the community and ostracized because they were not eligible for a Jewish day school education. Although there is a special-education-oriented Jewish day school in the local community, of the16 participants' 17 children with autism, only one attended that institution. Two participants were eventually able to find a yeshiva that would accommodate their child's differences within the mainstream classroom.

For the remainder of the participants, who were unable to place their children with autism in a yeshiva, a secular education was the only option. At the time of the interviews, five of the children were attending local public schools in self-contained classrooms for language-based learning disabilities or behavior maintenance, with mainstream options during the day. Nine of the children were attending secular, special education schools outside of the community—some up to an hour away. These schools are designated for children on the autism spectrum, with emotional-behavioral challenges, or with severe cognitive disabilities.

Participants additionally discussed difficulties with synagogue attendance and participation. Friendships within the community, for both mothers and their children, were felt to be compromised by the child's ASD and the subsequent differences of either or both clinical presentation and school affiliation. These experiences were especially painful for these participants because, for all of them, being Jewish means belonging.

When authenticating and validating qualitative data, Guba and Lincoln (1985) discussed the importance of including all voices. In the discussion of each theme below, the experience of the majority of participants is detailed first, followed by a description of any minority voices within the theme. This presentation maintains the diversity of participants' experiences. Trustworthiness is enhanced by acknowledging minority voices and each participants' interpretation of their own experience.

Belonging Matters!

When asked what being Jewish means to her and her family, all participants concurred that being Jewish meant belonging: belonging to a synagogue, belonging to a community, belonging to a greater whole where all people believe, and practicing shared norms guided by culture and religious observance. Most participants (n = 15) identified as modern Orthodox, a community that necessitates living in close proximity to a synagogue, having kosher food opportunities, and yeshivas to educate their children. It was clear from the interviews that the Orthodox Jewish template for living is child-centric. Most participants had multiple children. For typical children without ASD or other forms of neurodiversity, Orthodox day schools were plentiful. For the participants' children with ASD, this was not the case. Furthermore, these mothers based their social lives and their support systems around being mothers who are members of the Jewish community; the practical differences in their lifestyles because of their ASD child's needs were both painful and alienating.

For example, Yaffa succinctly illustrated this theme by saying, "one of my goals in becoming a mother was to raise a Jewish child." For Yaffa, marrying into a family that she describes as having more *yichus* (religious standing and family prestige) was important to her sense of belonging, and she had hoped that she would raise her child accordingly. In this community, raising a Jewish child means sending the child to a Jewish school. Shulamit expressed the community expectation to send children to yeshivot: "In a Jewish community, you send to religious schools." Atara similarly echoed this expectation, saying "my parents were very, very, very pro-yeshiva. You have to send to Yeshiva; you have to send to Yeshiva. What will the community think?" However, as most of the mothers relayed, the yeshivot were either not equipped or not willing to accommodate children with neurological and behavioral differences like ASD. For example, Elisheva has three children who display some form of neurodiversity that precludes their attendance in a Jewish day school. Because of experiences with her older child, who is diagnosed with attention deficit hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD), being "kicked out" (cruelly, she felt) of two Jewish day schools, she did not attempt to enroll her second child, who was diagnosed with high-functioning ASD, in any Jewish day school. Reflecting on this experience, Elisheva said, "I went to Jewish day school growing up. My husband went to Jewish day school growing up. So, it's important for us to give that to our children, but our children don't go to Jewish day school." She went on to express her disappointment by saying, "Jewish education is based on the concept of *hadracha al pi darcho* [teaching children according to their needs] and that doesn't seem to exist for children who don't walk the solid line," or, in other words, present with neurodiversity.

Lori sensed and experienced consequences of having an atypical child. She was hesitant to share her son's ASD diagnosis with anyone in the community; she said, "you want your child to feel accepted and so you don't want to let too much out, you know how people talk." However, she did share the information with the school, and the results were devastating. She felt the ASD diagnosis affected how the Jewish day school staff perceived her son, with the result that he was asked to leave after 1 year. After 3 years in public school and a new diagnosis of semantic–pragmatic language disorder, a common differential diagnosis for high-functioning ASD, a different Jewish day school accepted him and he was successful there. Lori felt that as long as she did not tell people her son was diagnosed with ASD, he would be successful in a mainstream Jewish day school environment. Lori's perception of her experience with two different diagnoses and two different Jewish day schools sheds light on the mothers' sense of how their community, specifically the schools in the community, might respond negatively to a child with a diagnosis of ASD.

Three mothers were able to find a place for their child within the local Jewish education system; however, their experiences still underscore the way belonging is wrapped up in the school one's child attends. After enormous struggles, Dinah's child was admitted to the special-education yeshiva. Eventually, Shulamit's and Lori's children were successfully mainstreamed with support in other yeshivot, but not without heartache.

For these mothers, having an atypical child in a conformist community prevents participation and inclusion in acceptable Orthodox Jewish life. This Jewish community mandates religious and cultural practices for both living and child-rearing. Being excluded from these practices can cause mothers to doubt themselves, their ability as mothers, and the viability of their family in the Jewish community. The grief of losing normalcy because of a child's disability is compounded by the child not being fully accommodated in the Jewish educational system, which alienates the entire family. This exclusion from yeshivot sets the stage for the practical and emotional social rejection of the child and the family.

Mothers' Emotions and their Behavioral Consequences

All of the mothers interviewed discussed emotions in relation to being the mother of a child with ASD. These were mostly difficult emotions, such as grief, shame, embarrassment, fear, anger, feelings of failure and incompetence, disappointment, shock, hopelessness, anxiety, isolation, loneliness, resentfulness, desperation, and the need for affirmation. In response to all these emotions, the mothers adopted specific behaviors that tended toward closing down, opening up, or both. For example, closing-down behaviors were protecting their child and themselves by isolating from the community, withdrawal from family and friends, and shielding themselves from others' judgements and attempts to offer helpful (yet ignorant) advice. Opening-up behaviors included advocating for their child beyond a previously experienced personal comfort level, educating people ignorant about ASD and neurodiversity, being overly open about their struggles raising a child with ASD, attempting to use ASD language positioning (i.e., using outdated terms such as Asperger's Syndrome to describe their child's level of functioning) in an effort to control how other people see their child, and a conscientious effort to stay positive. Most of the mothers engaged in both opening-up and closing-down behaviors in various situations, depending on context and internal feelings and perceptions.

For example, Dinah discussed how she closed down as a result of her loneliness, isolation, and fear of connecting with members of her modern Orthodox community. She said,

> I don't know so many people in the community that have either a kid with special needs or autism, so there's no one to connect with. And I'm always embarrassed or ashamed of

> what's going to happen […] So it's a lot of avoidance because I'm scared of the stigma or what people are going to think.

Her difficult emotions led to the behavior of avoidance. Similarly, Shulamit illustrated withdrawal because of her son's school experiences. Although Shulamit was one of the few participants whose child was able to attend a mainstream yeshiva because of his intellectual normalcy, she encountered many issues stemming from her son's social–behavioral presentation. The judgment and negative feedback she received from parents of her son's classmates, as well as members of her modern Orthodox community, made her wary of exposing him or her love and appreciation for him. When talking about the negative and judgmental feedback she receives, she described how it is safer to isolate, saying, "That makes me want to shelter him, that makes me want to pull in and not reach out to people and just not, I just want to pull in and keep him safe." Revealing the internal struggle she feels socially in the community, Shulamit tearfully stated, "if you don't like my child, I don't want to like you."

To protect themselves and their children from rejection, some mothers closed down by criticizing the community's rejection of their child. Eliana said: "my child is not disordered, you have a disordered way of looking at him." Rather than feeling dejected, Eliana directs her frustration and disappointment at the community. These feelings can lead to isolation and subsequent emotional withdrawal.

An extreme example of closing down was when Beth described moving away and feeling rejected in the new community. Beth has two children on the spectrum. She came from a very tight-knit, highly observant, and strictly Orthodox community, where she was comfortable and spiritually fulfilled prior to her children's symptoms and diagnoses. However, what she perceived as the community's judgment and rejection drove her to move to a nearby, more religiously diverse community that she hoped would be more accepting. However, issues of acceptance persisted for Beth in the new community:

> I have tremendous anxiety in my own community […] I feel like I have to explain myself. I feel like I have to tell people that they're autistic and that's why they're behaving the way they're behaving, and to please accept them […] and please accept me.

Beth closed down by moving away from one community; however, in the new community, she felt compelled to explain herself and her children's behavior in an attempt to be accepted.

Although many descriptions showed the difficult emotions leading to closing-down behavior, the mothers also shared instances where they opted for opening-up behavior, such as advocacy. For example, Elisheva explained that after multiple traumatic experiences in the community resulted in her feeling outcast, she has discovered that openness preempts judgement. She explains: "I've learned to be very open, and to wear what I am and who I am and who my family is on my sleeve. I'm very open about it." Furthermore, she has built a community of her own where she feels competent and valued and is able to help others counter the tendency toward shame and isolation. She relayed: "In fact, I actually started a support group for Jewish parents with kids who are not neurotypical, and I find that, it's just because everyone is so nervous about being stigmatized, but we don't use each other as a resource."

The mothers shared that they reacted to painful emotions regarding their child with a degree of defensiveness. For two of these mothers, their defensiveness was exemplified by overemphasizing their ASD child's accomplishments. Several mothers discussed how they became defensive when they felt threatened, judged, or ridiculed. Shoshana said "tough noogies" when describing an instance where she was drawing attention to her son's odd and potentially dangerous behavior. This defensiveness can appear as both closing down and opening up at the same time. For example, Elisheva described multiple situations where she has brought her neurodiverse children, one of whom has ASD, to community events. She explained her embarrassment at her children's behaviors and idiosyncrasies and how she feels forced to hover as if she is a "helicopter parent." Elisheva tries to prevent her children's unacceptable behavior and also to repair or divert attention away from it when it inevitably happens. Despite her hypervigilance, she described feelings of failure, incompetence, and anger: "I felt like a terrible parent. Like an awful, terrible parent. I felt like a terrible parent, and then enraged that I have to explain it to somebody." She physically and emotionally exhausts herself trying to appear normal in the community (closing down), she feels angry about having to expend this effort, and then she overshares (opening up) to compensate for feelings of inadequacy.

When asked to describe how they experience their child's ASD diagnosis in their Jewish community, these mothers shared a multitude of emotions and behavioral consequences. The mothers were inconsistent in their behavioral reactions to extreme emotion; the same mother behaved differently at different points in time. They were constantly looking for ways to defend themselves against the pain of disappointment and rejection and tried closing down, opening up, or both. Rejection and painful emotions intensified the strong need for connection, appreciation, and community these mothers crave.

The Need for Friendship

All of the mothers described how being a parent of a child with ASD affects their abilities to socialize with other parents within their Jewish community and to build and maintain friendships. The majority of mothers primarily socialized with other Jewish people prior to having a child with ASD. For most mothers in the Orthodox community, motherhood takes on a certain trajectory and routine, involving play groups with young children, then arranging activities for school-age children, and then becoming involved in their children’s school organizations. However, all of the mothers interviewed found it hard to navigate socially in the Jewish community with a child with ASD. All but one of the mothers described finding that their child’s needs prevented them from being part of the larger community. For various reasons, many mothers found that their involvement in the Jewish community was limited to the Jewish special-needs community. All mothers but one (Shoshana) discussed their relationships with other mothers of neurodiverse children as being different than their friendships with mothers of neurotypical children. Many found it easier to socialize only with other families that had children with special needs. One mother felt intolerant of mothers with only neurotypical children because she found their child-rearing concerns superficial. Three mothers discussed keeping their close circle of friends despite their child’s ASD diagnosis, whereas the remainder (n = 13) discussed the pain of losing friends who had neurotypical children and therefore could not understand or tolerate the behavior of the ASD child or the mother’s hardship and grief. Their friendships with mothers of neurotypical children dwindled, and the need for comradery with people in the same situation led to new friendships with kindred spirits with neurodiverse children.

Friendships and socializing are complicated by having a child with behavior that is outside the norm. All of the mothers interviewed described barriers to social engagement because of their child’s behavior. For example, Shulamit said, “we tried to have other people over for meals or go to their house for meals. It just didn’t work because people’s tolerance for anything that’s not just typical and standard, they just don’t have that tolerance.” Mothers not only described withdrawing, but also being excluded. Jamie shared that she often felt excluded from social overtures in the community because her son has high-functioning ASD. She said that she found herself unable to enjoy adult interaction at social gatherings because she had to make sure her son was behaving appropriately, and then people came to experience her as a disinterested guest. Jamie perceived others thinking, “Oh, her kid doesn’t get along with other kids” and then the invitations stopped, as she said, “So they’re not going to invite me.” Going to other people’s homes or having people over for Shabbat meals is the main social opportunity in this community, yet several mothers talked about the difficulty of doing this. For example, Tamar’s son is extremely behaviorally challenged, making socializing as a family very difficult. She says:

> I would say a lot of moments are really hard. Like not being able to sit together at a Shabbos table because one of us is always with [our son], and having to leave early, and having to tag team all of it. That’s super hard.

Many mothers talked about the pain of losing friends after their child’s ASD diagnosis. As Beth put it, “there are not enough words to really express that disappointment of years of a committed friendship that you thought was solid, but it was conditional.” Beth’s community was particularly insular, and anything outside of the communal norm was perceived as threatening. Beth was forced to leave that community after experiencing rejection and excommunication due to her ASD child’s proclivities and eccentricities. This was devastating for Beth, who came into the Jewish community as an adult and worked very hard to fit in.

Most of the mothers talked about how their socializing and friendships shifted to the special-needs community, where they felt included, valued, and accepted. As previously discussed, many young mothers develop friendships with other mothers of same-age children, and many of these women look forward to growing together through motherhood. However, for these mothers, that experience shifted from the larger Jewish community to the special-needs community. Debbie explained her experience:

> In the past when I was much younger with younger kids…I wanted to connect with people in my community. I wanted to make friends, you know, you usually make friends when you have a kid, but I wasn't able to do that. The parents I made friends with, with kids my son's age, were other parents of special needs kids, which was fine for me in the sense of I made connections that I needed, but, in the [larger Jewish] community I did not.

Another mother, Becky, described feeling socially and emotionally stunted because her son was not able to have the same experiences of same-age peers in the Jewish community. She said:

> I don't necessarily feel I can be myself and be open and have social networks for myself outside of the special needs community because you immediately create a big barrier between you and other parents when there is a sense that your kid doesn't know Yiddishkeit.

Relatedly, Elisheva explained, "You're not going to the same events as certain other people. You tend to find yourself in different crowds." She continued to say that the special-needs community is a "separate community. It's separate. And it's great that we're together, but it's separate" from the Jewish community. This separateness is particularly hard for Elisheva; she and her husband both grew up in a Jewish community, but feel exiled due to the special needs of their children.

Elisheva further explained how she feels more valued in the special-needs community (both Jewish and secular), in contrast to how she feels judged in the Jewish neurotypical community:

> I really surround myself in the special ed parenting community because those are my people. I feel very welcome. Like I have a lot to offer. In the neurotypical [Jewish]

> community, I'm this horrible parent who doesn't know how to parent her children. In the special ed community, I'm a person with a lot of insight, and I know what I'm talking about.

Despite her disappointment in the Jewish community for not offering an inclusive and accepting environment for her children, Elisheva works hard to remain observant in faith, but finds her community and her value elsewhere.

Although most of the mothers felt left out of the larger Jewish community, Shoshana did not. Shoshana was severely disappointed to have to remove her son from a local yeshiva when the insurance company stopped paying for his ABA shadow; however, she still felt connected to her general community. She said:

> We live amongst and near Kosher and Jewish everything, Shul, and what not. Emotionally it means that we all have friends. Each and every member of our family has friends here in this community that we get along with, that accept us for who we are, as we are, and we don't have to be friends with everybody, but everybody in this household has at least a small handful of friends that they can turn to.

Shoshana did acknowledge that there have been times when other parents did not want their child to play with her son.

Additionally, Danit described friendships that she made long before having her child that were not based primarily on the common thread of motherhood. For Danit, these friendships were enduring and supportive. She said, "My two best friends are Jewish, but they know me, so I don't feel like they're judging because they know me and they love me and they accept us." Finally, Atara offered a mixed perspective on how having a child with ASD affects her social relationships within the community. On the one hand, she said, "Some relationships I think it's helped, just because they want to be friends with the parents of the kid who's slightly different [...] I think sometimes people think it's cool." On the other hand, she went on to say:

> Other people have distanced themselves from us once they find out our son is autistic. They're like, oh, yeah, your son goes to public school? Public school is a big, big issue. I'm going to be honest that it is a huge issue, actually.

When Atara and her family see these past friends, they say hello, but have a very clear sense that these people feel they "can't be affiliated with them."

Having a child with ASD presents many family challenges because the child's behavior limits involvement in community activities. The chain of consequences of having an atypical child includes not being able to send the child to a Jewish school, the child attending a public school or another secular program, and then the family being ostracized for having a child attending a nonreligious institution. The emotions resulting from being different and being judged for being different lead to closing-down and opening-up behaviors. These behaviors can both alienate and facilitate friendship. This theme makes clear that these mothers need support, understanding, comradery, and welcoming. They want to belong.

Affiliate Stigma Precludes Belonging

Affiliate stigma is the self-stigmatization process that includes internalizing negative emotions experienced when a family member or closely associated person is stigmatized (Mak & Cheung, 2008; Mitter et al., 2019). The term, affiliate stigma, was new for most of these mothers, but all mothers understood the concept of stigma and how people closely associated with a stigmatized person could also experience a form of stigma. All mothers (*n* = 16) said they experienced negative emotions while watching their child be stigmatized. Most mothers (*n* = 15) expressed internalizing those negative emotions. Some mothers said that they feel they are different from other mothers in the community because their child is different. All mothers discussed their awareness of other people's perceptions, and many discussed their own negative emotions, resulting from affiliate stigma. All feared future stigmatization. All mothers discussed the pain of watching their child be excluded from participating Jewish life. The majority of mothers felt that they experienced affiliate stigma more in their Jewish community than in the secular community. Several said that people in the Jewish community are afraid of people who are different. They offered examples of how both stigma and affiliate stigma play out, specifically in the Jewish community. The mothers' sense of how their lives as Jewish mothers would unfold was obfuscated by being the mother of a child with special needs.

For mothers of children with ASD, affiliate stigma begins with the stigmatization of the child. As Beth put it, referring to the invisibility of the diagnosis, "something seems different, but that's where the stigma starts to happen because it's sort of like, well I thought you were, you don't have it labeled on your forehead." Eliana observed that stigmatization can follow a lack of knowledge: "They don't know to include him, they don't know how to understand him, they don't know how to be nice to him." Atara shared that "within the Orthodox community, I think that parents are scared to have their child play with my child" because "parents primarily are scared to have their kid hang out with another kid who is different." Another way the mothers saw their children being stigmatized inadvertently was when others tried to show or were required to provide kindness to their ASD children and their families. Community programs, including the Friendship Circle, offer neurotypical children the opportunity to volunteer with their special-needs peers. Additionally, Jewish high schools require students to volunteer for a minimum number of hours doing *chesed* (kindness between people). Some mothers felt that their ASD child and their situation was being used just to meet this requirement. Elisheva expressed her anger about this, saying, “my child is not a chesed project. I don’t need some teenage girl coming to my house helping in the afternoon because that marks off [her] chesed hours.” Atara similarly experienced personal discomfort at a bar mitzvah; during the mother’s speech: “She’s like ‘Oh I want to give a shout out to [Atara’s son], who’s here today and [bar mitzvah boy] does chesed with him all the time.” By pointing out Atara’s son as a “chesed project,” the other mother had stigmatized Atara’s son, who otherwise, Atara felt, was able to blend into the crowd. Having her son identified publicly was particularly difficult for Atara because, with an invisible diagnosis like ASD, there are times when a high-functioning child can “pass” for neurotypical, relieving the mother of the burden of being different.

For most of the mothers, the stigmatization of their children launched the self-stigmatization process of affiliate stigma. Illustrating the mothers’ experience of affiliate stigma, Elisheva said:

> You stigmatize my kid, you stigmatize me. If people look at my kid in a not positive light, that affects me as a mother. It affects me as a human being. These are the people that I’ve created. If you’re going to stigmatize them in a bad light, then that is a reflection of me.

Likewise, Beth worries how other mothers in her community perceive herself and her family. She wonders, “Are you going to reject me? Are you going to not be friends with me? Do you want your kids to not talk to mine?” Yaffa succinctly described how her feeling about her son led to an internalized feeling about herself, saying, “I was ashamed of my son’s behavior and I was ashamed of feeling ashamed.”

All but one of the mothers (*n* = 15) at least sometimes felt that affiliate stigma precluded their sense of belonging to their Jewish community. Debbie expressed this sense by saying, “I didn't feel like I was fully part of it [Jewish community]. Or fully part of what I wanted to be a part of […] the attitude of shame I felt was projected to me and my kid." Hadassah said, "It's painful because it's like rejection. Like he's mine, if you're rejecting him, you're rejecting me also." Shulamit discussed her experience in the Jewish community, saying it was

> painful for me to have to have [other people in the community] make comments and just look at him, and just feel their disdain for how he was acting […] people just show judgement, what kind of parent are you that you didn't push him? He's not normal, so you're not pushing him to be normal?

Becky said, "I feel like less of a member of the community, less important in the community. I've always felt sort of like an outsider, feeling like I'm not worthy of being in the community."

Voicing a minority perspective, one mother, Shoshana, admitted to feeling sad for her son when he was rejected, but she said she does not feel sad for herself. She went on to say that she cannot relate to her son or the stigma that he might experience. She shared: "I don't ever feel like my parenting ever comes under scrutiny. I think his behaviors and mannerisms come under more scrutiny than my parenting." Everyone other than Shoshana felt that they experienced some form of affiliate stigma.

Although the mothers were not asked directly about how they coped with affiliate stigma, some offered insight into the strategies they deployed. For example, Elisheva managed to cope with the phenomenon by actively engaging other women in the same situation. She said:

> The more that you are open about it, the less stigma exists because there's nothing to stigmatize with something that's out there in the open. If you're going to hide something, then people are going to say, "What are you hiding and why?" But if you're open about it, I find that people are open about it.

Elisheva is not shy about sharing her pain or the challenges her children experience. She decided to take control.

Affiliate stigma precludes belonging. Because people who are stigmatized do not belong, the people who are associated with them do not quite belong either. This Jewish American community emphasizes religious and cultural conformity, and mothers are often defined by their children, at least to some extent. Regardless of their other accomplishments, these women are often identified as being the mother of a child with special needs. The child's disability identifies the family as abnormal or challenged, which lowers the family's standing (*yichus*) in the community. In fact, feeling like they are different because other people see the difference, in either a positive or negative light, results in uncertain and uncomfortable emotions leading these mothers to question their worthiness to belong, their role in the community, and whether they are tainted. Despite the affiliate stigma most mothers reported experiencing, most of them have found compensation in their own personal growth.

Making Meaning, Meeting Challenges, and Personal Growth

All mothers felt that they experienced personal change since their child's diagnosis of ASD. For many of the mothers, this change included becoming more sensitive or empathetic toward children with special needs and their families. Others noted growth in terms of strength of conviction, advocacy, generalized sensitivity, increased introspection, self-awareness, and tolerance for the neurodiverse. Some mothers shared a belief that there was a greater spiritual purpose to ASD and being a parent of a child with an invisible disability.

Illustrating the sense of empathy, Shoshana said, "Having a child with autism, it has to change the way you experience things because you wouldn't have the same empathy and understanding if you weren't experiencing it yourself." Similarly, Jamie said, "if a kid is misbehaving or if a kid is off the wall, I'll just say, that's how he is. You can't blame the parent." Sarah, whose child is nonverbal, noncommunicative, and difficult to control, noted:

> I hear stories about a mother of an autistic child wanting to drive off a bridge, those stories come up in the news. And you'll see the comments like, "How evil," and I am like, that poor mother. There but for the grace of G-d go I.

All mothers discovered an additional abundance of understanding, empathy, and sympathy for others struggling with issues they may have judged negatively before raising a child with ASD.

The mothers discussed other intra- and interpersonal growth. For example, Shulamit expressed how she was able to create new boundaries around who she interacts with and befriends, saying:

> I think what was taken away from me was, or what maybe was given to me, was the discernment of people who accept me for not being perfect, for not being a perfect parent, for not being a perfect person for not…those people that accept me the way that I am, and the way that my family is. I really gravitate [to] them. They are few and far between because I think there is a lot of keeping up with Schwartz's, it's not really the Joneses because we're Jewish.

Tamar also spoke about how much she has changed as a person. She said, "I like myself better [now]. I like myself as the strong, outspoken, non-doormat person."

Some of the mothers expressed a newfound spiritual connection or purpose. For example, Becky said, "I'm given the honor of raising a child with special needs." Tamar expressed this idea in more detail when she described her son, saying:

> I still think he's a great person, and he lights up a room, and I feel like he's helped all of us become better people. And I know that sounds so cliché, but I really feel that way. I

> really feel like he’s made our family much more sensitive to other people and inclusive of other people, better listeners, better non-starers. I think he is some kind of *navi* [prophet].
>
> Like, was he put on this earth to teach us, not just our family, but the whole world.

This sense of heightened spiritual purpose gives meaning to the everyday stressors and caregiver burden associated with raising a child with ASD.

In striking contrast from most participants’ proclamations of intra and interpersonal growth, Dinah maintained that the experience of being the mother of a child with ASD has only served to strengthen her cynicism: “I see everything as negative. I’m very negative [Laughs], everything to me is negative. I can’t see anything in a positive.” Dinah says she was pessimistic before her daughter’s diagnosis, but her daughter’s diagnosis confirmed and exacerbated the negativity. This preexisting hopelessness complicates her ability to cope with the emotions surrounding her child’s ASD.

In a community where every struggle has a potential spiritual interpretation, it makes sense that some of these mothers found solace in the higher purpose of raising a child with a profound, invisible disability. Meeting the challenges of trying to belong when different may prompt a reframing. For these mothers, the world is limited to the culture and community that they live in, either by birth or choice, making it especially hard to have the mark of difference. Religious and spiritual aspiration proposes greater meaning. This can inspire personal growth. Not surprisingly, in this religious community where struggle has a spiritual undercurrent, people make spiritual meaning of challenges.

Summary

The experiences of these Jewish American mothers relating to their child diagnosed with ASD are complicated by belonging to a community that expects adherence to cultural standards for parenting, educating children, socializing, and participating in religious activities. In this community where belonging matters, the main consequence of having an atypical child is feeling left out of the Jewish life that was both expected and desired. The mothers experience not only the grief of not having a neurotypical or “normal” child, but also the loss of what is considered to be the typical life of a Jewish mother. This experience is illuminated by not being able to send the child for a Jewish education and the perceived rejection from mainstream Jewish educators. The mothers’ emotions in response to this inability to fulfill community expectations led to closing-down behaviors (like isolating or withdrawing) or opening-up behaviors (like advocating or showcasing). These behaviors can create new friendships or comradery with people in similar situations. On the other hand, they can challenge friendships with people unable to understand or appreciate the mothers’ newfound circumstances. These friendships often dwindle or dissipate, sometimes through a very painful process.

All but one of the mothers experienced affiliate stigma, at least to some extent. They reported being very aware of other people’s perceptions and feeling different than mothers of neurotypical children in the Jewish community. The majority of these mothers (*n* = 14) felt that they experienced more affiliate stigma in the Jewish community as opposed to outside the community. These mothers crave acceptance within the Jewish community because belonging matters, but they fear future stigmatization, not only of their child with ASD but also of themselves and their other children. All mothers interviewed were able to find meaning and personal growth in how they met the challenges presented by raising a child with ASD, both in general and within this particular community. In the following chapter, these findings will be discussed in relation to the existing literature and theory, and recommendations for social practice and education will be made.

Chapter 8: Discussion

This study explored the lived experiences of Jewish American mothers of children with ASD, specifically focusing on affiliate stigma, which is the self-stigmatization process of family members or affiliates of a stigmatized person (Mak & Cheung, 2008). The researcher thematized participants' lived experiences and meaning making regarding the phenomena of mothering a child with ASD within a Jewish American community and affiliate stigma. The themes of the mothers' experiences were *belonging matters, mothers' emotions and behavioral consequences, the need for friendship, affiliate stigma precludes belonging,* and *making meaning, meeting challenges, and personal growth.*

These themes parallel Broady's (2017) findings that caregivers of children with ASD had four domains of experience: lack of knowledge, judgement, rejection, and lack of social support. These domains were experienced across four contexts: school, the public, family, and friends (Broady, 2017). The Jewish American mothers in this study discussed all of these domains across all of the contexts. This study specifically focused on how mothers experience their circumstances within their Jewish American community, so the themes reflect nuances of these mothers' sociocultural need for belonging related to their children's schools and their own need for friendship.

This study also had a specific focus on affiliate stigma. These mothers do generally experience affiliate stigma and feel ostracized from the Jewish community or from Jewish life because of their child's differences. Werner and Shulman (2015) found that parents of children with ASD experience more affiliate stigma than parents of children with other physical or intellectual disabilities. Likewise, in this study, the mothers talked about their sense that they experience more affiliate stigma as a parent of a child with ASD than they would if their child had a visible disability. This sense may be explained by Pryor et al.'s (2004) description of social reactions to stigma as both reflexive (immediate and emotional) and deliberate (thought out). When a child presents with a physical disability, others' immediate fear response is curtailed by knowledge of how one should treat someone with a physical deficit, such as kindness and accommodation. However, when a child with an invisible disability, such as ASD, presents nontypical behavior, there is no knowledge of "how to treat someone with a disability" activated; instead, the person observing the behavior is often judgmental about how the parent is (mis)managing the child.

This study's findings contribute to the existing scholarship on parents of children with ASD by illustrating how a mother's experience of raising a child with autism is influenced by their cultural and religious background. The Jewish American mothers who were interviewed for this study largely felt their stress and stigmatization were compounded by their child's need for services outside their insular community.

Mothers' Experiences are Embedded in Their Culture

The culture of their Jewish American community affected how these mothers wanted their family lives to go. Mizrahi and Buren (2014) discussed the Jewish devotion to education and achievement and asked what this means for children with disabilities:

> The Jewish community, which values achievement so highly, can be an especially harsh and lonely place for someone with a disability and those who love them. Time and time again we in the Jewish community shut our doors to people with disabilities, or we serve them in segregated institutions when separate is never equal. Sometimes this is done intentionally, but far more often it is done because we simply do not know how to truly serve all. (p. 83)

What Mizrahi and Buren are pointing out here is the specific contours of a Jewish perception of success. It drives competitiveness and judgment and fear of being associated with anything or anyone deemed less than successful or normal. Several of the mothers who participated in this study expressed the idea of their Jewish community being hypercompetitive; they also talked about people not wanting to be associated with them because their child is different.

Similar to the Jewish American mothers in this study, parents in Kwok and Kwok's (2020) study talked about Hong Kong being a competitive society. They discussed losing a successful life trajectory because of their child's ASD. Kwok and Kwok's participants spoke about feeling socially rejected themselves, as did the Jewish American mothers. The neoliberal, social-climbing, and elitist attitude is a common thread between these two cultures. For parents in Hong Kong and these Jewish American mothers, wanting to belong and not to be different is an important element of their sense of well-being.

For the mothers in this study, their Jewish American culture also affected the magnitude of their disappointment when life did not go according to their vision of Jewish American life because of their child's ASD. Although any mother of a child with a disability is likely to experience disappointment and grieve the loss of the life they had anticipated, these mothers planned to experience their motherhood in a context of an insular community that values religious observance and tradition. Their lives are different because their child has a disability, and being different in a culture that values conformity is challenging. Previous studies of Chinese parents of children with ASD also touched on cultural expectations of conformity (Chan & Lam, 2021; Chan & Leung, 2021; Kwok & Kwok, 2020; Liao, 2019; Zhou et al., 2018). In Chinese contexts, being abnormal means losing face. Being different is especially shameful in Chinese culture. For example, Chinese parents of children with ASD may experience especially high levels of stress because of Chinese cultural beliefs and values about children with disabilities and how the concept of "face" influences self-perception and social identity (Mak & Kwok, 2010). For both this small sample of Jewish American mothers and parents in Chinese contexts, being different has significant emotional consequences.

Additionally, their Jewish American culture affected the mothers' overall sense of self in their community. They emphasized that belonging matters, and that they experience a distinct need for friendship. They recognize that parenting a child with ASD has come with very strong emotions and, consequently, their social behavior is affected. Although most mothers in this study felt that their experience of affiliate stigma precluded their attempts to fully belong to their community, many mothers were able to make meaning, meet challenges, and recognize personal growth.

Sense of self in this community is partially comprised of perceived status and adherence to spiritual authority figures. For example, parents' status in the community might impact how they interact with the authority figures in the community, such as heads of schools and rabbis. In this study, mothers felt that a *ba'al teshuva* (a person whose parents were Jewish but who is newly observant) or an Orthodox convert experience a lower or suspicious status in the community. This status seems like that of the "new immigrant" Mei Fung in Kwok and Kwok's (2020) study. As an immigrant, Mei Fung sensed that she had lower status compared to the social work professionals in her community; therefore, she did not feel she could challenge any of their positions. In this study, Becky said that as a *ba'al teshuva* she was already struggling to fit into her Jewish American community, and she felt that she could not challenge the rabbi's wife, who continued to push for Becky to get her son a Jewish education, not understanding that there was no Jewish education available to him. Becky felt that motherhood would help her fit into modern orthodox Jewish family life, but this dream was derailed by her son's autism.

Another way in which mothers' sense of self is embedded in their culture relates to how the community explains ASD. Cultural differences regarding parents' perceived roles in relation to their child's autism seem to relate to the existence and prominence of medical vs. social vs. spiritual models of ASD. For example, Shaked and Bilu (2006) found that in the Jewish ultra-orthodox community in Israel, biomedical and spiritual/religious frames of reference for explaining ASD coexisted. However, many people in their study were hesitant to move forward with therapeutic intervention without their rabbi's seal of approval. More recently, Selman (2018) studied Somali parents of children with ASD in the United Kingdom and found that the community's lack of a precise model for autism (there was no word in Somali for autism) contributed to a sense that the parents were to blame: "suspicion that parents might in some ways be implicated in causing their child's autism influenced other people's responses to them as well as the parents' self-perceptions" (p. 12). This was not the case for the Jewish American mothers studied here, as the themes of this study indicate that the medical and social models are prominent in this particular Jewish American community. The Jewish American mothers were not blamed for causing their child's ASD, but they were implicated in furthering the disability by not treating it "right" in how they parent or in where they send their children to school.

In some ways, the Jewish American mothers in this study had similar experiences as participants in Oti-Boadi's (2020) study of mothers of children with ASD in Ghana, which focused on Ghanaians' traditional west African and strong Christian belief systems. Both Ghanaian and Jewish American mothers experienced stigmatization from their families and the societies within which they live. However, the Ghanaian mothers discussed forgiveness as a coping resource, whereas the Jewish American mothers did not discuss forgiveness at all.

The Ghanaian mothers reported experiencing significant stigma because of their community's view of disability as a curse or punishment. The mothers blamed themselves. In contrast, the Jewish American mothers in this study did not believe that they had caused their child's ASD. The Jewish American mothers did not have people in the community saying they sacrificed their child's soul for money. However, some mothers wondered why others in the community assumed they had the money to send their child to the much more expensive special-needs yeshiva that may not even accept their child. Overall, the Jewish American mothers were more concerned about their child not fitting in and less about their child representing a demonic punishment for their own past wrongdoing. Yet, members of Beth's particularly insular community were concerned that Beth's daughter would expose other community children to secular evil, such as sitcoms, YouTube, and women wearing jeans. Most of the Jewish American mothers in this study lived in a more modern community; their criticizers did not focus on what spiritual failing brought on the child's behavior, but rather how the mother responded to it. In the Jewish American community, the stigma is not spiritual, but rather about nonconformity.

Although the Jewish American mothers were more concerned about how to help their children and families fit into their Jewish American community rather than what caused their child's ASD, some of their comments speak to religious and spiritual understandings of their child's behavioral presentation. Becky spoke of the honor of raising a child with ASD; Tamar said her son is a *navi* (prophet); Hadassah said she does not know why this happened to her family, but expressed that obviously this is what G-d wanted for them. Some of the mothers talked about experiences with Jewish American religious authorities offering spiritual or mystical suggestions to help with their child's ASD. The Jewish American mothers also mentioned spiritual and personal growth as a positive outcome of raising a child with autism.

Affiliate Stigma and Secular Education in this Jewish American Community

While managing a family and raising a child with ASD, the Jewish American mothers in this study experienced stressors and stigmatization similar to those described in studies of secular parents (Broady, 2017; Gray, 2002a, 2002b; Kinnear, 2016). These mothers also experience added affiliate stigma when their children attend secular schools. Although there is a Jewish community special education program, only 1 of 16 mothers in this study had a child who had been accepted to it. Only two were able to send their children to mainstream yeshivas (with support). The others sent their children to public schools or secular private special education schools.

Similarly, parents in Kwok and Kwok's (2020) study had experiences that highlighted problems with the schools:

> Although integrated education has been put into practice in Hong Kong it has been criticized as failing to offer appropriate support for special education needs children, including those with ASD. This is mainly due to systemic issues such as elitism, non-accepting school culture, insufficient teacher training, as well as a lack of real choice in mainstream society. (p. 6)

In both Hong Kong and the Jewish American community in this study, the school a child attends is very important, not only because of the school's offerings for the child, but also because the school's prestige is a reflection on the family's social status. In the Jewish American community, the school is seen as signaling the family's level of religious observance, impacting the family's community status.

Implications for Social Work Practice

Parenting children with ASD is a concern in the social work field because of the higher levels of stress these parents experience, putting them at risk for mental health struggles (Werner & Shulman, 2013, 2015). Stigmatization can contribute to this stress (Mak & Kwok, 2010). As in previous literature (Kwok & Kwok, 2020), this study has shown that culture can impact the experience and severity of the stress of stigmatization. The mothers who participated in this study shared that they want understanding, affirmation, belonging, empowerment, and inclusion. What they do not want is pity and praise; these mothers do not want to be pitied for their life circumstances, and they do not want grandiose praise for managing those circumstances.

Informed by this study's findings, clinical social workers can offer Jewish American mothers insightful, curated therapeutic interventions. At the same time, these social workers can avoid the pitfalls of negating the positive aspects of these women's lives or minimizing their struggles. Papadopoulos (2019) noted that culture is a nonchangeable phenomenon as it relates to a parent's experience of affiliate stigma. Culture cannot be changed in an intervention for an individual parent or family, but the intervention needs to acknowledge and be informed by cultural nuances.

For example, a social worker providing therapy to a Jewish American mother in this community needs to know how much belonging matters and how affiliate stigma precludes belonging. The social worker should understand that because of these cultural nuances, other community members fear neurodiversity. As Kwok and Kwok (2020) pointed out, in converging both the neurodiversity approach and the social and medical models, social workers are

> respecting individual value, reducing environmental barriers, creating positive niche, and improving the behavioral conditions of children with autism at the same time. However,

> as shown in [their] study, the neoliberal logic of elitism and the lack of social acceptance in the wider society has made it difficult for parents of children with ASD to live with the idea of seeing difference as internal worth. (p. 7)

Almost all of the Jewish American mothers in this study were concerned about how people saw them. A therapeutic intervention could be building self-esteem (Recio et al., 2021) and encouraging positive self-worth. This can help mothers ward off the internalization of courtesy stigma that could result in affiliate stigma.

Social workers also need to recognize the institutional structures that shape a mother's experience. Belonging to the Jewish American community is very important to these mothers, but the special needs services in the community are almost entirely limited to *chesed* (kindness or charity) and a few afterschool inclusion opportunities. Many of the families in this study felt that because their child was not accepted into a yeshiva, they were excluded from fulfilling their desired Jewish family lives. Kwok and Kwok (2020) agreed, pointing out that "the emotional needs of these families are not confined to obtaining comfort and distancing discomfort but should also be understood to include support for their fight against institutional barriers and stigma, and struggle for social recognition" (p. 7). In the Jewish American community, it may be possible that social workers are afraid to challenge the system. However, if change is going to happen, someone is going to have to be brave enough to instigate it.

In providing therapeutic intervention, social workers may consider Kwok and Kwok's (2020) findings about the *emotion work* these caretakers can do. Kwok and Kwok identified five domains of emotion work: a) diverting discomfort through managing annoyance, shame and loss; b) avoiding hurt feelings through mediating and negotiating in the family; c) surviving stigma and social rejection; d) surviving institutional barriers and disregard; and e) negotiating identity. This work can be done individually, as a couple, or in a group setting.

Support groups for families need to be formed and facilitated with the knowledge that implicit bias often trumps explicit bias (Jones et al., 2021). Without such knowledge and acceptance, support groups can backfire, marking the families as different, when what they really want is to be considered normal and to be included. A good model for a support group is SOLACE, an intervention designed to improve mental health of parents of children with ASD implemented by Lodder et al. (2020). The group of participants in Lodder et al.'s study used a blended format on Zoom, in person, and a private Facebook group. The intervention included psychoeducation, cognitive-restructuring strategies, and self-compassion techniques. These components were delivered through lecture, video material, group discussion, guided activities, and sharing. One of the important benefits pointed out by the intervention group participants in the acceptability/feasibility study was that they made friends while taking part, which would be helpful for the Jewish American mothers in this study who described a strong need for friendship.

Additionally, this intervention could help the Jewish American mothers in this study because it brings to the forefront that children with ASD and their parents experience stigma. The mothers in this study pointed out that in their Jewish American community, this stigma is not discussed. The SOLACE intervention is facilitated by a professional and is geared to supporting the mental health needs of parents. It acknowledges stigma head on. If the SOLACE intervention was offered in this community, parents sharing their experiences would help the intervention stay grounded in this community's culture; it would be important for the facilitator to be ensconced in the culture as well. SOLACE would not solve all the problems in the community (for example, it would not solve the school problems), but it would help parents cope with those problems and perhaps brainstorm solutions.

In a program development setting, Jewish American mothers of children with ASD need more than *chesed*. Programs should focus not only on inclusion, but also on community acceptance, respect, and equality. To facilitate this, social workers developing programs in these Jewish American communities should work to reduce social stigma of children with ASD and their families. Mizrahi and Buren (2014) offered guidance for how to serve Jewish children and their families, including steps such as getting leadership buy-in, implementing inclusion with authenticity, obtaining appropriate resources to do inclusion successfully, and offering support groups for families.

In their article, Mizrahi and Buren (2014) seemed to assume that people are inherently nice and inclusive. They neglect the problem that Cage et al. (2019) pointed out: that people without ASD see the autism in autistic people as troublesome. Mizrahi and Buren's checklist does not go far enough. It does not address implicit bias or change the nature of the community's motivation to offer inclusion in the first place; in this case, *chesed* is the community's motivation for inclusion. A different approach might focus on providing opportunities for heads of school and special educators to learn the perspectives of children with disabilities and their families. Real acceptance involves foregoing judgment and an emotional understanding that cannot be found through words and lectures; it can only be found through experience. An authentic attitude valuing inclusion needs to be both explicit and implicit.

Specifically, program developers in a Jewish American community need to recognize and accept how *chesed* stigmatizes people, not just in theory, but in practice. Link and Phelan (2011, 2014) explained that labeling is a precursor to stigma. Being identified as a person with a disability or the family member of a person with a disability (autism in this case) in this community labels that person as a potential recipient of *chesed*. This label sets the stage for further stigmatization, possibly leading to internalization of stigma or affiliate stigma. All of the mothers in this study described feeling inferior and further injured by being a recipient of *chesed*. The wider Jewish community needs to be less afraid of people with autism and to critically examine the current efforts toward "inclusion" of children with ASD as afterschool volunteer projects.

According to all the participants in this study, the Jewish day schools in this community must improve their ability and willingness to accommodate children with ASD. Based on this study's findings and theoretical frameworks, the first step toward this goal is reducing social stigma in the community. Social workers can help. Kwok and Kwok (2020) suggested that social workers advocate for children with ASD within the education sector. Social workers working within the Jewish American community should not simply accept that the yeshivas are not a good fit for a child with any social-educational differences, including ASD. The participants in this study felt that the obstacles to improving access to yeshivot are parents of neurotypical children who are adamant that their child should not be educated alongside children with disabilities, and the fact that the schools are effectively for-profit businesses.

Greene (2006) supported the recommendation to include all children in Jewish schools, arguing that providing a Jewish education for every child according to their abilities and including that child in the community is mandated by Jewish law. The majority of mothers in this study felt displaced because their children were displaced by the Jewish education system. This feeling of displacement was perceived by all of the mothers and affirmed as real for some (recall Atara talking about how people cannot be associated with children who go to public school and their families). The stigma experienced and the loneliness and isolation exacerbate the overall burden of having a child with a disability. Furthermore, the local special needs yeshiva is very selective with whom they feel they can accommodate, and many children are left without the opportunity to experience a Jewish education. These children are forced to attend a public school or other secular program, and yet many observant Jews look down upon this; remember Beth insisting that those children are forever exiled.

Implications for Social Work Education

Social work educators need to be aware of the serious implications of stigma and devote more time and resources to teaching newly minted social workers how to work with clients feeling stigmatized. There is a need for training on how to support parents, not just children with developmental disabilities, including ASD. Additionally, new social workers need to know more about stigmatization and invisible diagnoses. Werner and Shulman (2013, 2015) recommended supporting the caregiver of individuals with invisible disabilities to decrease their possible feelings of stigma. Resources such as Mazumder and Thompson-Hodgetts’s (2019) scoping review can help students and social workers understand perceptions of ASD, invisibility and judgment, preconceived social conceptions of the diagnostic label, social isolation of both parents and their children, negative impact on wellbeing and responses to stigma, and what needs to be done for stigma reduction.

Social workers need to be aware that the emotional responses of parents are tightly associated with the culture they live in. This awareness should be included in curricula preparing students to work with clients within any culture. The findings of this study, for example, can help inform future social workers who will work within a Jewish American community. Friedlander et al. (2010) commented that there are variations in how Jewish Americans identify with either religious or cultural components of Jewish American identity. Social work professors should be prudent in encouraging social work students to ask their clients to help them understand cultural nuances rather than making generalized assumptions based on preconceived notions or textbook descriptions.

Last, because this study brings awareness to the cultural subtleties and distinctions within affiliate stigma for parents of children with ASD, the findings inform social workers practicing in any community. Leaders of social work programs need to remember that "starting where the client is at" applies to all clients. Although there may be a stereotype of Jewish Americans as demographically, financially, and socially intact (Friedlander et al., 2010; Mizrahi & Buren, 2014), that might not always be the case. Social work professors who teach student social workers about working with people with developmental disabilities need to address cultural identification and the family dynamics behind clients' support systems. Furthermore, social work students involved in ASD research need to be aware that there may be deficits and discrepancies in communication between parents of children with ASD and researchers. Fischbach et al. (2016) found that better communication between parents of children with ASD and the researchers investigating issues involving ASD would help improve research and ultimately better serve individuals with ASD and their families.

Implications for Policy

On a policy level, social workers need to advocate for policies that treat families, not just individuals with disabilities, in an attempt to be mindful of caring for the caregiver. In this study, Sarah said, "there but for the grace of G-d go I" when reading about a mother who killed her autistic child. Extreme mental stress needs to be treated as urgently and fairly as any physical distress. There are laws stating that insurance companies must offer mental health care parity;

however, not all insurance carriers comply (Callaghan & Silvester, 2019). Policies, such as insurance mandates, need to facilitate mental health treatment for caregivers. With advocacy from groups like the American Psychiatric Association, Congress has just recently made a move to provide more funding for maternal mental health, specifically in the peri-partum period (Rennie, 2023). This is a positive step, and yet maternal mental health should be cared for beyond the peri-partum stage. This is especially true for parents of children with disabilities. For parents of children with ASD, depression and anxiety are linked to enacted and felt stigma (Chan & Lam, 2018; Chan & Leung, 2020). Professional organizations like the NASW can support advocacy efforts to enhance mental health care for family members of individuals with ASD.

Theoretical Contributions

This study also contributes to scholarship theorizing stigma experiences by adding the perspective of another subculture that had not yet been represented in the literature. As discussed in Chapter 4, theorists have pointed out that stigma is reliant upon power and control (Farrugia, 2009; Link & Phelan, 2001). In this Jewish American community, people who are religiously, traditionally, or spiritually observant depend on the approval of authority figures in their community, such as Rabbis, Rebbetzins, and heads of yeshivot. Heads of schools have power over the mothers because they have the power to reject or accept a child, and by extension, the mother and the family. Furthermore, these mothers are even dependent on the approval of the "normals" (Goffman, 1963) who hold relatively more power in the community. The mothers in the study were looking for approval and direction on how to belong to their own communities without feeling ostracized by having a child who cannot follow the expected Jewish path.

What the community did offer as a Jewish path for these children with ASD was to be a recipient of *chesed*. Pryor et al. (2004) discussed how one possible response to a stigmatized person is to be overly kind, and asked if this kindness is stigmatizing. For the mothers in this study, the answer is yes. Being labeled as a recipient of kindness and charity was further stigmatizing for them, their children, and their families.

Additionally, this study's findings show how the stigmatization process operates in this specific community. For these mothers, what the community finds acceptable and pleasing—or not—is quite powerful. As Farrugia (2009) theorized, stigmatization is a sociocultural process embedded in the values held on a macrosocial level. The findings of this study indicate that, in this Jewish American community, people with ASD and their families are devalued for their lack of conformity. Specifically, their inability to adhere to the prescribed life path is damning.

Limitations

This study's sample of 16 mothers from a small Jewish American community in northern New Jersey means the findings are nongeneralizable. This is true for most qualitative studies. The purposive and snowball sampling strategies used differ from the random sampling used in studies that aim to generalize their results. Qualitative research calls for small but meaningful samples (Padgett, 2017), and Marshall (1996) stressed that in qualitative research, "improved understanding of complex human issues is more important than generalizability of results" (p. 524). This study shed light on a specific phenomenon within a specific subculture and can be used to inform future generalizable research.

The study's findings must be understood as unique experiences within this small population in this small geographic region. The mothers who were recruited were all involved in or familiar with the special-needs services available within the Jewish community; thus, other mothers not connected to the services might have different perspectives not represented in these findings. The participants self-identified as Jewish American; specifically, 13 mothers identified as modern Orthodox, two identified as being more strictly observant and insular than their modern Orthodox counterparts, and one identified as Israeli American and culturally and traditionally Jewish. It is possible that other Jewish American mothers in different communities have different experiences and may have greater acceptance of anything secular and perceive less stigma around secular education.

Interview data should be understood with knowledge of social desirability bias, or “the tendency for participants to present reality to align with what is perceived to be socially acceptable” (Bergen & Labonté, 2020, p. 783). For some participants, it was very important to present their children very positively. Similarly, it was important for some to present the community in a positive light. At the same time, some participants seemed determined to point out negative information about their children, community, or circumstances. Bergen and Labonté (2020) stated that “taking active measures to detect and limit biases strengthens the rigor and transparency of qualitative research and provides opportunities for reflexive contemplation” (p. 789). The researcher’s experience in the community helped with detecting and reflecting on the biases presented by different participants. Additionally, the researcher was aware of the possibility of a power differential and therefore used gentle questioning techniques and built rapport with the participants (Bergen & Labonté, 2020). The researcher elicited experiences of affiliate stigma in the interview by explaining the terminology and asking about such experiences.

Analysis aimed to identify themes, not to prove linear causation. Although these mothers’ experiences with stigma influenced their perceptions of themselves as mothers, and their perceptions of themselves as mothers influenced their experiences, this study does not identify an exact causal chain. Following a naturalistic approach, this study assumes that “all entities are in a state of mutual simultaneous shaping, so it is impossible to distinguish causes from effects" (Lincoln & Guba, 1985, p. 38). Additionally, distilling the large amount of data into five themes required prioritizing and omitting some analytical insights, which seemed less pertinent to the research questions.

Future Research

Several questions remain unanswered at present. The foremost question is as follows: What similarities and differences exist between the themes found for this small sample and experiences in other Jewish American communities? A large-scale quantitative study could confirm or challenge this study's findings. Specifically, the Affiliate Stigma Scale tailored to ASD (Mak & Kwok, 2010) could be administered to a statistically representative sample of parents who identify as Jewish American. Data on levels of religiosity and observance could also be collected and compared to the affiliate stigma scores. Recall that the level of shame that Beth felt in her very insular community was different from other mothers who participated in this study, indicating that a possible correlation between levels of insular religiosity and affiliate stigma may be worth exploring.

Additionally, further research should investigate how experiences in Jewish American communities compare to those in other subcultures in the United States. For example, how do the experiences of Jewish American parents of children with ASD compare to their counterparts in White, African American, Latinx, Asian American, or Indigenous communities? How do their experiences compare to those of parents in Muslim, Christian, or other religious or nonreligious subcultures? Zuckerman et al. (2018) offered a potential model for such a large-scale quantitative study of parental perceptions of public stigma related to ASD. The scale developed for

Zuckerman et al.'s study could be used to gain insight into what communities or individuals within particular communities might be experiencing as parents of a child with ASD.

Because this study's participants were all mothers, further research should recruit Jewish American fathers of children with ASD. This line of research could begin with a qualitative study similar to this one and move on to larger-scale, statistical measures. Social workers and other professionals who support parents of children with ASD in the Jewish American community need to know if the affiliate stigma experience is different for mothers and fathers and how interventions might best be designed to support both parents.

Future researchers may examine the causes and effects within the stigmatization process for Jewish American parents. Specifically, is a parent of a child with ASD in this community stigmatized because their child has ASD or because the child does not attend yeshiva? An in-depth ethnographic study drawing on multiple data sources and gathering perspectives from across the community would be needed. Perspectives from not only parents of children with special needs, but also parents of neurotypical children as well as school staff would be required to answer this question. If this question could be answered, it would point to what changes would be most effective for reducing stigma of children with ASD and affiliate stigma of their families, in this community.

Concluding Thoughts

For the Jewish American mothers of children with ASD who participated in this study, belonging to their community matters enormously. However, most felt that they did not fully belong; they felt less valued and less accepted within their community than a mother with only neurotypical children. These mothers were able to recognize their strong emotions regarding mothering a child with ASD and how their behavior changed in response to those overwhelming emotions. The participants expressed a strong, unyielding need for friendship and felt deprived of it within their Jewish American community. Most mothers in this study experienced affiliate stigma because their child with ASD was stigmatized, either covertly or overtly. They went on to share how those experiences further precluded their sense of belonging in the community. Most of the Jewish American mothers in this study expressed that they strived to meet the challenges of raising their child with ASD and experienced personal growth and found spiritual meaning in their journey of motherhood.

As these Jewish American mothers try to raise and educate children within their Jewish American community, they are forced to deal with their children—and by extension their families and themselves—being educationally, spiritually, and socially ostracized. The community provides inclusion based on the principle of *chesed*. A goal for these mothers is that inclusion and acceptance not be an act of charity, but become inherent in the community's implicit and explicit actions. Though this goal remains to be realized, conditions could be inspired to allow it to happen. Stigma is contingent upon power. This study has shown how power manifests in this community, particularly pertaining to the Jewish day schools. To reduce stigma and help the community accept all children and families, this power needs to be addressed. Social workers could work with the schools, families, and community leaders to reduce stigma and help create a more just and equitable community.

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Appendix A: Study Participation Invitation

Dear Leah and Zeesy,

Thank you for agreeing to assist me with my research exploring how Jewish-American parents of children with autism spectrum disorder (ASD) experience affiliate stigma. This research study will inform the dissertation I am writing in partial fulfillment of a PhD in social welfare from Yeshiva University's Wurzweiller School of Social Work.

In keeping with the Friendship Circle's philosophy and goals, this study will help inform social workers and other mental health professionals of the unique experiences and needs that parents of Jewish-American children with ASD have and how best to include them in the broader Jewish community.

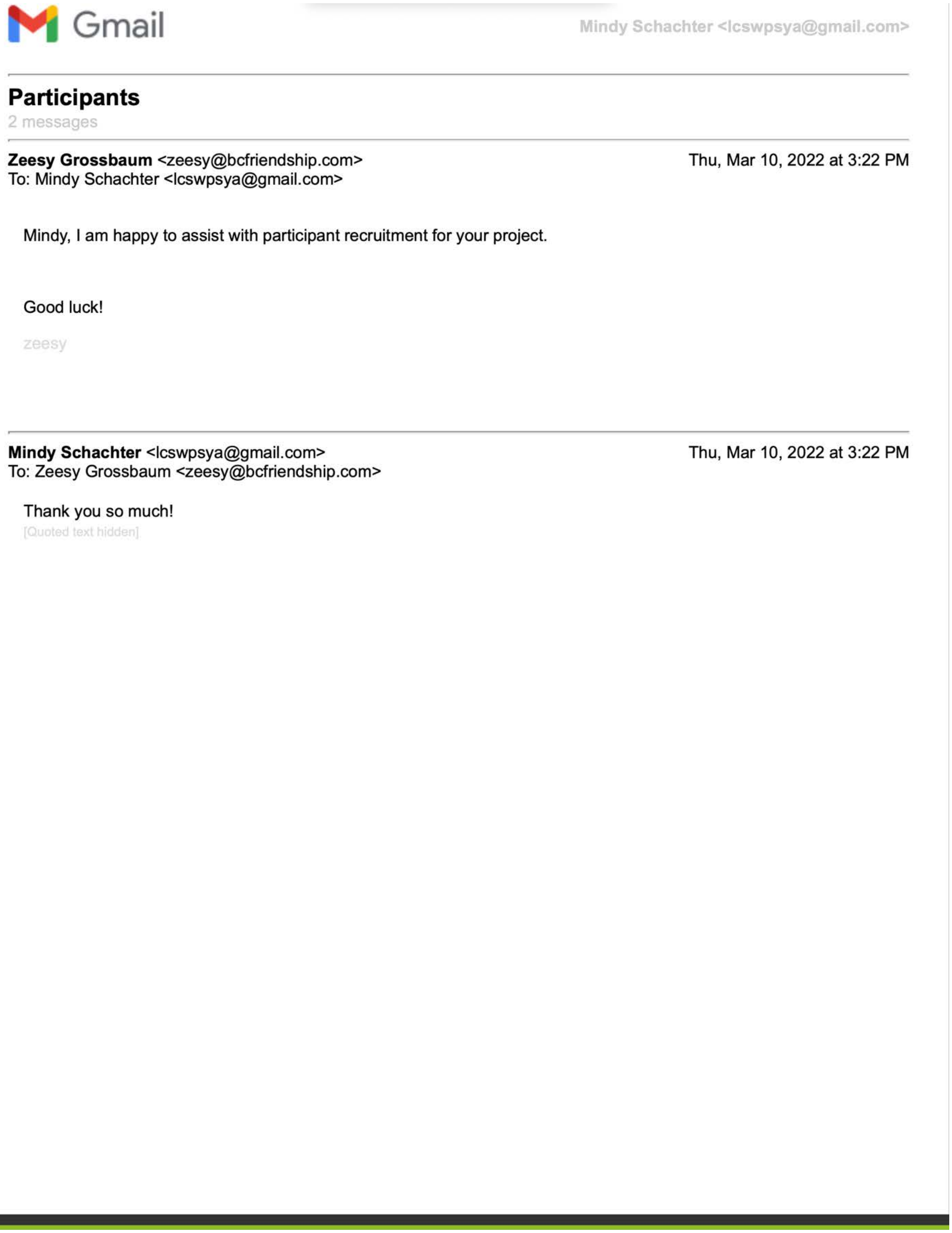
This study requires 15 participants. Each participant must be a biological or adoptive parent of a child with ASD and identify as Jewish-American. Their degree of religiosity or observance is not important. Each participant will be asked to participate in a semi-structured interview that will last between 30 and 45 minutes. This interview can take place in person, by Zoom, or in written form by filling out an open ended question survey. Participants will be compensated for their time with a gift card.

To ensure confidentiality and anonymity all participants will be assigned a pseudonym. Additionally, I am a licensed clinical social worker (LCSW) and I will be able to refer anyone who requests further counseling to local psychotherapists.

Please reach out with any additional information you need from me before we begin the process of finding participants.

All the best,

Mindy Schachter, LCSW, PhD candidate
Wurzweiler School of Social Work
Yeshiva University
New York, NY



Mindy Schachter <lcswpsya@gmail.com>

Participants

2 messages

Zeesy Grossbaum <zeesy@bcfriendship.com>
To: Mindy Schachter <lcswpsya@gmail.com>

Thu, Mar 10, 2022 at 3:22 PM

Mindy, I am happy to assist with participant recruitment for your project.

Good luck!

zeesy

Mindy Schachter <lcswpsya@gmail.com>
To: Zeesy Grossbaum <zeesy@bcfriendship.com>

Thu, Mar 10, 2022 at 3:22 PM

Thank you so much!

[Quoted text hidden]

Figure 1Email from Friendship Circle of Bergen County Executive Director

Appendix B: Informed Consent Form

INFORMED CONSENT

The researcher and Principal Investigator, Mindy Schachter, LCSW, is currently A PhD Candidate at the Wurzweiler School of Social Work, 2945 Amsterdam Avenue New York, NY 10033. For questions about the research study, please contact Ms. Schachter directly at lcswpsya@gmail.com and 2014176800 if you require additional information about this study. You may also contact her PhD Advisor, Dr. Susan Mason at masonse@yu.edu or 646-592-6806.

This research study has been approved by the WCG Institutional Review Board (IRB) for Yeshiva University's Wurzweiler School of Social Work.

We would like to talk to you about a research study on your experiences as a Jewish American parent of a child with autism. You will be interviewed privately, at your convenience. This study is designed to learn more about the impact of affiliate stigma. If you join the study, you will participate in an interview of approximately 45 minutes, which will be recorded with your permission using an audio recorder. If you decide you do not want to be recorded, the recording will either not start or will be stopped immediately. You may still participate in this study even without being recorded. Recording is to assist the researcher with details of your response. Recordings will be destroyed when the research project is completed. If necessary, with your permission, researcher may call to obtain clarification of comments made during the interview. Clarifications may or may not be recorded, subject to your permission.

You have a choice about being in this study. If you decide to take part, you are free to stop participating at any time without giving a reason.

Possible discomforts or risks include evoking uncomfortable feelings related to the subject of this study. There may be risks the researchers have not thought of. If you experience distress while participating, you may contact a counselor or therapist by calling the Institute for Psychoanalytic Studies (IPS) Referrals hotline at 201-457-0809.

It is hoped that your participation in this study will generate important information about impact of how Jewish American parents of children with autism spectrum disorder (ASD) experience affiliate stigma.

Every effort will be made to protect your privacy and confidentiality by not using your name, meeting on Zoom, or by phone with the researcher. Additionally, interview information will be kept in a locked file available only to researchers and IRB personnel.

Please sign below if you agree to participate in this research study.

I have read the consent form and I understand that it is up to me whether or not I participate. I know enough about the purpose, methods, risks and benefits of the research study to decide that I want to take part in it. I understand that I am not waiving any of my legal rights by signing this informed consent document. I will be given a signed copy of this consent form.

Printed name of participant: __________ Date: __________

Signature of participant: ___________ Date: __________

Printed name of the person conducting the consent process: __________

Signature of the person conducting the consent process: __________ Date: __________

Appendix C: Interview Schedule

RQ: What are the experiences of Jewish American parents relating to their child diagnosed with autism spectrum disorder?

Family context/story and demographics

1. Tell me about your family.
    a. Children's birth order
    b. Parents' marital status
    c. Other adults in the home
    d. Is there anyone else in your family with autism?
2. Tell me about your child with autism.
    a. What was it like when they were diagnosed?

Experience of stigmatization

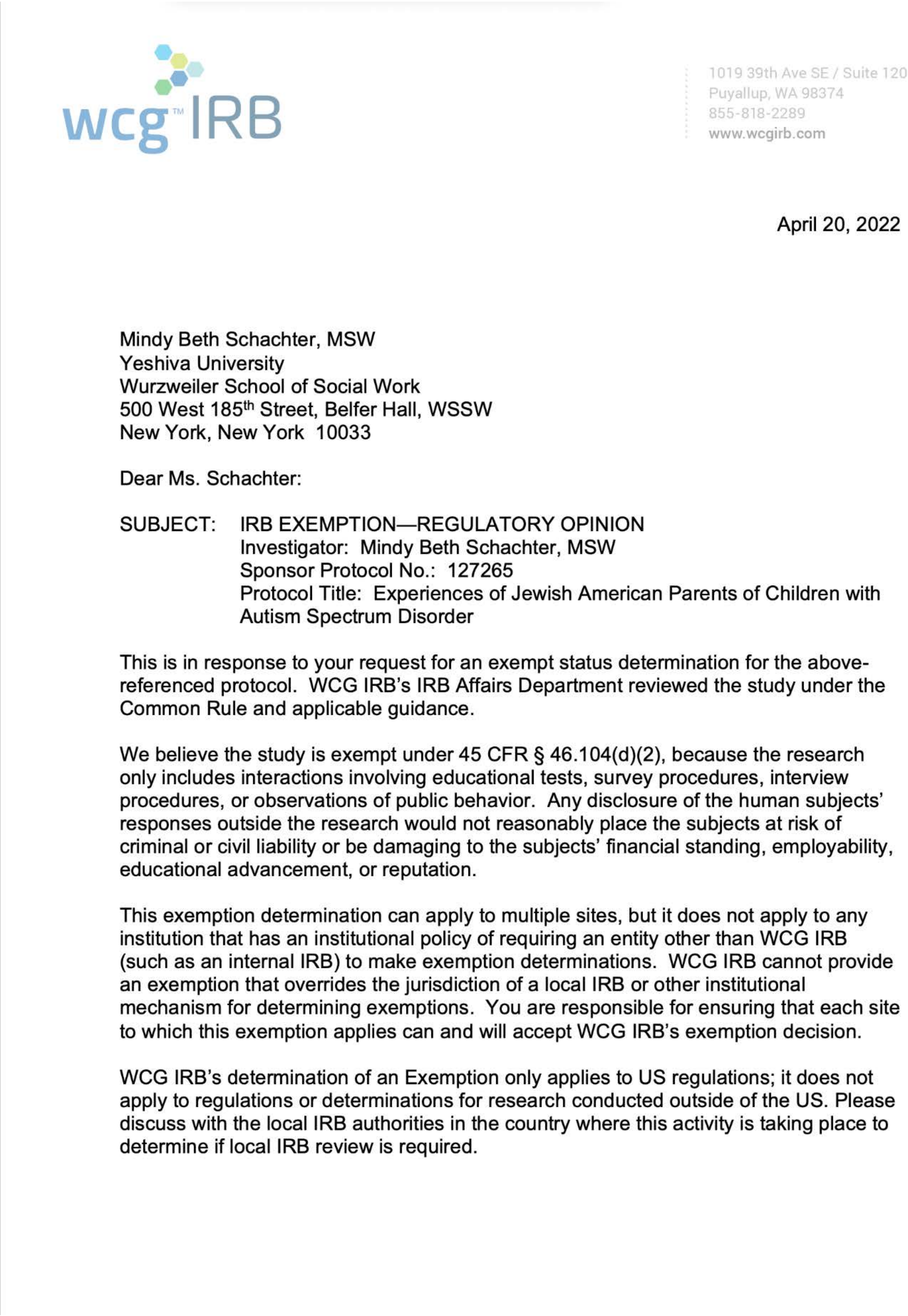
3. Can you tell me about a meaningful interaction where you felt inferior/embarrassed/discriminated against/lesser than because your child is autistic?
    a. What did that feel like for you?
4. How often do things like that happen?
5. After an experience like that, how are you feeling about yourself?
6. How do these experiences affect how you perceived yourself as a person?
    a. As a parent?
    b. how you perceive your child?
    c. As a member of your community?

Experiences within Jewish community

1. What does belonging to a Jewish community mean for you and your family?
2. Have your experiences as a parent of child with ASD affected how you behave within your community?
3. Can you describe how being a parent of a child with ASD affects your relationships with other people in your community?
4. How do you think other people in your community see you? Your parenting?
5. What differences do you see between how you are treated within your community versus outside the community?
6. Do you see yourself differently in your community now than you did before your child was diagnosed with autism?

Is there anything else you want to share about your experience?

Appendix D: IRB Exemption Letter



wcg IRB

1019 39th Ave SE / Suite 120
Puyallup, WA 98374
855-818-2289
www.wcgirb.com

April 20, 2022

Mindy Beth Schachter, MSW
Yeshiva University
Wurzweiler School of Social Work
500 West 185th Street, Belfer Hall, WSSW
New York, New York 10033

Dear Ms. Schachter:

SUBJECT: IRB EXEMPTION—REGULATORY OPINION
Investigator: Mindy Beth Schachter, MSW
Sponsor Protocol No.: 127265
Protocol Title: Experiences of Jewish American Parents of Children with Autism Spectrum Disorder

This is in response to your request for an exempt status determination for the above-referenced protocol. WCG IRB's IRB Affairs Department reviewed the study under the Common Rule and applicable guidance.

We believe the study is exempt under 45 CFR § 46.104(d)(2), because the research only includes interactions involving educational tests, survey procedures, interview procedures, or observations of public behavior. Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation.

This exemption determination can apply to multiple sites, but it does not apply to any institution that has an institutional policy of requiring an entity other than WCG IRB (such as an internal IRB) to make exemption determinations. WCG IRB cannot provide an exemption that overrides the jurisdiction of a local IRB or other institutional mechanism for determining exemptions. You are responsible for ensuring that each site to which this exemption applies can and will accept WCG IRB's exemption decision.

WCG IRB's determination of an Exemption only applies to US regulations; it does not apply to regulations or determinations for research conducted outside of the US. Please discuss with the local IRB authorities in the country where this activity is taking place to determine if local IRB review is required.

Please note that any future changes to the project may affect its exempt status, and you may want to contact WCG IRB about the effect these changes may have on the exemption status before implementing them. WCG IRB does not impose an expiration date on its IRB exemption determinations.

If you have any questions, or if we can be of further assistance, please contact Zach Burr, J.D., at 360-252-2475, or e-mail RegulatoryAffairs@wirb.com.

ZHB:dj
D2-Exemption-Schachter (04-20-2022)
cc: Edward Berliner, Yeshiva University
WCG IRB Accounting
WCG IRB Work Order #1-1539674-1